Despair
Healthcare Disparities at the Crossroads with Healthcare Reform
Healthcare Disparities at the Crossroads with Healthcare Reform

Edited by

Richard Allen Williams, MD, FACC
Clinical Professor of Medicine
UCLA School of Medicine

President/CEO
The Minority Health Institute, Inc.
Founder, The Association of Black Cardiologists, Inc. USA

Chairman of the Board, Emeritus
Institute for the Advancement of Multicultural and Minority Medicine
Washington, DC
Book Symbol

The symbol for the new book is the African Sankofa bird, a mythical animal depicted in the Akan (Adinkra) writing system as flying forward with its head turned backward. The egg in its mouth represents the “gems” or knowledge of the past upon which wisdom is based; it also signifies the generation to come that would benefit from that wisdom. This symbol may be associated with the Akan proverb, “se wo were fi na wasankofa a yenki”, which means “it is not wrong to go back for what you have forgotten”.

Book Theme

“Baraka Sasa”, an old Swahili expression meaning “blessings now”.

This book is dedicated to the late Senator Edward M. Kennedy of Massachusetts, who was a champion for eliminating healthcare disparities and was the nation’s strongest advocate for healthcare reform. His book, In Critical Condition, written in the 1970’s, was one of the first to call attention to the crisis in our healthcare system.
By ten things is the world created,
By wisdom and by understanding,
And by reason and by strength,
    By rebuke and by might,
By righteousness and by judgment,
By loving kindness and by compassion.

–Talmud Higaga 12A
Health disparity elimination studies and analyses did not only recently start to emerge, but they began in 1899 with the release of *The Philadelphia Negro* by Dr. William Edward Burghardt (W.E.B.) DuBois – a report that exposed the health disparities that existed between Blacks and Whites in a Philadelphia community. While numerous additional studies emerged after that landmark publication, they often remained under the sociopolitical radar, until *The 1985 Report of the Secretary’s Task Force on Black and Minority Health* (The Heckler Report), which was the key federal effort to identify and draw national attention to the tragedy of racial and ethnic minority health disparities. The report, issued by then Department of Health and Human Services Secretary Margaret Heckler, formally detailed for the American consciousness the existence and extent of racial and ethnic health disparities for African Americans and three other identified racial and ethnic minority groups (defined during that time as Hispanics, Asians/Pacific Islanders, and Native Americans, including American Indians, Alaska Natives, and Native Hawaiians).

Fortunately for purposes of increasing awareness, health disparity reports did not and have not ceased since. In fact, in addition to the plethora of health disparities studies that have been published in academic journals since the Heckler Report, the Agency for Healthcare Research and Quality (AHRQ) – every year since 2003 – has published a report entitled the *National Healthcare Disparities Report* that measures and analyzes racial and ethnic differences in access and use of healthcare services, as well as impressions of quality of such services, by different populations. Today, not only are we well versed in the negative civil rights and health and healthcare repercussions of health disparities, but also the economic consequences of these disparities.

This cumulative knowledge about health disparities is what contributed to making Tuesday, March 23, 2010 such an important day in the health equity movement. That was the day the nation witnessed history unfold when the once-deemed insurmountable goal of overhauling the nation’s healthcare system was attained with President Barack Obama signing into law the Patient Protection and Affordable Care Act (PPACA). Numerous key successes of this new law – including the expansion of health insurance coverage to more than 30 million Americans who currently
are uninsured; and the guarantee of numerous consumer protections to ensure that the patients’ healthcare needs, instead of health insurance executive determinations, are at the forefront of healthcare decision-making – have rightfully received due attention and accolades. However, there are myriad provisions in PPACA – many of which go beyond expanding access to healthcare coverage and consumer protections – which have received far less attention, but which are nonetheless pivotal to ongoing and future efforts to reduce and ultimately eliminate racial and ethnic health disparities.

The newly enacted healthcare reform law includes numerous health equity provisions that were modeled after the legislative effort that the Congressional Black Caucus, the Congressional Hispanic Caucus, and the Congressional Asian Pacific American Caucus (collectively known as the Congressional TriCaucus) have championed for numerous Congresses – the last of which was H.R. 3090, the Health Equity and Accountability Act of 2009. This legislation was based almost entirely on the recommendations that arose from the landmark 2003 Institute of Medicine Report, Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Thankfully, many were included in PPACA, including the following:

- Emboldened investment in existing (such as Medicaid) and forthcoming (such as public health exchanges) public health programs
- Bolstered and standardized data collection provisions across a broader range of demographic data, including subpopulation data, language preference, and history of disability
- Language services and cultural competency education provisions
- Health workforce provisions, especially those that aim to recruit, train, retain, and graduate healthcare providers from racially and ethnically under-served communities
- Community health centers, community health workers and healthier community provisions, as well as the expansion of prevention information and services that aim to reduce health disparities
- Increased accountability through the elevation of the Office of Minority Health at the Department of Health and Human Services, the establishment of additional Offices of Minority Health across numerous other federal agencies, and the elevation to an Institute of the National Center on Minority Health and Health Disparities at the National Institutes of Health

Dr. Richard Allen Williams and colleagues clearly had the foresight to see this moment coming when they conceptualized the successor to his 2007 book, Eliminating Healthcare Disparities in America: Beyond the IOM Report. This foresight is particularly evident in this edition’s inclusion of recent evidence-based research findings and analyses that build upon the preceding edition, thus providing a more robust understanding of the extensive dynamics that sustain and often exacerbate racial and ethnic health disparities. Additionally, the scholarly contributions in this edition provide a foundation upon which a roadmap to health equity – particularly in an era of healthcare reform – can and should exist.
It is sad that overall, health disparity trends have not improved for racial and ethnic minorities, especially when compared to the health and healthcare trends of whites. However, the promising news is that the health equity-related provisions of PPACA could play an integral role in curbing some of these disastrous and disturbing trends – which makes the release of this book – *Healthcare Disparities at the Crossroads with Healthcare Reform* – richly serendipitous.

In the previous edition, Dr. Risa Lavizzo-Mourey, President and Chief Executive Officer of the Robert Wood Johnson Foundation, aptly quoted the following African proverb at the conclusion of the Foreword she developed: “Those who dig the well should not be denied a drink from the well.” That proverb is completely correct: those who dig, should receive. But it is not the passage of PPACA that will ensure that they receive; those details lie in how the numerous health equity provisions are implemented. In fact, that this book will be read in the very months and years that key provisions of healthcare reform are being implemented affords a rare but fertile environment within which to stress that the truly hard work is only now beginning, for healthcare reform passage is one thing and implementation is something altogether different.

It is imperative that those reading this book, as the bearers of the torch and as the nation’s health equity ambassadors, recognize the need to stand up and work to ensure that the health equity provisions included in this new law are implemented as intended. There is little doubt that if we gain contentment only from seeing these provisions written, the motivation needed to push for these provisions to be implemented will be lost. It is up to the bearers of this torch to demand that the health equity provisions that this law promises come to full fruition.

This imperative is not lost on the Congressional Black Caucus (CBC) Health Braintrust. In fact, the CBC Health Braintrust assembled the Health Equity Leadership Commission – a commission that includes the nation’s greatest experts on minority health policy and health disparity elimination – to ensure that we seize upon this unique and rare opportunity that is finally before us, more than one hundred years after *The Philadelphia Negro*. Today, we are finally poised to take bold and definitive action towards health disparity elimination. If we do not come together and stand firm on the front lines of the health equity movement, then we have failed those who have the greatest need: those who have been denied a drink for far too long.

And, that is a legacy that we – as a nation, as a community, and as human beings – simply cannot and should not accept.

Donna M. Christensen, M.D.
Member of Congress and
Chair, Congressional Black Caucus (CBC) Health Braintrust

With contributions from:
Britt Weinstock, M.A., Director of Health Policy, CBC Health Braintrust
Preface

Upon this gifted age, in its dark hour,
Rains from the sky a meteoric shower
Of facts ... they lie unquestioned, uncombined,
Wisdom enough to leech us of our ill is daily spun, but there exists no loom
To weave it into fabric ....

“Huntsman, What Quarry?”
Edna St. Vincent Millay

The Healthcare Crisis: Why We Can’t Wait to Resolve It

More than 50 years ago, during the civil rights crisis, Reverend Dr. Martin Luther
King, Jr. was asked why black people could not just take their time and allow dis-
 crimination to die out and for prejudicial attitudes to change rather than pushing so
hard in a confrontational way, which often resulted in deadly consequences. His
response, delivered while he was imprisoned in Birmingham Jail in 1963 and later
published in his 1964 book, Why We Can’t Wait, was ground-shaking in what it
revealed about the state of social conditions for blacks throughout the country. For
the first time, people were given a profile of the suffering and pains that had been
endured by blacks for centuries. It was clear that discrimination was not only a
social injustice, but it also caused death and destruction and was leading to the
demise of the largest minority group in America. If allowed to continue, this dev-
astating practice might lead to the realization of a prediction made by the eighteenth
century demographer Hoffmann, who observed that the physical state of the black
population was so dire that they could become extinct by the twenty-first century.
As Dr. King later stated, injustice in health care is the worst injustice of all.

Dr. King’s response to the question of why we can’t wait defined the purpose and
the driving force of the civil rights movement. In like fashion, the reformation of
health care and the elimination of healthcare disparities are moral imperatives that
are being pushed by the most startling statistics. For example, in terms of overall
quality of healthcare delivery, the United States, which spends about 2.5 trillion
dollars each year on health care, or $7,000 per capita, ranks only 37th among the
nations of the world, in proximity to Cuba and other emerging countries. Between 2005 and 2008, about 880,000 deaths were attributable to healthcare disparities, according to a study done by Dr. David Satcher, the former Surgeon General, and the annual cost of disparities is estimated to be over $50 billion, according to the Joint Center.

At this juncture in the twenty-first century, we have a Janus-like vantage point for viewing the pestilence of healthcare disparities that has been visited upon the minority population of the United States. We can look back and see the terrible ravages which have led to the crisis in which we find ourselves, and we can also look forward into the future possibilities offered by healthcare reform measures that were signed into law on March 23, 2010 by President Barack Obama. In that sense, this book encompasses within its covers the grief and despair that have been endured in the past with a fast-forward shift to the hope and expectations that ensue from the passage of the law.

This is a simple book about two complex things: healthcare disparities, healthcare reform, and the intersection between the two. Our previous book, *Eliminating Healthcare Disparities in America: Beyond the IOM Report* (Humana, 2007), was published before Barack Obama was elected President of the United States and prior to the furious debate about altering the prodigious healthcare system in this country. The latter has become one of the top issues for the Obama administration, and while this book was being written, Congress passed the Patient Protection and Affordable Care Act (PPACA) which was signed into law. This landmark law is funded by a governmental expenditure of $938 billion dollars over the next decade. Thus, the frustrated efforts to reform our healthcare system over the past century, which were begun by President Theodore Roosevelt in 1912, have finally come to fruition.

Prior to the passage of PPACA, the healthcare disparities issue has largely been ignored, except for literary interest, and almost no federal funding was devoted to it. People in Congress, who used to consider mention of healthcare disparities *de rigueur* when discussing health matters concerning minorities, the poor, and the elderly, avoided any serious dialogue about it recently except for what might be called “lip service.” I heard some very liberal politicians say that the important thing was to pass a reform bill that would benefit everyone rather than to focus on the special needs of certain segments of the population for fear that such a focus will distract attention from the greater, more important issue and might even cause it to fail. Besides, it was argued, when there is universal healthcare insurance, there will be no disparities, and the benefits which will result from concentrating our efforts on the majority of Americans will “trickle down” to those who are less fortunate. It is claimed that a rising tide lifts all boats.

This illustrates one of the great myths about healthcare reform measures. It is widely believed that possession of insurance coverage will provide greater access to care and will magically create health equity; disparities will no longer exist. Nothing could be farther from the truth. The establishment of healthcare reform with its major ingredient, near-universal insurance coverage, is exactly the best opportunity for eliminating disparities. There must be a well-funded, activist effort
to connect the two entities rather than reliance on a passive, “trickle down” mechanism.

Our previous book cited above extended the knowledge base on healthcare disparities and made recommendations for their elimination that went beyond those included in Unequal Treatment, generally referred to as the IOM Report, published in 2002. This new book will not focus on increasing the data base but instead will consider how elimination of disparities can be accomplished through targeted efforts made within the context of healthcare reform. That is, we will analyze the benefits that can be derived at the intersection of disparities and reform. We will also analyze how much of that $938 billion will be devoted to really eliminating inequity in health care. “Show me the money”, as the star athlete said in the movie Jerry Maguire. This is important because unless serious funding is applied to the initiatives in the law, implementation will not happen, and there will be no chance to level the playing field.

That said, no one should get the idea that improving health in America is just about how much money we spend on it. For too long, we have been monolithic in having a “money fixes everything” approach. We already spend almost $3 trillion dollars per year on health care, much more than any other nation on Earth, and yet the system is still broken; better insurance coverage will not completely fix it. I believe that the Commission to Build a Healthier America, created by the Robert Wood Johnson Foundation, has it right in saying that improved access to care is not enough, and that we need to focus on conditions outside of medical care per se that fall into the category of prevention and wellness such as promoting good nutrition, early childhood education, and healthy communities. One specific area in which early childhood education can have an impact on health is through educational and intervention programs concerned with obesity; more than 23 million children and adolescents in this country are either overweight or obese, which puts them at risk for health problems such as diabetes and coronary heart disease, resulting in death at an early age. Most of these children are racial and ethnic minorities. First Lady Michelle Obama should receive kudos for organizing the “Let’s Move!” campaign to combat this problem primarily through the schools.

In this new publication, I am privileged to have the authoritative contributions of the best health policy analysts, researchers, key opinion and thought leaders, politicians, health administrators, theoreticians, professors, clinicians, and medical writers in this country. This assemblage of noteworthy contributors is important because our aims are to assure that the federal government does not ignore the unfinished job of eliminating healthcare disparities but instead gives consummate attention to this task and provides transparency for the American public about the intricacies embedded in this massive law as concerns its impact on healthcare disparities.

This book is entirely pertinent and timely regarding the two issues of healthcare disparities and healthcare reform. We have already seen that the federal government’s decade-long program, Healthy People 2010, has failed fully to live up to expectations, although there has been some progress made on a small number of the measures. We need to start preparing for the next iteration, Healthy People 2020, and the new impetus towards healthcare reform may give us a reasonable
chance of making a real difference by the end of the next decade, through the elimi-
nation of disparities.

Attempts are being made by opponents of healthcare reform to scuttle the efforts
that are being made to make it work on behalf of the American people; some of
these efforts began well before the bill was passed. For example, there are those
who are trying to decrease the already deficient state of diversity in training of
medical professionals. I refer specifically to the fact that the U.S. Commission on
Civil Rights (USCCR) sent a letter to President Obama on October 9, 2009 protest-
ing any funding preferences for medical schools and other medical education insti-
tutions that provide incentives to minority group applicants; this is alleged by the
USCCR as evidence of “reverse discrimination” contained in the healthcare reform
bill and is unneeded because the USCCR perceives that there are no real disparities
in healthcare provision. For the premier government institution designated to pro-
tect the civil rights of our citizens to take such a stand is an egregious example of
how even government, which is sworn to protect the welfare of the people, can
operate adversely against those in need. This is an issue that is critical to the devel-
opment of more minority group doctors, nurses, and other health professionals.
Fortunately, Congress did not heed the advice of the USCCR and included special
appropriations for institutions of medical education that provide incentives to racial
and ethnic group applicants, and the federal government deserves to be credited for
its attempts to increase diversity in the healthcare workforce. Although the job is
not done, the government has made a good start to resolving the healthcare crisis,
and all Americans should come together to create the loom that will weave the
pieces of a currently fragmented and dysfunctional healthcare system into a solid
fabric of healthcare equity. The nation cannot afford to wait any longer.

Los Angeles, CA

Richard Allen Williams, M.D., F.A.C.C.
Acknowledgments

I was privileged to receive significant assistance from a number of individuals in producing this book. They helped me in many areas, not the least of which was encouragement to take on the task in the first place. The editorial staff of Springer Science + Business Media, the publishers, including Paul Dolgert and Frances Louie, deserves consummate credit for inviting me to reprise the effort made in producing the widely acclaimed book, *Eliminating Healthcare Disparities in America: Beyond the IOM Report*, which I edited in 2007 that was the forerunner of this book. They foresaw the emergence of healthcare reform and correctly anticipated the need for a scholarly analysis of the impact of the new law on healthcare disparities. I must also thank all of my contributing authors who selflessly dedicated their time and effort to write their excellent manuscripts for the book. Others who helped in various ways are Dr. Sachin Jain, Jeryl Bryant, Dr. John Ayanian, Jeff Allen, and Dr. Augustus White III. I am eternally grateful to all of them and to others who are too numerous to name.

Richard Allen Williams, M.D., F.A.C.C.
About the Editor

Dr. Richard Allen Williams is a product of segregated educational and healthcare systems and has experienced disparities since birth. Because of lack of access to medical facilities for blacks when he was born in Wilmington, Delaware, he was delivered by a mid-wife at home. As a boy growing up in Wilmington, Delaware, he attended all-black schools from kindergarten through 12th grade, graduating at the top of his class and winning a full scholarship to Harvard University as the first black student from Delaware to matriculate there. His Harvard class, which celebrated its 50th reunion in 2007, was the first to have integrated dormitories and dining facilities on that campus. He was an honors graduate and went on to medical school at the State University of New York (Downstate), subsequently becoming the first African American intern at the University of California San Francisco Medical Center, and was the first black postgraduate fellow (Cardiology) at Brigham and Women’s Hospital and Harvard Medical School.

After establishing a program (The Central Recruitment Council) at Harvard Medical School to recruit minorities for the school and for hospital residencies and postgraduate trainees in collaboration with Dean Robert H. Ebert, he moved to Los Angeles where he was appointed Assistant Medical Director at the new Dr. Martin Luther King, Jr. Hospital in Watts, California in 1972. He succeeded in securing a multi-million dollar grant from the National Institutes of Health to establish the King-Drew Sickle Cell Center, which he and Dr. David Satcher administered. He moved to UCLA in 1974 and eventually headed the Cardiology Department at the UCLA-West Los Angeles Veterans Administration Hospital. Dr. Williams rose to full professor at UCLA in 1984.

In 1975, McGraw-Hill published his first book, the pioneering *Textbook of Black-Related Diseases*, which covered the broad spectrum of medicine from the perspective of how African Americans experience illness. It set the tone for recognizing
the importance of race and ethnicity in the evaluation, diagnosis, and treatment of patients, and the need to collect health data according to racial and ethnic designation, which the federal government and other healthcare entities now do. He also served as editor of *Humane Medicine*, vols. I and II (1999, 2001), *The Athlete and Heart Disease* (1999), *Eliminating Healthcare Disparities in America: Beyond the IOM Report* (2007), and was co-editor of *The Heart of the Matter* (2008).

Dr. Williams is the Founder of the Association of Black Cardiologists (ABC, 1974) and of the Minority Health Institute (MHI, 1985). He continued his involvement on the healthcare disparities community scene as Chair of the Institute for Multi-cultural and Minority Medicine (IAMMM, 2006). He was honored recently with a Lifetime Achievement Award from Harvard Medical School, and was inducted as a Fellow into the American College of Cardiology.
Contents

Part I Underlying Causes of Healthcare Disparities

1 Introduction: An Overview of the US Healthcare System and US Health Disparities at the Beginning of the Twenty-First Century ................................................................. 3
Louis W. Sullivan

2 Historical Perspectives of Healthcare Disparities: Is the Past Prologue? ......................................................... 7
Richard Allen Williams

3 Epidemiologic Profiles of Racial and Ethnic Disparities in Health and Health Care ............................................. 23
George A. Mensah and Maleeka J. Glover

4 Cultural Diversity in Medicine: Health Status of Racial and Ethnic Minorities ..................................................... 41
Richard Allen Williams

Part II Current Problems

5 Perspective: Health Care and the Politics of Race ......................... 71
M. Gregg Bloche

6 Perspective: The Spectrum of Health-care Disparities in the USA ........................................................................ 85
Thomas A. LaVeist

7 Perspective: Barriers to Eliminating Disparities in Clinical Practice – Lessons from the IOM Report “Unequal Treatment” .................................................................................. 97
Joseph R. Betancourt, Angela Maina, and Marina C. Cervantes
8 Perspective: Second-Class Medicine – Implications of Evidence-Based Medicine for Improving Minority Access to Health Care .............................................................. 115
Randall W. Maxey and Richard Allen Williams

9 Perspective: The Compelling Need for Health Literacy ....................... 135
Monica L. Joyner

Part III Approaches to Correcting the Problems

10 The Good, the Bad, and the Ugly: Overview of the Health Reform Law and Its Impact on Health-Care Disparities .................... 145
Richard Allen Williams

11 The Diversity Benefit: How Does Diversity Among Health Professionals Address Public Needs? ...................................................... 167
Brian D. Smedley and Ilana S. Mittman

12 The Role of Communities in Eliminating Health Disparities: Getting Down to the Grass Roots .......................................................... 195
JudyAnn Bigby

13 The Potential Impact of Performance Incentive Programs on Racial Disparities in Health Care ..................................................... 211
Alyna T. Chien

14 Eliminating Disparities in Health Care Through Quality Improvement ........................................................................................... 231
Kevin Fiscella

15 Monitoring Socioeconomic Determinants for Healthcare Disparities: Tools from the Public Health Disparities Geocoding Project ........................................................................ 269
Nancy Krieger, Pamela D. Waterman, Jarvis T. Chen, S.V. Subramanian, and David H. Rehkopf

16 Perspective: Title VI, Healthcare Reform, and the Need for a State Antidiscrimination Law ................................................... 313
Vernellia R. Randall

17 Quality of Care and Health Disparities: The Evolving Role of the Government ................................................................. 329
Garth N. Graham
18 The Association of Black Cardiologists: A Small-Group Success Story in Addressing Healthcare Disparities ....................... 351
Richard Allen Williams and Icilma V. Fergus

19 Breathing Easier in Seattle: Addressing Asthma Disparities Through Healthier Housing .................................................. 359
James W. Krieger, Tim K. Takaro, and Janice C. Rabkin

20 Breast and Prostate Cancer Healthcare Disparities .................. 385
Elise D. Cook

21 The Role of Health IT in Eliminating Health Disparities ............ 399
Sachin H. Jain and David Blumenthal

22 Remote Area Medical®: Pioneers of No-Cost Health Care .......... 413
Stan Brock and Amanda Wilson

23 Principles for Eliminating Racial and Ethnic Disparities in Health Care Under Healthcare Reform ............................................... 421
John Z. Ayanian and Richard Allen Williams

Index .................................................................................................................. 433
Contributors

John Z. Ayanian, M.D., M.P.P., F.A.C.P.
Professor of Medicine and Health Care Policy, Harvard Medical School
Professor of Health Policy and Management, Harvard School of Public Health,
Boston, MA, USA

Joseph R. Betancourt, M.D., M.P.H.
Director, The Disparities Solutions Center Senior Scientist,
The Institute for Health Policy, Director of Multicultural Education,
Massachusetts General Hospital, Associate Professor of Medicine,
Harvard Medical School, Boston, MA, USA

JudyAnn Bigby, M.D.
Secretary, Executive Office of Health and Human Services,
Commonwealth of Massachusetts, Boston, MA, USA

M. Gregg Bloche, M.D., J.D.
Professor of Law, Georgetown University, Senior Fellow,
The Brookings Institution, Adjunct Professor, Bloomberg School of Public Health,
Johns Hopkins University, Washington, DC, USA

David Blumenthal, M.D., M.P.P.
National Coordinator for Health Information Technology,
Department of Health and Human Services, Washington, DC, USA

Stan Brock
President/CEO, Remote Area Medical, Knoxville, TN, USA

Marina C. Cervantes, B.A.
The Disparities Solutions Center, Massachusetts General Hospital,
Boston, MA, USA

Jarvis T. Chen, Sc.D.
Department of Society, Human Development and Health,
Harvard School of Public Health, Boston, MA, USA

Alyna T. Chien, M.D., M.S.
Assistant in Medicine, Children’s Hospital Boston, Harvard Medical School,
Boston, MA, USA
Contributors

Honorable Donna M. Christensen, M.D.
United States Congresswoman, House of Representatives, Washington, DC, USA

Elise D. Cook, M.D., M.S.
Associate Professor, Department of Clinical Cancer Prevention,
MD Anderson Cancer Center, University of Texas, Dallas, TX, USA

Icilma V. Fergus, M.D., F.A.C.P., F.A.C.C.
Assistant Professor of Clinical Medicine, Columbia University Medical Center,
Head of Cardiology, Harlem Hospital Center New York,
NY, USA

Kevin Fiscella, M.D., M.P.H.
Associate Professor, Family Medicine, Community and Preventive Medicine,
and Oncology, University of Rochester School of Medicine, Rochester,
NY, USA

Dr. Maleeka J. Glover, ScD, M.P.H.
LCDR, U.S. Public Health Service,
Senior Research Scientist Officer—Epidemiologist,
Centers for Disease Control and Prevention, Atlanta, GA, USA

Garth Graham, M.D., M.P.H.
Deputy Assistant Secretary for Minority Health, Director,
Office of Minority Health, Department of Health & Human Services,
Washington, DC, USA

Sachin H. Jain, M.D., M.B.A.
Special Assistant to the National Coordinator for Health Information Technology,
Department of Health & Human Services, Washington, DC, USA

Monica L. Joyner, M.D.
Executive Director, The Health Literacy Foundation, Indianapolis, IN, USA

James W. Krieger, M.D., M.P.H.
Chief, Chronic Disease and Injury Prevention Section Public Health—Seattle
and King County, Clinical Associate Professor of Medicine and Health Services,
University of Washington, Seattle, WA, USA

Nancy Krieger, Ph.D.
Professor, Department of Society, Human Development and Health,
Harvard School of Public Health, Boston, MA, USA

Thomas A. LaVeist, Ph.D.
William C. and Nancy F. Richardson, Professor in Health Policy Director,
Hopkins Center for Healthcare Solutions, Johns Hopkins Bloomberg,
School of Public Health, Baltimore, MD, USA
Angela Maina, B.S.
Department of Multicultural Education, Massachusetts General Hospital,
Boston, MA, USA

Randall W. Maxey, M.D., Ph.D.
Past President, National Medical Association, President and CEO,
Executive Healthwatch, Inc., Los Angeles, CA, USA

George A. Mensah, M.D., F.A.C.P., F.C.P. (SA) Hon
Former Chief Medical Officer, National Center for Chronic Disease Prevention
and Health Promotion, CDC Director, Heart Health and Global Health Policy
Pepsico Global Research & Development, Purchase, NY, USA

Ilana S. Mittman, Ph.D., M.S.
Director, Health Policy Research, The Sullivan Alliance to Transform the Health
Professions, Inc., Washington, DC, USA

Janice C. Rabkin, Ph.D., M.P.H.
Affiliate Faculty, School of Public Health and Community Medicine
University of Washington, Seattle, WA, USA

Vernellia R. Randall, B.S.N., M.S.N., J.D.
Professor of Law, The University of Dayton School of Law, Dayton, OH, USA

David Rehkopf, Sc.D.
Department of Epidemiology and Biostatistics, UCSF, San Francisco, CA, USA

Brian D. Smedley, Ph.D.
Vice President and Director, Health Policy Institute, Joint Center for Political
and Economic Studies, Washington, DC, USA

S.V. Subramanian, Ph.D.
Department of Society, Human Development and Health, Harvard School
of Public Health, Boston, MA, USA

Louis W. Sullivan, M.D.
President Emeritus, Morehouse School of Medicine Secretary, 1989–1993,
U.S. Department of Health and Human Services Chairman
The Sullivan Alliance to Transform
America’s Health Professions, Washington, DC, USA

Tim K. Takaro, M.D., M.P.H., M.S.
Associate Professor, Associate Dean for Research
Faculty of Health Sciences, Simon Fraser University, Burnaby, BC, USA

Pamela D. Waterman, M.P.H.
Department of Society, Human Development and Health, Harvard School
of Public Health, Boston, MA, USA
Richard Allen Williams, M.D., F.A.C.C. (Editor)
Clinical Professor of Medicine, UCLA School of Medicine,
President/CEO, The Minority Health Institute, Inc.,
Founder, The Association of Black Cardiologists, Inc.,
Chairman of the Board, Emeritus Institute for the Advancement
of Multicultural and Minority Medicine,
Washington, DC, USA

Amanda Wilson
Program Associate, Remote Area Medical Foundation, Knoxville, TN, USA
Part I
Underlying Causes of Healthcare Disparities
Chapter 1
Introduction: An Overview of the US Healthcare System and US Health Disparities at the Beginning of the Twenty-First Century

Louis W. Sullivan

The health of the citizens of the USA improved in many ways during the twentieth century with advances in public health practices, expansion of the scientific basis of medicine, and improvements in the training of America’s health professionals. Average life expectancy at birth increased from 47.3 years in 1900 to 77 years in 2000. Smallpox was eliminated from the world with a worldwide comprehensive vaccination initiative. By 1982, poliomyelitis had been eliminated from the western hemisphere, although a few foci of this viral disease remain in the developing world. Many other infectious diseases, which were prevalent in the USA in 1900, are much less frequent today, such as tuberculosis, pneumonia, diphtheria, and others.

The introduction of sulfa drugs in the 1920s, followed by the discovery of penicillin in the 1930s, ushered in a decades-long cascade of new anti-infective “wonder drugs,” which improved the effectiveness of medical care.

US infant mortality rates decreased from approximately 100 per 1,000 live births in 1900 to 6.89 per 1,000 live births by 2000, along with significant improvements in maternal care during pregnancy [1].

Surgical techniques introduced in the twentieth century included new procedures in 1944 to correct congenital heart defects, operations on heart valves malformed by rheumatic fever in 1957, transplantation of the human heart in 1967, and stents for occluded coronary or carotid arteries, and numerous mechanical devices to assist the failing heart, introduced during the final quarter of the twentieth century. Transplantation techniques developed for other essential organs, including kidneys, livers, and bone marrow are now in common use.

Impressive gains were made in treating various cancers, including surgery, X-ray therapy, chemotherapy, and immunotherapy.

L.W. Sullivan
President Emeritus, Morehouse School of Medicine, Secretary, 1989–1993, U.S. Department of Health and Human Services, Chairman, The Sullivan Alliance to Transform, America’s Health Professions, Washington, DC, USA

E-mail: sullivan@pemsm.com
The field of orthopedics has been transformed from a twentieth-century focus on setting fractures and use of physiotherapy for musculoskeletal disorders to the development and use of artificial joints for severe arthritis, to delicate muscle and joint surgery, including sports medicine and other subdisciplines.

In this first quarter of the twenty-first century, we are using our new information on the structure and function of the human genome to confidently declare the beginning of a new era of “personalized medicine,” providing more individually tailored medical therapies based upon our specific genetic profile.

In spite of this stunning array of scientific advances in the twentieth century, new capabilities for diagnosis of disorders, sophisticated treatments of illness and injury, and prevention of disease, the USA today has unacceptable deficiencies in its healthcare system: simply put, “we have a distribution problem.” Not all of our citizens have access to this abundant array of healthcare capabilities [2]. Those who are poor, do not have health insurance, are members of US minority populations (African American, Hispanic Americans, and American Indian/Native Alaskan/Pacific islanders) encounter too many barriers to “the best healthcare system in the world.” These barriers are often financial, but may be also the result of bias (overt and subconscious), communications difficulties due to language or cultural differences, mistrust of the system by minority populations, and underutilization, nonuse or inappropriate use of the healthcare system [3].

Combinations of these factors have historically contributed to significant disparities in access to health care and to differences in health status and continue to do so today.

The presentations and descriptions in this publication, edited by Richard Allen Williams, MD, one of the leading scholars in the field of health disparities, are intended to analyze the present status of health disparities in the USA and to provide strategies to eliminate them. They focus on those areas where significant progress is being made, as well as other areas which need more (or better) attention and resources.

One of those areas that clearly needs more attention is the status of health manpower in the country [4, 5]. For too long, we have had a growing shortage of nurses for our increasingly sophisticated healthcare system; our nation is on the cusp of a shortage of physicians, which will become more apparent as more of our citizens try to utilize the health insurance being made available by the recently passed health reform legislation. Shortages of public health personnel are increasingly acute, particularly for our local and state public health agencies. More pharmacists are needed, as the range and complexity of our therapies increase, and as more of our citizens seek information about using the medicines they are prescribed.

Our nation is undergoing a profound demographic shift, with racial and ethnic minorities comprising one-third of our population today. Because of the projected increase in our nation’s minority populations, the US Census Bureau states that by 2042 (some three decades from now), there will no longer be a white majority in our country [6].

When we examine the racial and ethnic make-up of our nation’s health professionals, we see that Hispanic Americans, African Americans, and Native Americans/
Alaskans/Hawaiians make up only 9% of our nurses, 6% of our physicians, and 5% of our dentists [7]. This mismatch between the US population and our health professions can, and does, lead to difficulties in communication, understanding, and establishing trust between the physician (or nurse, dentist, etc.) and the patient. This affects compliance with proposed therapies and with recommended return visits, thus compromising the quality (and/or effectiveness) of the care received and health outcomes attained.

Efforts to increase the racial and ethnic diversity of our health professionals should be expanded. One such effort is being undertaken by the Sullivan Alliance, which is stimulating the development of alliances within states, between academic health centers and undergraduate colleges with significant enrollments of minority students [8]. These alliances promote programs to strengthen the preparation of minority students for success in applying, enrolling, matriculating, and graduating from a health professions program. Participation in competitive, peer-reviewed research programs is part of the summer internship experience of the undergraduate students. The state alliances also encourage the recruitment, retention, and advancement of minority faculty in health professions schools, to serve as teachers, role models, counselors, researchers and to enrich the academic environment for all health professions students.

The new health reform bill passed by the congress and signed by the President represents the beginning of a noble effort to reform our nation’s healthcare system. Success in this undertaking will take time (a decade or more), manpower, financial resources, and a number of administrative efforts to increase efficiency and effectiveness and to reduce medical and administrative errors.

It will also require measures to improve the health literacy and the health behaviors of our citizens, who must be active partners with their health providers in achieving healthier lifestyles. This means healthier diets (to reduce obesity and diabetes), more regular exercise (for cardiovascular, pulmonary, and musculoskeletal health), avoiding tobacco use and not using addictive drugs, improving air quality in our communities (to reduce asthma and lung disease), and other environmental health challenges.

Most of all, we need leadership from the President, the US Secretary of Health and Human Services, our state and local health commissioners, from our health professionals (individually and from their professional associations), from our business leaders, our teachers, community health centers, and from community leaders (lay and religious). We need to change the culture of our healthcare system from a “culture of sick care,” focused on repairing damage from illness and injury, to a “culture of wellness,” in which health is everyone’s responsibility – the individual, health professionals, employers, teachers, insurers, architects and builders (residential and commercial), community leaders, federal, state and local governments, and others.

To the degree that we succeed in this reorientation, in this culture change, we will succeed in eliminating the startling disparities between the health of white Americans and that of Americans of color.

So, let us begin this journey to a healthier future for our citizens and our country – with enthusiasm, with commitment, with confidence, and with determination.
References

Chapter 2
Historical Perspectives of Healthcare Disparities: Is the Past Prologue?

Richard Allen Williams

Abstract What is the historical background of disparities in healthcare delivery and how did these disparities evolve? The history goes back to slavery, where what Byrd and Clayton have termed the slave health deficit originated and was nourished. In this chapter, the concept that slavery gave rise to a racist system of healthcare delivery is explored, and the observation that this system is still operative is documented by several pointed examples. The historical spectrum includes examples from ancient times to the present, from the inception of slavery through emancipation, Reconstruction, the Civil Rights era, and other periods and demonstrates heavy medical, legal, sociological, and religious involvement in shaping the current picture of healthcare disparities.

Keywords Slavery • Healthcare disparities • Supreme Court • Race • Racist • Superior • Inferior • Skin colour • Great Chain of Being • The Bible • Phrenology • Complexion • Mythology • Discrimination • Ku Klux Klan • Prince Henry the Navigator • Galen • Plato • Linnaeus • Abraham Lincoln • Samuel George Morton • Crania Americana • Unitarian Hypothesis • Samuel Stanhope Smith • Dred Scott decision • Tuskegee Syphilis Study

R.A. Williams (✉)
Clinical Professor of Medicine, UCLA School of Medicine, President/CEO, The Minority Health Institute, Inc., Founder, The Association of Black Cardiologists, Inc., Chairman of the Board, Emeritus Institute for the Advancement of Multicultural and Minority Medicine, Washington, DC, USA e-mail: mhinst@aol.com

Roots

As was expertly shown in their monumental book, *An American Health Dilemma* [2], Byrd and Clayton have drawn a picture of racist ideology and thinking regarding people of color that has led to a historical profiling of blacks and others as inferior, undesirable, inadequate, and unfit to be placed in the same species as whites. This negative profiling began early on in recorded history, and evidence for this type of attitude can be found in some of the very early writings by noted scholars, scientists, educators, professors, and physicians [3]. Thus, the psychological and attitudinal roots for perceived differences between peoples became established in the minds of the intelligentsia and the power elite, and it was just a short jump to concluding that darker-skinned persons should be subjugated and should receive a different standard of care and handling. Although it is difficult to pinpoint exactly where and when this differential thinking began, there are several instances in recorded ancient history of its existence, such as in Greece during the eras of Plato, Aristotle, Herodotus, and Galen and in Rome during the reign of the Caesars [4].

The practice of discrimination according to skin color may have begun in ancient Greek mythology, which related that differences throughout the world in skin color were created when Helios, the sun god, allowed his son Phaeton to drive the sun chariot. An erratic driver, Phaeton flew too close to certain parts of the earth, causing the residents to become burnished, and too far away from other areas, causing people there to have blanched skin and the environment to be cold.

As to the roots of slavery, a distinction must be made between the ancient form, which resulted principally from warfare with many of the losers being forced into bondage, and modern slavery, which was based largely on subjugating what were deemed to be inferior beings to involuntary servitude. The former was seen in almost every country [5] and white, black, and brown slaves were to be found during the Middle Ages in Christian Europe and in Africa. Christians and Moslems made a crucial modification of this pattern before European trade opened, by capturing and enslaving each other on religious grounds. In the fifteenth century, in the year 1444, to be exact, Prince Henry, the Navigator of Portugal, made another fateful deviation in the annals of slavery when he visited the west coast of Africa seeking the storied great wealth that allegedly lay within its borders. He and his men captured many black natives and sailed back to Portugal with their human booty [6]. Thus, the European slave trade was opened and was to continue for centuries.

During the time that the practice of slavery was flourishing, many scientific opinions were advanced about the physical characteristics of the enslaved blacks. Most of the arguments were about whether blacks were of a separate species from whites. Theories abounded from those who believed in a unitary origin of humans and those who believed in multiple origins or pluralism [7]. The former group included scientists such as Buffon, Cuvier, Darwin, Rush, and Smith; the latter group consisted of others with equally impressive credentials such as Agassiz, White, Caldwell, Meigs, Warren, Morton, Nott, and Glidden. It should be clear that all of these scientists believed that blacks were inferior to whites, no matter what they thought about origins. One of the earliest scientists of the Middle Ages to
espose the separate-origin theory was Paracelsus (1493–1541), a Swiss who did not believe that non-whites were descended from Adam and Eve as whites were. Two foci of the argument about whether all humans were of one creation and therefore were of a single species were the statements by the English philosopher John Locke and the pronouncements of Thomas Jefferson. Jefferson, who essentially wrote the Constitution of the United States, held that all men are created equal and by inference are entitled to equal rights and freedoms in a democratic society (although he himself was a slaveholder of note). Locke stated that there was nothing “more evident, than that creatures of the same species and rank, … born to all the same advantages of nature, and the use of the same faculties, should also be equal one amongst another without subordination or subjection.” The Swedish anthropologist Linnaeus (Carl von Linne’, 1707–1778) produced the monumental work *Systemae Naturae* in 1735 [8], which established the binomial nomenclature that allowed a specimen to be identified by genus and species, and although it included all races of man under one species, it also extolled the alleged physical and other characteristics of Caucasians while denigrating those of non-whites, especially blacks. Nonetheless, it derailed the Great Chain of Being theory [9] which dictated that there was a hierarchical progression of animals from the lowest, apelike forms upward to the Caucasian or Aryan form which occupied the pinnacle position atop the animal world. It suggested that the black race was closest to the apes. This theory had held sway from the time of Plato in the fifth century BC for 2000 years and was the basis of racist dogma relating to physical differences between the races. It was bolstered in the eighteenth century when S.T. von Sommerring, a German professor of medicine, performed dissections on blacks and allegedly showed that the anatomy of blacks was closer to that of the apes than was the white man [10].

This concentration on physical differences between the races was reprehensible and was debated in the major medical universities of the eighteenth and nineteenth centuries such as Harvard, Pennsylvania, and South Carolina. Lecturers on the subject of anthropology, which was a relatively new science created by Linnaeus, often drew thousands of attendees. Ethnology was born, and pseudosciences arose, such as phrenology, which purported to document the inferiority of all races to Caucasians based on skull measurements. The most prominent men of medicine and science provided documentation of their ideas that there were substantive differences in physiognomy between whites and the other races, which led them to declare that whites were naturally the dominant race. One example was Baron Georges Cuvier of France [11], the world’s foremost zoologist, who put on display in Europe the so-called Hottentot Venus, a woman from Africa whose most outstanding physical feature was a large derriere due to steatopygia or storage of fat in the buttocks area. At autopsy, other differential features were found, and Cuvier made this a *cause celebre* to exemplify his points about racial differences. Another proponent of this point of view was Dr. Louis Agassiz of Harvard, who held to the single-origin theory on religious grounds based on the Book of Genesis but felt that environmental exposure was the reason for the vast differences between black and white (he later changed over to the multiple-origin side after his first close encounter with blacks in Boston, being struck by the tremendous physical differences between blacks and whites). Count G.L.L. Buffon of France (1707–1788)
apparently subscribed to the same view based upon his concept of specific infertility:
the production of fertile offspring by the crossing of different organisms was
evidence of a common origin, although Buffon had no doubt about the superiority
of whites over other races.

It should be clarified that although Linnaeus, Cuvier, Agassiz, Buffon, and many
other anthropologists and scientists of the period from the seventeenth
through the nineteenth century were tenuous advocates of the single-origin theory,
they were also strong opponents of the idea that there was parity between the races,
and they used all of their research efforts to “document” a hierarchy of the races of
man based on physical differences. Even Thomas Jefferson’s close friend Dr. Benjamin
Rush, an anti-slavery, liberal activist of the time who wrote, “The history of the cre-
ation of man and of the relation of our species by birth, which is recorded in the Old
Testament, is the … strongest argument that can be used in favor of the original and
natural equality of all mankind,” felt that blacks were defective as evidenced by their
black skin, which he pronounced was caused by “the LEPROSY.” He used the cele-
brated case of ex-slave Henry Moss of Philadelphia as an example of a black man
who was spontaneously turning white (the dermatological condition vitiligo which
Moss almost certainly manifested had not yet been described), and he prescribed a
number of remedies such as the topical application of muriatic acid and unripened
peach juice to be used on Negroes to “cure” their blackness and reveal the whiteness
that lay under their skin. A similar view was held by Dr. Samuel Stanhope Smith, who
was Professor of Moral Philosophy at the College of New Jersey (Princeton) and later
president of that institution. Dr. Smith attempted to reconcile the views of those who
favored the single-origin theory based on religious grounds (Genesis) and those
who opposed this view based on scientific observation. He attempted to “establish the
Variety of Complexion and Figure in the Human Species*, which he published in
Philadelphia in 1797. Smith contended that the black color of the Negro was due to
the effect of climate and noted that there was a gradation in complexion in proportion
to latitude. He further concluded that blacks were covered by a “universal freckle”
caused by the sun. His philosophical opinions about the origin of skin color thus mir-
rored Greek mythology cited above.

Professor Smith’s unitarian hypothesis set off a firestorm of controversy and
debate among the scientific *cognoscenti*. The most important negative reaction
came from Dr. Samuel George Morton of Philadelphia, a professor of anatomy and
a physician, who put forth an alternate hypothesis based on multiple origins, and in
1839 he published the results of his research in his epochal book, *Crania Americana.*
In his book, he provided details of his studies of the skull specimens of the races of
man with the intent of demonstrating that there were very important differences to
be observed in skull size and inferences to be drawn about corresponding brain size
and intelligence. Thus, the pseudoscience of phrenology, created by Viennese phy-
sician Franz Joseph Gall (1758–1828) [12], was perpetuated in the USA, with
measurements of the human skull with calipers replacing esthetic description.
Morton measured the internal capacity of the cranium and determined that the largest
skulls were found in Caucasians and the smallest in Ethiopians. In 1840, Morton
concluded “that the brain in the five races of men,” Caucasian, Mongolian, Malay, American, and Negro, was “successively smaller in each,” with corresponding differences in intellect. He also alluded to the superiority of the Caucasian brain. His findings attracted the attention and belief of prominent Americans such as Horace Mann and Dr. John Collins Warren of Harvard Medical School. Morton carried his arguments to the pinnacles of scientific scrutiny, and on the cold night of February 8, 1848 when the distinguished fellows of the Academy of Natural Sciences of Philadelphia met to hear him lecture about phrenology, he presented an 18-year-old Hottentot boy, provided as a courtesy by the American Vice Consul in Egypt, George Robins Gliddon, who was also an amateur anthropologist and fervent phrenologist and collector of skulls. Morton, commenting on the South African boy’s head, described it as completely foreign to the European concept of the ideal physical features for the human species. The “ideal physical features” had been rapturously commented upon in 1799 by the English surgeon Charles White (1728–1813) in his Account of the Regular Gradation in Man when he intoned, where else shall we find “that nobly arched head, containing such a quantity of brain …? Where that variety of features, and fullness of expression; those long, flowing, graceful ringlets; that majestic beard, those rosy cheeks and coral lips? Where that … noble gait? In what other quarter of the globe shall we find the blush that overspreads the soft features of the beautiful women of Europe, that emblem of modesty, of delicate feelings …? Where, except on the bosom of the European woman, two such plump and snowy white hemispheres, tipt with vermilion?” White’s conclusion was that Caucasians were the initial link in the “immense chain of beings, endued with various degrees of intelligence … suited to their station in the general system,” extending from “man down to the smallest reptile …” To him, this was evidence of species differences among humans [12].

Shackles and Chains

Advocates of slavery used Morton’s scientific information to justify keeping Negroes in bondage, since it had been scientifically proven that blacks were inferior to whites and quite probably were of a separate species.

How could the deliberations of the most brilliant minds in America be refuted? All that remained was for a legal opinion to be rendered on the rights of the Negro regarding Thomas Jefferson’s principle that all men are created equal and thus were privileged to enjoy the same right to freedom that whites did. An unfortunate decision concerning the question of freedom for a black man was rendered in 1857, which was one of the heaviest blows suffered by anti-slavery and pro-equality forces that would echo through the annals of history for decades up to the present time. This was the infamous case of Dred Scott, a Missouri slave who sued for his freedom after he had spent 4 years in a free state where he had been taken by his master. The case was argued before the US Supreme Court in 1857 which ruled against Dred Scott, who was remanded to slavery. In reading the opinion, Chief
Justice Roger Taney declared that a Negro was worth only three-fifths of a white man and therefore was an inferior being of a separate species who could not be a citizen and who had “no rights that a white man was bound to respect.” This ruling gave legal status to prejudice, stereotyping, and discrimination, and it has had ramifications in all fields, including health care. Effectively, when the Dred Scott decision was handed down, it gave official scientific and legal approval by the federal government for slavery and poor healthcare delivery to blacks.

Another federally related incident, which bolstered the cause of slavery, was associated with the US Census of 1840. Dr. Edward Jarvis, a physician in Boston, made the alarming discovery that the sixth Census had apparently been defrauded to indicate an increase in insanity among free Negroes in the North as compared to enslaved Negroes in the South. The incidence of insanity among free Negroes in the North was 1 in 162.4, whereas it was only 1 in 1,558 among slaves in the South. There seemed to be a correlation between lunacy and latitude among blacks, with an increased frequency or gradient of insanity in the territory from Mississippi to Maine, where every fourteenth Negro was noted to be either a lunatic or an idiot. The pro-slavery forces claimed that this was evidence of the protective effect of slavery over the mental status of blacks, who apparently could not compete in a free society without going completely mad. Determining by detailed analysis that the figures on allegedly insane blacks in many towns in the North exceeded the total numbers of blacks living there, Dr. Jarvis exposed the statistics as fraudulent and published his findings in *The American Journal of the Medical Sciences* in 1844 [13]. Historians suspect that the fraud was perpetrated by John C. Calhoun of South Carolina who, as Secretary of State, was in charge of the Census. His co-conspirators were Gliddon and Morton, who provided scientific consultation to him. This fraud perpetrated by a federal official on a United States Government document was embarrassing, and Calhoun’s conduct was attacked by John Quincy Adams as “so total a disregard of all moral principle” [14]. Dr. Jarvis continued his efforts to have the Census of 1840 corrected or expunged, but he was rebuffed.

This fraud was not an isolated instance of an attack on black mental status. It was part of a pattern that had been seen before and would be seen again. Some of the more recent attacks were by Dr. Arthur Jensen of Stanford and the eugenics movement during the 1960s, by Dr. William Shockley of the University of California at Berkeley (the Nobel Laureate inventor of the transistor who proposed a government plan to sterilize individuals with low IQ scores), and by Dr. Richard Herrnstein and Dr. Charles Murray of Harvard in their 1980s book, “The Bell Curve” [15], which impugned black intelligence and suggested that blacks were intellectually inferior to whites, according to their experiments.

**Reconstruction or Deconstruction?**

After the Emancipation Proclamation was signed (New Year’s Day, 1863) by a less than egalitarian President Abraham Lincoln (“I will say … there is a physical difference between the white and black races which I believe will forever forbid the
two races from living together on terms of social and political equality," Lincoln had declared in his debate with Judge Douglas) [16], the nation entered what was called the Reconstruction era. The ostensible purpose was to bind up the wounds of war, which ended in 1865, and also to provide some type of health-related benefits for poor Negroes who were now on their own, away from the plantations and slave masters. The federal government created the Freedman’s Bureau which authorized certain public land grants dedicated to Negro welfare. The first of these was the establishment of Freedman’s Hospital in Washington, DC followed in 1868 by the building of the first college of medicine for the training of black doctors, called Howard University College of Medicine, near the site of the hospital. This was followed in 1876 by the opening of Meharry Medical School in Nashville, Tennessee.

There seemed to be genuine progress towards increasing the standard of healthcare delivery to blacks, but that was not to last. Jealous Southern whites, rebounding from their losses and reversals of fortune during the Civil War, became determined to reclaim their land, their political status, and their control over healthcare matters. In effect, they became dedicated to deconstructing Reconstruction, by kicking out the so-called carpet-baggers whom they viewed as Yankees who ventured into the South to exploit the defeated Confederates and were using the freed slaves as their foils. The Reconstruction Era, which lasted from 1865 to 1877, was established by the Reconstruction Act of 1867 by the Congress in an effort to shore up the miserable post-war conditions in the South. Promises were made to the freed slaves that they would receive reparations from seized confederate property (40 acres and a mule were supposed to be given) [17] in the form of land grants to male heads of households; although the proposal was pushed by powerful Pennsylvania congressman Thaddeus Stevens, this did not materialize to any great extent, and any land that had been confiscated from whites and distributed to blacks was repossessed by the former by order of the Freedman’s Bureau. This was one of the compromises agreed to between the government and the rebel Confederate states to entice the Southerners to rejoin the Union. An effort was made to improve health care for the liberated blacks, who were experiencing their worst health conditions in the immediate post-war period. This dire health situation was partially ameliorated by the Freedman’s Bureau programs cited above, but most of them were not to last, and the Freedman’s Bureau was totally eliminated in 1872. This left freedmen truly on their own and that included responsibility for their own medical care. Fortunately, the move to educate blacks in the medical sciences was growing, and by the turn of the century, 9 of the 11 medical schools dedicated to producing black doctors opened since 1868 were thriving [18] and had produced over 1,000 black doctors. However, the government decided to investigate the quality of all medical colleges in this country and in Canada, and Dr. Abraham Flexner was commissioned to do the job. In 1910, he published his book, *Medical Education in the United States and Canada* [19], in which he recommended that all but two of the nation’s black medical schools be closed – and they were; the only ones allowed to continue were Howard and Meharry, which he suggested should concentrate not on training surgeons or other specialists but should devote their efforts to producing “Negro sanitarians” because Negroes were a source of infection and contagion and as such were a threat to the health of whites. The deficit of schools dedicated to training black doctors
remained until recent years when Morehouse Medical College in Atlanta, Georgia and Drew University in Los Angeles, California, were added. The deficit still remains and still impacts the racial and ethnic minority workforce in the health professions.

**Fifty Centuries of Blacks in Medicine**

The history of blacks involved in medicine began with Imhotep, an Egyptian from sub-Saharan Africa who lived in Egypt in approximately 3000 BC during the reign of King Zoser the Great in the Third Dynasty. Imhotep was renowned as a sage, philosopher, scribe, poet, chief lector priest, magician, and architect who designed and constructed the Step Pyramid at Sakkarah, the world’s first large, human-made stone structure. He was most famed as a physician and was the first person to be known throughout the world as a doctor. Imhotep was probably responsible for the production of the seminal Ebers papyrus, which detailed the treatment of more than 700 diseases. There is evidence that he knew of the circulation of the blood and the beating of the heart thousands of years before William Harvey rediscovered these phenomena and wrote about them in his 1628 treatise, *Exercitatio Anatomica De Motu Cordis et Sanguinis in Animalibus* (Anatomical Treatise on the Motion of the Heart and Blood in Animals), published approximately 4,500 years after Imhotep’s initial discoveries. Imhotep was deified about 2850 BC, and thus this great African physician whose skills were acknowledged by the noted Greek historian Herodotus came to be recognized as the god of medicine 50 centuries ago – almost 2,500 years before Aesculapius laid claim to the same title in Greece.

In the eighteenth century, a number of slaves contributed to medical science despite their bondage. Onesimus, a slave of Cotton Mather in Boston, is credited with initiating the practice of smallpox inoculation along with Dr. Zabdiel Boylston. Onesimus’ work helped to stem the spread of smallpox in the American colonies in 1782, and it no doubt gave Jenner the idea for widespread vaccination that led to his fame. Interestingly, Onesimus and Boylston were vilified for their work because the whites of Boston did not wish to be subjected to medical treatment that emanated from a black person.

In Philadelphia, James Derham was a slave who bought his freedom with the proceeds from a successful medical practice. Papan, a Virginia slave, learned medicine from his masters and became so skilled at treating skin and venereal diseases that the Virginia legislature set him free. Cesar, enslaved in South Carolina, was also rewarded with freedom because of his medical expertise. Primus, another “slave-doctor,” was a pioneer in the treatment of snakebite and rabies; when his master died, Primus took over his surgical practice.

There is abundant evidence that, given a chance, blacks could be educated in medicine, could establish and conduct successful medical practices, and could learn to take care of their own healthcare needs. The earliest black doctor in America was Lucas Santomee, who received his medical education in Holland and practiced in
New York during the Colonial period. The first African American person to graduate from a medical school was Dr. James McCune Smith, who graduated from Glasgow, Scotland in 1837. The first black graduate of an American medical school was Dr. David John Peck in 1847. Martin Robison Delaney was the first black to matriculate at Harvard Medical School; he did not graduate; he was blocked by white students from attending classes, and he was eventually expelled after 2 years by the famous Dean Oliver Wendell Holmes along with two other black classmates. Delaney subsequently obtained his medical degree through preceptorship training and went on to serve with distinction as an Army major during the Civil War.

Other notable early black physicians were Dr. John V. DeGrasse, a graduate of Bowdoin College who studied medicine in Paris and was elected to membership in the Massachusetts Medical Society; Dr. Peter W. Ray, born about 1820 and a Bowdoin graduate who practiced in New York City and became a member of the New York State Medical Society; Dr. Edward C. Howard, born in 1846, who graduated from Harvard Medical School and later cofounded Mercy-Douglas Hospital in Philadelphia; Dr. Major R. Abbott, a graduate of Toronto University Medical School; and Dr. A.T. Augusta, an Army doctor who was the first superintendent of Freedman’s Hospital [20]. Some other outstanding black doctors in medical history were Dr. Daniel Hale Williams, who performed the first operation (a pericardiotomy) on the living human heart in 1893; Dr. Charles Richard Drew, who was head of the British blood plasma project for the US Army in 1941 and conceived the idea of the blood bank during World War II (this project ran into difficulty caused by those who were upset by the possibility that blood from blacks might be given to whites); and Dr. John Beauregard Johnson, chairman of medicine at Howard University School of Medicine, who first called attention to the serious problem of hypertension in blacks.

**Governmental Involvement in Health Care for Blacks**

Many times, the federal government has been the instigator and the supporter of biased healthcare. The government aided and abetted racial discrimination in hospitals by supporting (through the provision of Hill-Burton funds in 1946) the concept of “separate but equal” in which it allowed for separate hospitals for blacks and whites with the proviso that the facilities be equivalent. (The “separate but equal” provision had been established by the 1896 Supreme Court decision in the *Plessy vs. Ferguson* decision, in which the Court held that segregation of facilities such as railroad cars and educational facilities was legal as long as the facilities for blacks were equal to those for whites [21]. This ruling was overturned by the *Brown vs. the Board of Education* decision of the Supreme Court [22] in 1954 when segregation in public education was ruled illegal.) This duplication of medical services was difficult to maintain. I had the opportunity to speak with Dr. W. Montague Cobb, the late brilliant scholar/activist/physician/civil rights leader on April 28, 1988 regarding this quandary. He simply stated, “If they can’t maintain one hospital
system, how in the world can they hope to operate two?” [23]. When it became obvious that this “Jim Crow” hospital arrangement was a farce, black patients were eventually allowed admission to white hospitals, but only to specially isolated black wards, a situation that Dr. Cobb labeled “deluxe Jim Crow.” Black doctors were barred from practicing on their own patients within such institutions. The National Medical Association, an organization of mostly black doctors that had been formed in 1895 to advocate for the right of Negroes to receive a higher level of healthcare delivery and for black doctors to practice freely, held a number of Imhotep Conferences from 1957 to 1963 led by Dr. Cobb at the White House in an attempt to gain equal treatment for blacks, because despite the 1954 Supreme Court decision on Brown vs. the Board of Education, segregation in hospitals persisted. The eighth conference in 1963 got the ear of President Lyndon Johnson, who was at that time debating what should be in the Civil Rights Act that he was preparing for 1964. At about the same time, an important test case went to trial; it was to be the “granddaddy” of all hospital desegregation cases. Entitled Simkins vs. Moses H. Cone Memorial Hospital and originating in Greensboro, North Carolina, this case led to the declaration by the Fourth US Circuit Court of Appeals that the “separate but equal” portions of Hill-Burton were unconstitutional. Thus ended a 17-year period in which federal funds were used to reinforce hospital segregation. To President Johnson’s credit, Title VI of the new Civil Rights Act that was passed in 1964 prohibited racial discrimination in public accommodations, which included hospitals, and it made “separate but equal” illegal. In 1965, Dr. Cobb and his colleague Dr. Hubert Eaton won a discrimination case against Walker Hospital in Wilmington, North Carolina which was the first test case of the new law; it destroyed any vestiges of the “separate but equal” provision and opened up Southern hospitals to black doctors. However, this did not guarantee that the healthcare delivery playing field would be leveled; discrimination did not disappear because it was outlawed by legislation, and in any event, enforcement was almost non-existent and penalties for non-compliance were absent. Indeed, the 1960s may be considered the time period when blatant segregation metamorphosed into subtle discrimination within the healthcare system; racism continued to prevail despite all of the putative legal gains and civil rights advances. Essentially, medical care for blacks was contained in large part within the borders of several urban ghettos and was dispensed through several large municipal medical centers, such as Dr. Martin Luther King, Jr. Hospital in Watts, California, Grady Hospital in Atlanta, Georgia, D.C. General Hospital in Washington, DC, Cook County in Chicago, Charity Hospital in New Orleans, Louisiana, Boston Medical Center in Roxbury, Mass., and Kings County Hospital in Brooklyn, New York. When these institutions became overcrowded, the municipal governments built others like them as well as outpatient clinics, rather than opening the doors and beds of existing hospitals outside the restricted zone. Several high-quality hospitals spurn poor minority patients by simply declining to accept the Medicaid insurance which would pay for the patients’ care. Their excuse has been the burdensome paperwork and bureaucratic process which Medicaid requires. In addition, a large percentage of minority patients have no health insurance coverage, and therefore they could not be treated
at private and some public hospitals and in private doctors’ offices for financial reasons. This essentially protects such hospitals and most white private doctors’ offices from incursions by large numbers of blacks and Latinos, and it has maintained de facto segregation in healthcare delivery in a format of institutional racism, in which the dynamics are driven more by financial incentives rather than medical needs [24]. This renders our system what might be called “wealth care” rather than health care.

The end of the nineteenth century and the beginning of the twentieth century were indeed the hardest of times for blacks. All of the political gains made during Reconstruction were lost, including a total wipeout of all black legislators from Congress, and a loss of voting privileges. There was virtually no organized medical care system for blacks, who had to treat themselves by using root doctors, herbalists, midwives to deliver babies, and voodoo. This neglect continued from the end of Reconstruction into the 1920s and beyond. Some of the responsibility for improving black health was assumed by some charity organizations; the two most active and most effective ones were the Julius Rosenwald Fund, started by the head of Sears Roebuck, and the Duke Foundation. Their public health programs saved countless lives, but more was needed. Having no support system from federal or state sources and having lost all of their political and economic power, blacks were forced to retreat into a situation which was very similar to the serfdom and feudalism that had been found in Europe in agrarian societies. The American version was called sharecropping, which made blacks totally dependent on and welded to white landowners, a situation which was not very different from slavery. To keep the black sharecroppers docile and submissive, the white South invented fearful, repressive, intimidating, and murderous tactics to subvert the Negro and undermine Reconstruction, and the main conduit of these tactics, the Ku Klux Klan, was born in April 1867, in Room 10 of the Maxwell House in Nashville, Tennessee [25]. The notorious Black Codes, which restricted or banned movement and gatherings of Negroes and involvement in political activities, were rigidly enforced in Mississippi and several other Southern states. In essence, the South had declared war on the vulnerable black population and was operating in a decidedly genocidal fashion against its former slaves. Soon blacks were being lynched all over the South on almost a daily basis, and their re-subjugation was complete.

It should be clear that white physicians had been indoctrinated by the teachings of scholars such as Louis Agassiz, Josiah Clark Nott, Charles Caldwell, Baron Cuvier, G.L.L. Buffon, Samuel George Morton, John Augustine Smith, and many others, who essentially declared that blacks were inferior beings. They therefore developed certain stereotypes and attitudes about blacks and the medical and psychological conditions that they suffered. These attitudes became mixed into the manner in which white doctors approached black patients. One notorious exponent of the view that blacks were inherently inferior and possessed defects of the nervous and cardiovascular systems making them susceptible to diseases such as syphilis, yaws, and degeneration of the circulatory system was Dr. Samuel A. Cartwright of New Orleans. In 1851, he wrote in the *New Orleans Medical and Surgical Journal* that the difference in health status between blacks and whites was
due to the perception that “the Negro’s brain and nerves, the chyle and all the humora are tinctured with a shade of pervading darkness” [26]. Similarly demeaning and pejorative statements were made by Dr. M.M. Weiss when he wrote in the American Heart Journal in 1939 that blacks experienced less chest pain or angina pectoris than whites because “more than moronic intelligence” is necessary to perceive the sensation of pain [27]. Blacks also felt distrustful of white doctors, believing that they might become unwilling and unwitting subjects of human experimentation; these suspicions were confirmed in 1928 by E. Franklin Frazier [28]. They were later upheld by the notorious Tuskegee Syphilis Study, carried out by the US Public Health Service from 1932 to 1972. In this study, 400 black male residents of Macon County, Georgia, who were found to have syphilis were given only placebo treatment by medical professionals and were followed to their deaths. The purpose was to allow the Public Health Service doctors to study the natural history of the disease and to observe its pathological effects at autopsy [29].

Racial and Ethnic Differences in Disease Expression

The racist statements cited above by Cartwright and Weiss indicate the interest that was generated in whether blacks and whites experience illness differently and whether everyone should be treated the same (the “one size fits all” controversy). Are blacks more susceptible to certain diseases than whites? Do African Americans exhibit resistance to particular illnesses that are seen in Caucasians? If there are differences, are they due to genetic causes, or is environment the reason (the “nature or nurture” controversy)? Do differences in manifesting illness and responding to treatment imply that one race is more or less fit for survival than another (the “superiority vs. inferiority” debate)?

These issues have been argued down through the centuries, and they still are. Many books have been written and positions have been taken to put forward one point of view or the other. Suffice it to say that there is no uniform agreement on any of these key issues, but there is a recognition today that some differences in disease expression and response to treatment do exist and that it is best to individualize treatment and tailor it to the person as he or she presents with various characteristics such as race and ethnic group.

In 1975, I edited the Textbook of Black-Related Diseases [30] in an attempt to address some of these concerns. The book was a large compendium of information available on diseases across the medical spectrum as they are experienced by blacks compared to whites in America. It was intended to fill a void, because only a small literature was available on the principle diseases affecting blacks. This was due in part because vital statistics containing morbidity, mortality, longevity, incidence, and prevalence figures, which have only been collected in recent years, were not collated according to race. Medical decisions were based on anecdotal information, and expert opinion and judgment were the standards for doctors’ treatment. Prior to the establishment of federal health programs and the creation of clinical trials and studies of health phenomena, there were no objective, evidence-based data to use.
This book started a trend involving the collection of health data by race and ethnicity as well as consideration of the patient’s racial background in diagnostic and therapeutic applications. It also documented clear differences in vital statistics between blacks and whites and showed the tremendous disparities in health care and outcomes in graphic terms. It led to further exploration and analysis of the background, causes, and extent of the disparities and was a direct stimulus and precursor of the Malone-Heckler Report on the status of healthcare delivery for blacks and other minorities, which was issued by Secretary Margaret Heckler’s Department of Health, Education, and Welfare in 1985 [31]. A recent example of the value of the collection of health data by race and ethnicity was a study presented at the American Society of Chest Physicians in October 2006. The study of 10,053 deaths from pulmonary arterial hypertension from 1994 to 1998 which were recorded by the National Center for Health Statistics revealed that black women had the highest risk of dying from the idiopathic form of the disease, a previously unrecognized and extremely important epidemiological fact. According to the lead investigator, Kala Davis, M.D. of the Stanford University School of Medicine, “race, gender, and age have become defining factors in assessing the risk of death in idiopathic pulmonary arterial hypertension. Clinicians must therefore be cognizant of this emerging demographic profile, which contrasts with the classic description of the condition as being a disease of middle-aged Caucasian women [32].”

From 1985 to 2000, there were no major publications on the health status of blacks and other minorities in the USA. In 2000, An American Health Dilemma was a breakthrough book, which revisited the problem of black health care in a major way for the first time in 15 years. The Institute of Medicine (IOM) Report was the next step in the progression. Once again, as in 1985, the problems have been described and recommendations for solving them have been made. There seems to be an overwhelming inertia that prevents us as a nation from putting a halt to these discrepancies in healthcare delivery and leveling the playing field. The next milestone that has been established for improvement of health goals is Healthy People 2010, which has two overarching goals: increased longevity and a significant reduction of healthcare disparities. Sadly, history indicates that we will not achieve the latter by that date.

Conclusion

The historical saga of blacks and American medical care is an ongoing story, and what is detailed above is but part of the litany of morbid events. The purpose of this overview is to familiarize the reader with the events, which are directly responsible for the healthcare disparities that we are witnessing today, and to realize how much we as medical practitioners are the cause of those disparities. The principle focus has been upon how racist attitudes developed over the centuries and how they have impacted the delivery of health care to African Americans. As one reads the remainder of this book, one should keep these events and attitudes in mind, because they influence every aspect of black and minority health care and also because the nation
is still very much affected by these influences. Hopefully, this brief review of the past will help us to eliminate current healthcare disparities and to resist similar events from occurring in the future. The survival of an entire race of people depends on our ability to interrupt such a negative impetus.

References

1. The Bible.
23. Personal communication with Dr. W. Montague Cobb, 28 Apr 1988.
Chapter 3
Epidemiologic Profiles of Racial and Ethnic Disparities in Health and Health Care*

George A. Mensah and Maleeka J. Glover

Abstract  Disparities in health status and healthcare delivery have been documented in the USA throughout most of the last two centuries (Ewbank, Milbank Q 65 (Suppl 1):100–128, 1987; Krieger, Int J Health Serv 17(2):259–278, 1987; Kochanek et al., Am J Public Health 84(6):938–944, 1994). More recently, the Institute of Medicine (Unequal treatment: confronting racial and ethnic disparities in health care. Washington, DC: National Academies Press, 2003) and the Agency for Healthcare Research and Quality (AHRQ) (U.S. Department of Health and Human Services, National Healthcare Disparities Report. http://www.ahrq.gov/qual/nhdr05/nhdr05.pdf, Accessed on 1 July 2006) have confirmed that disparities are pervasive and that improvements are possible. Eliminating these disparities is one of the two overarching goals of the Healthy People 2010 national public health agenda. In this endeavor, the availability of reliable, population-based indicators of disparities can be crucial for assessing the magnitude, trends, and impact of interventions designed to reduce and eventually eliminate disparities. These indicators can also serve to inform policy and program development, help set priorities, and assist in identifying areas where additional research is needed.

In this chapter, we use published data from national health statistics and surveillance reports to present epidemiologic profiles of established disparities in health status and health care for population subgroups defined by race and ethnicity. We first introduce the categories of race and ethnicity and define the concept of disparities in health care. The distribution and demographic changes in the racial and ethnic categories are presented along with current projections to the year 2050. Selected examples of the Healthy People 2010 objectives and targets

*Disclaimer: The findings and conclusions in this chapter are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

G.A. Mensah (✉)
Former Chief Medical Officer, National Center for Chronic Disease Prevention and Health Promotion, and Health Promotion, CDC, Director, Heart Health and Global Health Policy, Pepsico Global Research and Development, Purchase, NY, USA

e-mail: george.mensah@pepsico.com
for elimination of disparities are discussed. Current data and trends on life expectancy, risk factor and chronic disease prevalence, other morbidity, mortality, access to care, and quality of care are then presented. The need for continued refinement of conceptual and methodological issues in the collection of healthcare data by race and ethnicity is also emphasized. The chapter concludes with caveats on the challenges and limitations in the interpretation of racial and ethnic comparisons in the healthcare setting and future opportunities for the development and implementation of programs and strategies to eliminate these disparities in health and health care.

**Keywords**  Chronic diseases • Mortality • Life expectancy • Race and ethnicity • Healthy People 2010 • *Eight Americas Study* • Risk factor data • Quality of life

### Race and Ethnicity in the USA

In 1997, the Office of Management and Budget revised the standards for classification of individuals by race and ethnicity for the collection of federal statistics and administrative reporting within federal data systems [1]. This revision produced five racial groups: American Indian or Alaska Native (AI/AN), Asian, Black or African American, Native Hawaiian or Other Pacific Islander (NHOPI), and White. Two categories of ethnicity, Hispanic or Latino and non-Hispanic, were created. Persons of any race with Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin were designated Hispanic/Latino ethnicity, and all others were designated non-Hispanic.

In this review, we follow this classification of race and ethnicity whenever complete data on all race/ethnic groups are available. Often, complete stable estimates are not available for all race/ethnic groups. In these instances, data are presented typically for blacks and whites; non-Hispanic blacks, non-Hispanic whites, and Hispanics; or for blacks, white, and Mexican Americans depending on the data source.

As seen in Table 3.1, whites constituted 81% of the total population in 2000. However, in 2010 and 2020, respectively, they will represent 79.3% and 77.6%. By 2050, whites will make up 72.1% of the total population, a substantial decrease from the 2000 census data. The proportion of the population made up by ethnic minorities will increase, with the sharpest increase projected for the Hispanic population. For example, the proportion of blacks will increase from 12.7% in 2000 to 13.5% in 2050. For Hispanics of any race, their proportion will nearly double from 12.6% in 2000 to 24.4% in 2050. This substantial increase in the proportion of ethnic minority populations, who often have poorer health and access to health care, could have significant adverse implications for national health indicators unless disparities in health and health care are addressed and eliminated.
### Table 3.1 Projected population of the United States, by race and Hispanic origin: 2000, 2020, and 2050 (U.S. Census Bureau [2])

<table>
<thead>
<tr>
<th>Population (%) and race/Hispanic origin</th>
<th>2000</th>
<th>2020</th>
<th>2050</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population total</td>
<td>282,125</td>
<td>335,805</td>
<td>419,854</td>
</tr>
<tr>
<td>White alone</td>
<td>228,548 (81.0)</td>
<td>260,629 (77.6)</td>
<td>302,626 (72.1)</td>
</tr>
<tr>
<td>Black alone</td>
<td>35,818 (12.7)</td>
<td>45,365 (13.5)</td>
<td>61,361 (14.6)</td>
</tr>
<tr>
<td>Asian alone</td>
<td>10,684 (3.8)</td>
<td>17,988 (5.4)</td>
<td>33,430 (8.0)</td>
</tr>
<tr>
<td>All other races</td>
<td>7,075 (2.5)</td>
<td>11,822 (3.5)</td>
<td>22,437 (5.3)</td>
</tr>
<tr>
<td>Hispanic (of any race)</td>
<td>35,622 (12.6)</td>
<td>59,756 (17.8)</td>
<td>102,283 (24.4)</td>
</tr>
</tbody>
</table>

White: origins in any of the people of Europe, the Middle East, or North Africa
Black or African American: origins in any of the black racial groups of Africa
Hispanic or Latino: Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race
Asian: origins in any of the original peoples of the Far East, Southeast Asian, or the Indian subcontinent
Native Hawaiian/Pacific Islander: origins in any of the original people of Hawaii, Guam, Samoa, or to the Pacific Islands
American Indian/Alaskan Native: origins in any of the original people of North and South America, including Central America, and who maintain tribal affiliation or community attachment

### Concept of Disparities and the Healthy People 2010 Goals

The term “disparities,” as defined by the National Institutes of Health First Working Group in Health Disparities, refers to “differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions” [3]. In a broader sense, “health disparities” refer to preventable differences in the health indicators of different population groups, often defined by race/ethnicity, sex, educational level, income, socioeconomic status (SES), and geographic location of residence. In this chapter, we discuss epidemiological profiles of disparities based only on race and ethnicity although we recognize the importance of eliminating all forms of health disparities in accordance with the Healthy People 2010 goals [4].

The overarching goals of Healthy People 2010 are (1) to increase the quality and years of healthy life and (2) to eliminate health disparities [4]. The overall Healthy People 2010 goals and objectives are divided into 28 focus areas, each of which contains a concise goal statement. Some of the goals include access to quality health services, diabetes, nutrition/overweight, heart disease and stroke, health communication, and physical activity and fitness. In addition to the disease specific goals outlined in HP2010, a small set of measures identified as the ‘leading health indicators’ were selected to address individual behaviors, both physical and social environmental factors and health system issues [5]. These factors include: physical activity, overweight/obesity, tobacco use, substance abuse, responsible sexual behavior, mental health, injury and violence, environmental quality, immunization, and access to health care. In the subsequent sections, we use several of these indicators in characterizing the epidemiological profile of health disparities.
The Burden of Disparities

The magnitude of the burden of health disparities can be appreciated by examining the published data on racial and ethnic differences in life expectancy, disease specific mortality among the leading causes of death, hospitalization and other indicators of morbidity, disability and quality of life, and the major risk factors and health risk behaviors. Data on racial and ethnic differences in access to care and the quality of health care delivered further supplement these epidemiologic profiles.

**Life Expectancy and Mortality**

Life expectancy at birth in the USA increased dramatically by 30 years (from 47.3 years in 1900) to 77.3 years in 2002 and reached a record high of 77.5 years in 2003 [6, 7]. However, marked racial disparities have persisted. As shown in Fig. 3.1, life expectancy is highest in white women (80.5) followed by black females (76.1), white males (75.3), and lowest in black men (69.0) [7]. Blacks had higher death rates at all ages and more premature mortality compared with whites, as measured by years of potential life lost (YPLL) from diseases of the heart and stroke (Fig. 3.2). Data are presented for only blacks and whites because the National Center for Health Statistics does not report data on life expectancy in the other racial/ethnic groups because of inadequate stability of estimates [6].

Other data that also demonstrate an enormous excess of deaths in blacks resulting from disparities in life expectancy include the analysis by Satcher et al. [8] that showed that an estimated 83,570 excess deaths in blacks could be prevented each year in the USA if this black–white mortality gap could be eliminated.

In their *Eight Americas Study*, Murray et al. [9] divided the US population into eight distinct groups with different epidemiologic patterns and mortality

![Fig. 3.1](image-url)  
*Fig. 3.1* Life expectancy at birth by race and sex: United States, 2003 (Hoyert et al. [7])
experience. The Eight Americas included Asians (America 1), below-median-income whites living in the Northland (America 2), middle America (America 3), poor whites living in Appalachia and the Mississippi Valley (America 4), Native Americans living on reservations in the West (America 5), black middle-America

**Fig. 3.2** Years of potential life lost (YPLL) before 75 years of age resulting from diseases of the heart, ischemic heart disease, and stroke, according to sex, race, and Hispanic Origin, United States, 2002 (National Center for Health Statistics [6])
G.A. Mensah and M.J. Glover

(America 6), poor blacks living in the rural South (America 7), and blacks living in high-risk urban environments (America 8) [9]. They estimated that the disparity between the life expectancy for males in America 8 and females in America 1 was 21 years. They identified an “enormous excess” of mortality in young and middle-aged persons that was largely attributable to chronic diseases [9].

**Chronic Diseases as Leading Causes of Death and Disparities**

The leading causes of death vary by race and ethnicity. However, for all race/ethnic groups, most of the leading causes of death are chronic diseases (Table 3.2). Heart disease and cancer rank first and second in all race groups except in Asians and Pacific Islanders where cancer ranks first and heart disease ranks second. Stroke is the third leading cause of death in all race/ethnic groups except in Hispanics (where it ranks fourth) and in American Indians/Alaska Natives (where it ranks seventh) [7].

These chronic diseases contribute substantively to overall racial/ethnic disparities in life expectancy and overall mortality. In the study of cause-specific risks of death using data from the National Health Interview Survey conducted from 1986 through 1994 and from linked vital statistics, Wong et al. [11] demonstrated that cardiovascular diseases and cancer alone accounted for 35.3% and 26.5%, respectively, of the black–white differences according to education level. The contribution of cardiovascular diseases to the black–white disparities was in large part due to hypertension. When examined across all race/ethnic groups, the mortality from all diseases of the heart, ischemic heart disease, or stroke remain highest among blacks (Fig. 3.3). One important reason for this high risk, as recently emphasized by Williams et al. [12] is the high prevalence of multiple cardiovascular and chronic disease risk factors in African Americans.

**Morbidity and Quality of Life**

Hospital admissions serve as a useful measure of the burden of morbidity and an important contributor to overall quality of life as well as health disparities. Although hospital admissions per 1,000 population have declined for both blacks and whites since the early 1990s, the rates have remained higher and statistically significant in blacks [13]. In American adults over the age of 65 years, data from the Medicare program show that hospitalization rates are significantly higher in black, Hispanic, and Native Americans than in white beneficiaries and lowest in Asian American beneficiaries [13, 14].

Whites have the highest prevalence of hospitalization for acute myocardial infarction [15]. However, hospitalization for chronic heart failure is higher in blacks, Hispanics, and American Indians/Alaska Natives than among whites [15]. Blacks have the highest prevalence of hospitalization for stroke in the Medicare
Table 3.2  Deaths and percentage of total deaths for the 15 leading causes of death, by race and Hispanic origin, United States, 2002 (Anderson and Smith [10])

| Cause of death (based on the International Classification of Diseases, Tenth Revision) | White | % of total deaths | Rank | Black | % of total deaths | Rank | American Indian | % of total deaths | Rank | Asian/Pacific islander | % of total deaths | Rank | Hispanic | % of total deaths | Rank |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Diseases of the heart | 1 | 28.9 | 1 | 26.8 | 1 | 19.9 | 2 | 26.0 | 1 | 23.8 |
| Malignant neoplasms | 2 | 22.9 | 2 | 21.6 | 2 | 17.5 | 1 | 26.1 | 2 | 19.8 |
| Cerebrovascular diseases | 3 | 6.6 | 3 | 6.5 | 5 | 4.6 | 3 | 9.2 | 4 | 5.5 |
| Chronic lower respiratory diseases | 4 | 5.5 | 8 | 2.7 | 7 | 3.6 | 7 | 3.0 | 8 | 2.6 |
| Accidents (unintentional injuries) | 5 | 4.3 | 5 | 4.3 | 3 | 12.0 | 4 | 4.9 | 3 | 8.6 |
| Diabetes mellitus | 6 | 2.8 | 4 | 4.4 | 4 | 6.0 | 5 | 3.5 | 5 | 5.0 |
| Influenza and pneumonia | 7 | 2.8 | – | – | 9 | 2.4 | 6 | 3.1 | 9 | 2.4 |
| Alzheimer’s disease | 8 | 2.6 | – | – | – | – | – | – | – | – |
| Nephritis | 9 | 1.6 | 9 | 2.6 | – | – | 9 | 1.7 | – | – |
| Intentional self-harm (suicide) | 10 | 1.4 | – | – | 8 | 2.6 | 8 | 1.7 | – | – |
| Septicemia | – | – | 10 | 2.1 | 10 | 1.1 | – | – | – | – |
| Chronic liver disease and cirrhosis | – | – | – | – | 6 | 4.4 | – | – | 6 | 2.9 |
| Assault | – | – | 6 | 2.9 | 10 | 2.2 | – | – | 7 | 2.7 |
| Human immunodeficiency virus (HIV) disease | – | – | 7 | 2.7 | – | – | – | – | – | – |
| Certain conditions originating in the perinatal period | – | – | – | – | – | – | – | – | 10 | 2.1 |
population [15]. Many of these hospitalizations are preventable through increased adherence to and uniform application of established clinical preventive guidelines.

Significant disparities in the utilization of hospital emergency departments (EDs) exist by race and age group [13]. Bernstein et al. have shown that among persons aged 45–64 years, the ED visit rate for blacks in 2000 was almost twice the

Fig. 3.3 Age-adjusted death rates for selected causes of death, according to sex, race, and Hispanic origin: United States, 2002 (National Center for Health Statistics [6])
rate in white persons [13]. Among those aged 65 years and older, the ED utilization in 2000 was also higher in blacks than whites, and compared to the 1992–1993 period, increased significantly in blacks (51%) compared to whites (19%) [13].

Measures of health-related quality of life over time demonstrate important racial and ethnic disparities. For example, self-reported “healthy days,” an estimate of a population’s sense of physical, emotional, and mental well-being, reliably assesses people’s overall perceptions about their health over time and can identify groups in the general adult population with potentially unmet perceived health needs [16]. The greatest burden of unhealthy days or impaired health-related quality of life is reported by American Indians/Alaska Natives, African Americans, and Hispanics and is lowest in Asians and Whites [16]. This disparity may even be underestimated for American Indians because of survey-related underreporting, as demonstrated by Gilliland et al. in their analysis of health-related quality of life for rural American Indians in New Mexico [17].

**Risk Factor Differences**

Tobacco use, poor nutrition, physical inactivity, high blood pressure, and high blood cholesterol are the major risk factors that underlie cardiovascular diseases and other chronic diseases that constitute the leading causes of death and disability worldwide [18, 19]. An important contributor to and effect of many of these risk factors is obesity, which is not only highly prevalent in the USA but is increasing and demonstrates marked racial, ethnic, and geographic disparities (Fig. 3.4). All of these risk factors are not only common in the US, but marked disparities exist among population subgroups in their prevalence and associated morbidity and mortality.

Self-reported data from the Behavioral Risk Factor Surveillance System show that the prevalence of “no physical activity” is common in all race/ethnic groups, especially in women with less than a high school education. Similarly, the daily consumption five servings of fruits and vegetables is low in all groups and lowest in black and white men with less than a high school education [15]. Blacks have the highest prevalence of diagnosed diabetes and high blood pressure (Table 3.3). Hispanics have the highest prevalence of poor or fair health and are the least likely to have health insurance or receive vaccination for seasonal influenza or pneumonia [15].

Measured risk factor data from the National Health and Nutrition Examination Survey (NHANES, 1999–2002) also show that in general, blacks have a high prevalence of hypertension, regardless of sex or educational status. In addition, black women have a higher prevalence of obesity and abdominal obesity regardless of educational status, when compared to the other race groups, and measured levels of glycosylated hemoglobin $\geq 7\%$ was highest in black men [15]. The prevalence of hypercholesterolemia is generally high among white and Mexican American men and white women regardless of educational status.

Measured surveillance data for the emerging cardiovascular risk factors also show significant racial/ethnic disparities within educational and socioeconomic strata.
Fig. 3.4  Trends in obesity (defined as BMI $\geq 30$ kg/m$^2$) among US Adults, BRFSS 1990, 1996, and 2003 (Mensah et al. [15])

For example, among men who have not completed a high school education, the prevalence of elevated concentrations of C-reactive protein (CRP) is high among white men. However, among men who have completed high school, CRP prevalence is highest among black men [15]. The prevalence of elevated CRP concentrations is high in black women but is lower in those who have completed a high school education. In both men and women of all race/ethnic groups examined, the prevalence of elevated homocysteine ($\geq 10$ μmol/L) is higher in those with less than a high school education [15].
### Table 3.3 Unadjusted prevalence of risk factors for CVD among US Adults ≥18 years of age, BRFSS, 2003 (Mensah et al. [15]; Table 3.1)

<table>
<thead>
<tr>
<th></th>
<th>White &lt;High school&gt;=high school</th>
<th>African American &lt;High school&gt;=high school</th>
<th>Mexican American &lt;High school&gt;=high school</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>SE</td>
<td>%</td>
</tr>
<tr>
<td><strong>Current smoker</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>40.6</td>
<td>1.1</td>
<td>22.9</td>
</tr>
<tr>
<td>Women</td>
<td>34.6</td>
<td>0.9</td>
<td>19.9</td>
</tr>
<tr>
<td>Total</td>
<td>37.5</td>
<td>0.7</td>
<td>21.4</td>
</tr>
<tr>
<td><strong>No physical activity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>40.1</td>
<td>1.0</td>
<td>17.7</td>
</tr>
<tr>
<td>Women</td>
<td>45.3</td>
<td>0.9</td>
<td>21.5</td>
</tr>
<tr>
<td>Total</td>
<td>42.8</td>
<td>0.7</td>
<td>19.7</td>
</tr>
<tr>
<td><strong>Five servings or more of fruit and vegetable</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>13.3</td>
<td>0.7</td>
<td>18.6</td>
</tr>
<tr>
<td>Women</td>
<td>20.6</td>
<td>0.7</td>
<td>29.5</td>
</tr>
<tr>
<td>Total</td>
<td>17.1</td>
<td>0.5</td>
<td>24.3</td>
</tr>
<tr>
<td><strong>Told have diabetes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>11.9</td>
<td>0.7</td>
<td>7.0</td>
</tr>
<tr>
<td>Women</td>
<td>13.3</td>
<td>0.5</td>
<td>5.9</td>
</tr>
<tr>
<td>Total</td>
<td>12.6</td>
<td>0.4</td>
<td>6.4</td>
</tr>
</tbody>
</table>
Disparities in Access to and Quality of Care

The provision and accessibility of “health care of equal quality based solely on need and clinical factors” is the essence of health equity envisioned by the Institute of Medicine [20]. In issuing the guidance for preparing the national annual healthcare disparities report, the Institute of Medicine stated that disparities in access to care and quality of care “… are among this nation’s most serious health care problems” [20]. The National Healthcare Quality Report (NHQR) and the National Healthcare Disparities (NHDR) Report provide a comprehensive overview of the quality of health care in America and the spectrum of disparities that exist in health care in the US population. Although modest improvements have been made in several measures of quality (such as effectiveness, patient safety, timeliness, and patient centeredness) especially in the treatment and control of diabetes, heart disease, respiratory conditions, and in nursing home and maternal and child health care, disparities have persisted or widened in many areas [21, 22].

For example, areas of significant disparities in the effectiveness of care documented in the National Healthcare Quality Report include the prevention of female cancer deaths (poorest in blacks) mammography for breast cancer screening within the previous 2 years (fewest in Asians and Hispanics); prevalence of limb amputations in diabetes (worst in blacks); prevalence of glycosylated hemoglobin testing, and eye and foot examinations in monitoring diabetes control (fewest in Hispanics); suboptimal care for heart attack patients (worst in blacks, American Indians and Alaska Natives, and Hispanics), prevalence of physician advice to quit smoking (lowest in Hispanics); suboptimal prenatal care in first trimester (worst in blacks, Native Hawaiian and other Pacific Islanders, and Hispanics); high infant mortality (highest in blacks); low prevalence of childhood vaccinations (lowest in blacks and Hispanics); and preventable asthma hospitalizations (highest in blacks). As shown in Tables 3.4 and 3.5, the major disparities in health care are among black and Hispanic adults, who indicated they sometimes/never get care when needed/wanted and have left an ER visit without being seen (timeliness). Asian, AIAN, and Hispanic adults reported that providers never listen, explain, respect, and spend enough time with them or their children.

The 2005 Health Care Disparities Report provided data on disparities in health care access that encompassed facilitators and barriers to care and health care utilization [21]. It addressed health care access including gaining entry into the healthcare system, getting access to sites of care and finding providers who meet individual patient needs, with mutual communication and trust. Health insurance was a key barrier to health care among blacks and Hispanics, resulting in difficulties and or delays in care due to their socioeconomic status and insurance coverage. Blacks, Hispanics, and Asians also indicated that they did not have a usual source of care and more often used the emergency department as a source of usual care. Hispanics in particular reported difficulty with patient–provider communication among both adults and children [21]. Several racial and ethnic minority groups still have significant disparities with regard to dental visits (fewer among blacks, Asians, American Indian/Alaska Natives, and Hispanics), potentially avoidable
### Table 3.4 Increasing disparities in health care by race and ethnicity relative to reference group
(National Health Disparities Report 2005)

<table>
<thead>
<tr>
<th>Group</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black vs. White</td>
<td>Children with hospital admissions for asthma</td>
</tr>
<tr>
<td></td>
<td>Children with all recommended vaccines</td>
</tr>
<tr>
<td></td>
<td>Elderly with pneumococcal vaccine</td>
</tr>
<tr>
<td></td>
<td>Hospital treatment of pneumonia</td>
</tr>
<tr>
<td>Asian vs. White</td>
<td>Elderly with pneumococcal vaccine</td>
</tr>
<tr>
<td>American Indian/Alaska</td>
<td>Hospital treatment of heart attack</td>
</tr>
<tr>
<td>Native vs. White</td>
<td>High-risk nursing home residents with pressure sores</td>
</tr>
<tr>
<td></td>
<td>Home health care patients admitted to hospital</td>
</tr>
<tr>
<td></td>
<td>Dialysis patients on waiting list for transplantation</td>
</tr>
<tr>
<td>Hispanic vs. non-Hispanic White</td>
<td>Needed and received substance abuse treatment</td>
</tr>
<tr>
<td></td>
<td>Persons with diabetes with three recommended services</td>
</tr>
<tr>
<td></td>
<td>Mental health treatment for serious mental illness</td>
</tr>
<tr>
<td></td>
<td>Adults with patient–provider communication problems</td>
</tr>
<tr>
<td></td>
<td>Illness/injury care received as soon as wanted</td>
</tr>
<tr>
<td></td>
<td>Tuberculosis patients who complete treatment within 12 months</td>
</tr>
<tr>
<td></td>
<td>Children with patients-provider communication problems</td>
</tr>
<tr>
<td></td>
<td>Hospitalized smokers who receive advice to quit</td>
</tr>
<tr>
<td></td>
<td>Elderly who receive pneumococcal vaccine</td>
</tr>
<tr>
<td></td>
<td>Children with dental visit</td>
</tr>
<tr>
<td></td>
<td>Hospital treatment of heart attack</td>
</tr>
<tr>
<td></td>
<td>New AIDS cases</td>
</tr>
</tbody>
</table>

### Table 3.5 Three largest disparities in quality of health care for selected groups: measure and rate relative to reference group
(National Health Disparities Report 2005)

<table>
<thead>
<tr>
<th>Group</th>
<th>Measure</th>
<th>Relative rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black vs. White</td>
<td>New AIDS cases</td>
<td>10.4</td>
</tr>
<tr>
<td></td>
<td>Children with hospital admission for asthma</td>
<td>3.7</td>
</tr>
<tr>
<td></td>
<td>Left emergency department without being seen</td>
<td>1.9</td>
</tr>
<tr>
<td>Asian vs. White</td>
<td>Mental health treatment for serious mental illness</td>
<td>1.6</td>
</tr>
<tr>
<td></td>
<td>Illness/injury care as soon as wanted</td>
<td>1.6</td>
</tr>
<tr>
<td></td>
<td>Elderly with pneumococcal vaccine</td>
<td>1.5</td>
</tr>
<tr>
<td>American Indian/Alaska</td>
<td>New AIDS cases</td>
<td>2.1</td>
</tr>
<tr>
<td>Native vs. White</td>
<td>Illness/injury care as soon as wanted</td>
<td>1.8</td>
</tr>
<tr>
<td></td>
<td>Children with patient–provider communication problems</td>
<td>1.3</td>
</tr>
<tr>
<td>Hispanic vs. non-Hispanic White</td>
<td>New AIDS cases</td>
<td>3.7</td>
</tr>
<tr>
<td></td>
<td>Illness/injury care as soon as wanted</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
<td>Children with patient–provider communication problems</td>
<td>1.8</td>
</tr>
</tbody>
</table>
hospital admissions (greater among blacks and Hispanics) and suboptimal mental health care (worst among blacks, Asians, American Indian/Alaska Natives, and Hispanics) [21]. Tables 3.4 and 3.5 highlight the major areas that demonstrate the largest disparities in quality health care for selected racial and ethnic groups compared to whites and areas where disparities are increasing.

**Limitations and Challenges in Racial and Ethnic Comparisons of Healthcare Data**

The limitations and challenges in these comparisons are very well recognized [23, 24] and include misclassification of race and ethnicity, stability of estimates, complex determinants of disparities and lack of outcome data on effective programs. The miscoding or misclassification of race, which disproportionately affects American Indians and Alaska Natives [25–27], can lead to flawed data in these comparisons. For example, Rhodes [25] recently showed that vital event data unadjusted for racial misclassification show AIAN as having the lowest mortality rates from major cardiovascular diseases. However, after appropriate adjustment, AIAN had the highest mortality rates that demonstrated a rapidly growing disparity between cardiovascular mortality rates in AIAN compared with rates in the US all-races and white populations [25]. Often data on specific racial and ethnic groups are not collected or collected in formats that differ from federal standards [23]. When appropriately collected, the data may be insufficient to generate reliable estimates for specific racial and ethnic groups [23].

The causes of the disparities profiles presented here are legion and complex [28]. While genetics and the gene–environment interaction are important, disparities presented here should not be assumed to be caused by genetic differences. Race and ethnicity in these settings should be viewed as social, not biological constructs [29, 30]. Other key determinants of disparities, such as access to care, quality of care delivered, systems of care, geographic and environmental influences, income and educational levels, prejudice, discrimination, provider bias, psychosocial stressors, and personal behaviors and lifestyle choices, all play important roles in causation of the disparities.

Finally, the availability and quality of data on race and ethnicity may also vary by factors such as the type of data collected, the source of information, and the definitions and methods used for measurements. The lack of consensus regarding “conceptual and operational definitions of disparities” as well as the “complexity of measuring health and health determinants” remains major programmatic and research challenges as recently emphasized by the Institute of Medicine [31].

**Unique Opportunities for the Future**

The epidemiologic profiles presented in this chapter can be useful for informing policy and environmental changes that can lead to the elimination of health disparities. However, it is the actions and program interventions that present the
real opportunities for improvements in the future. At present, there is a lack of readily accessible, well-documented, “credible and comprehensive database” [32] or registry of interventions effective in eliminating disparities. Development, implementation, and formal evaluation of such interventions are crucial and far more important in the effort to eliminate disparities than the continued documentation of the existence of disparities [33].

Several recent developments provide a unique opportunity in this regard. The Cochrane and Campbell Collaborations’ planned assessment of the effect of interventions on health disparities and health equity represent an important opportunity for building a database of effective interventions for reducing and eliminating disparities [32]. Similarly, the proposal to apply clinical epidemiologic methods in the “equity effectiveness loop” [34] as a comprehensive framework to highlight the assessment of health needs, cost effectiveness of interventions, and the evaluation of evidence-based health policy also represents important opportunities. The recent Institute of Medicine recommendations [31] on the health disparities research plan of the National Institutes of Health provides additional opportunities for improving the strong science base for research to understand and help eliminate health disparities.

Summary and Conclusions

The epidemiologic profiles presented here demonstrate that racial and ethnic disparities in health status and health care are pervasive in the USA. Incomplete data and often unstable estimates in some racial/ethnic groups preclude complete comparisons. Although modest progress has been made, significant differences still persist in life expectancy and indicators of mortality, morbidity, and quality of life. Additionally, marked disparities persist in the delivery of quality care for the prevention and control of the leading causes of death, disease, disability, and their major determinants. The extensive documentation and our vast knowledge of these disparities are unmatched by availability of effective interventions for eliminating disparities. Thus, the primary challenge remains the development and implementation of programs, interventions, and strategies to eliminate these disparities in health status and health care.

References


Abstract The past century has borne witness to a most unique development in the annals of American medicine. The patients whom we treat have become more complex, not only in regards to the variety of illnesses that they present, but especially in regards to the increasing mixture of cultures, ethnic groups, and races. This steady progression of heterogeneity presents a challenge of major proportions to the practicing physician who must now acknowledge that the approach to patients cannot be monolithic, but instead should be tailored to fit their special needs.

Interest in the public health aspect of healthcare delivery began in 1789 when the Reverend Edward Wigglesworth performed an assessment of American health and produced the first mortality tables in the United States. Since that time, the accumulation of data relating to the health of the country has been systematically compiled, and this vital statistics information has revealed changing patterns of illness and disease over the years. For instance, whereas the main causes of death in 1900 were influenza, pneumonia, tuberculosis, and gastrointestinal infections, and Americans could expect to live an average of 47 years, 100 years later it is found that the main causes of death are cardiovascular disease (CVD), cancer, stroke, and diabetes mellitus (DM), and the average life expectancy from birth is now more than 75 years. With the emergence of chronic diseases as the leading health problems in this country, the focus has shifted from acute intervention approaches to population-based preventive programs designed to identify and eliminate risk factors for these conditions. The federal government has taken the initiative in this regard through campaigns for improved health constructed by various agencies of the Department of Health and Human Services, such as the Centers for Disease Control and Prevention, and the Office of the Surgeon General. More recently, these governmental organizations have undertaken the monumental task of dramatically reducing and eradicating poor health through initiation of a program called Healthy People 2010. Among the objectives of these programs is the elimination of...
healthcare disparities, which exists between minorities and the major part of the population, an increase in longevity, an improvement in the quality of the healthcare delivered, an increase in access to care for minorities, and recognition of the importance of cultural diversity as we view the health status of the Americans.

Beginning with the author’s medical education and continuing to the present time, he has been able to develop a perspective on the diverse nature of the patients who are treated, which spans a 40-year period. During this period, the author has looked critically at healthcare delivery dispensed to patients representing different cultures, and has found that the system of healthcare is sorely in need of change that would allow more considerate treatment of those with special needs. In this presentation, the author draws from personal experiences as a medical practitioner, educator, researcher, consultant to corporate organizations, and author of books and papers on the subject. A focus will be placed on experiences with various racial/ethnic groups, especially African Americans (AA). The purpose for providing this information is to attempt to influence medical providers to adopt more “patient-centered,” culturally sensitive approaches to treatment with the hope that there will be improved outcomes. In other words, the author’s main objective is to demonstrate why physicians should become culturally competent, and how this goal can be accomplished – at the level of the private practitioner, for the provider working in the managed care setting, and for the healthcare administrator within the governmental structure.

**Keywords**  Cultural diversity • OMB-15 • Hispanic Americans • African Americans • Asian/Pacific Islander Americans • American Indians • Alaska Natives • White Americans • Hypertension • Diabetes • Heart failure • Stroke • Fertility rate • Health status • Racial • Ethnic minorities

**Definition of Terms**

Cultural diversity is defined as the spectrum of customs, mores, traditions, patterns, habits, and lifestyles exhibited or possessed by the totality of distinct cultural groups in a society. Within the context of medicine, this term is used to indicate the fact that considerable variation exists between such groups regarding manifestations of disease, understanding of the healthcare delivery process, expressions of illness, acceptance of treatment, differential response to therapy, and compliance with prescribed treatment.

**The Diverse Patient Universe in America**

Figure 4.1 illustrates the diversity of the American population by minority race and ethnicity. According to the 2000 US census, minority groups include approximately one-third of the population, with Hispanics replacing African American (AA) as
the largest subgroup. Hispanics are 12.5% of the population, up from 9% in 1990, blacks are 12.3%, and Asian Americans are 3.6%. On October 30, 1997, the Office of Management and Budget (OMB) issued what is now regarded as the official racial and ethnic categorization in the United States [1, 2]. The directive, a revision of one called OMB-15, recognizes the following distinctions:

Five minimum race categories:
1. American Indian and Alaska Native
2. Asian
3. Black or African American
4. Native Hawaiian and other Pacific Islander
5. White

Two ethnicity categories are:
1. Hispanic or Latino
2. Non-Hispanic or Latino

The key minority groups in the United States, which are considered to be of disadvantaged status, are Hispanic Americans (HA), AA, Asian/Pacific Islander Americans (APIA), and American Indian and Alaska Native (AIAN). The author will briefly discuss the distinct characteristics of each group with particular reference to their health status, demographics, cultural aspects, and medical needs. This discussion will be both comprehensive in scope and targeted to just a few of the medical problems, which have cultural relevance, such as cardiovascular disease (CVD). It should be noted that because health data were not kept by race/ethnic group until about the last half of the twentieth century, and because there is still a deficiency of record-keeping with the use of race/ethnicity identifiers, this is

Fig. 4.1  Population by race/ethnicity
somewhat of a disadvantage. However, the available information can be used to draw a reasonably accurate profile of each group. An effort will be made to cite the work of those investigators who have had the greatest amount of experience with a particular group as well as the key studies that have best defined the health characteristics of that group.

**Hispanic Americans**

This group consists of a number of racial, ethnic, and cultural entities, most of which utilize a common language, Spanish. Sometimes also referred to as Latinos, there are five subgroups in the United States, based on country of origin, for example, Mexican, the largest subgroup (66% of Hispanic Americans), Puerto Rican, Cuban, Central or South American, and “other” Hispanics [1, 2]. Currently, HA are the most populous minority group in the United States followed by AA, including 9% of the overall population in the 1990 census but rising to 11.3% by the year 2000 and increasing further to 15% or 46.9 million people, according to US Census Bureau figures in 2008 (see Fig. 4.2, Hispanic/Latino Profile). It is estimated that by 2050, Hispanics will constitute 25% of the US population [3].

![Hispanic/Latino Profile](image_url)

**Fig. 4.2** Hispanic/Latino profile (Map of the United States with the top ten cities displaying the largest Hispanic/Latino population according to the Census Bureau). New York City, NY; Los Angeles, CA; Chicago, IL; Houston, TX; San Antonio, TX; Phoenix, AZ; El Paso, TX; Dallas County, TX; San Diego, CA; San Jose, CA
Socioeconomic factors are a very significant part of the healthcare access and delivery picture for HA. For instance, a study of HA attending an inner city clinic identified the following factors as barriers to adequate medical care: language problems, cultural differences, poverty, lack of health insurance, transportation difficulties, and long waiting times [4]. If each one of these factors is examined, an evolving profile can be observed: language problems were cited most frequently (26%) as the greatest single barrier to healthcare for HA children. Specifically, medical staff speaking no Spanish often led to adverse health consequences such as misdiagnosis or incorrect prescription of medicines. It should be noted that only 26% of the patients themselves spoke English. Thus, two-way communication between patients and providers was severely impacted by language difficulties. In addition, poverty was a critical component; the median annual household income was only US$11,000. Education was an issue in that 40% of the parents did not graduate from high school. Almost half of the families were single-family households. Significantly, 43% of the children in such households were uninsured for medical care.

Hispanic Americans are at particular risk for several diseases, such as diabetes mellitus (DM), tuberculosis, hypertension, HIV/AIDS, cirrhosis, alcoholism, cancer, and death as a result of violence [5]. However, attention has been focused on the health status of the HA community only recently. The Hispanic Health and Nutrition Examination Survey, or the so-called Hispanic HANES or HHANES [6] investigated hypertension prevalence, awareness, treatment, and control in Mexican Americans, Cuban Americans, and Puerto Ricans during the period 1982–1984. The prevalence was found to be lower in this group of HA than in comparable groups of whites and blacks. Specifically, when adults of ages 18–74 with systolic/diastolic blood pressures equal to or more than 140/90 mmHg were looked at, the following hypertension prevalence profiles emerged: Cubans had the highest rates of the three HA groups, with 22.8% of males and 15.5% of the females found to be hypertensive. Mexicans had the next highest percentages, 16.8% for men and 14.1% for women. For Puerto Ricans the rates were 15.6 and 11.5% for males and females, respectively. CVD in general has been found to have a surprisingly low prevalence in HA as compared with other ethnic groups despite the relatively high prevalence of risk factors. In 2007, according to the CDC, heart disease in Hispanics was found to be 10% lower than in non-Hispanic whites (see Table 4.1), and Mexican American men were 30% less likely to die from CHD than Caucasians. This has been called the “Hispanic paradox.” According to Fuentes, ethnicity may affect the mechanisms which facilitate the transition from stable to unstable coronary lesions leading to plaque rupture [7].

<table>
<thead>
<tr>
<th>Table 4.1</th>
<th>Age-adjusted heart disease death rates per 100,000 (2006)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hispanics/Latinos</td>
</tr>
<tr>
<td>Men</td>
<td>175.2</td>
</tr>
<tr>
<td>Women</td>
<td>118.9</td>
</tr>
<tr>
<td>Total</td>
<td>144.1</td>
</tr>
</tbody>
</table>

contributor to coronary artery disease (CAD) presentation, has been found to be less prevalent in HA than in whites; this suggests that a protective mechanism might be operating in HA, which shields them from developing CAD to the same extent as Caucasians in the American society. Such a mechanism has not been elucidated. The San Luis Valley study group also determined that HA with noninsulin-dependent DM had a paradoxically low prevalence of CAD. In fact, the risk of CAD was 50% lower in HA diabetics compared with a similar group of white non-Hispanic diabetics [8]. However, Hispanics are 1.6 times more likely to die from diabetes than non-Hispanic whites, and Mexican American adults are two times more likely to be diagnosed with diabetes. Obesity as a risk factor for CVD is seen 1.3 times more commonly in Mexican American women than in their Caucasian counterparts.

When Hispanic health and nutrition examination survey hypertension data on HA are age-adjusted and are juxtaposed with data from whites and AA contained in the Second National Health and Nutrition Examination Survey (NHANES II) of 1976–1980, it is clear that HA prevalence rates for hypertension are significantly lower. In addition, the San Antonio heart study [9] revealed that HA and non-Hispanic whites have a similar prevalence of hypertension, which is significantly lower than that found in the AA population. Other cardiovascular risk factors affecting HA are obesity, hypercholesterolemia, low high-density lipoprotein cholesterol (HDL-C) levels, and cigarette smoking. NHANES II demonstrated that HA and Caucasians had similar age-adjusted mean serum cholesterol values [10]. Two studies, the Stanford five-city project [11] and the San Antonio heart study [12], showed that HA have a higher body mass index (the ratio of weight to height in kg/m²) than non-Hispanic whites. Cigarette smoking appears to be less prevalent among HA compared with whites. The Stanford five-city project demonstrated that 24% of HA are current smokers as opposed to 32.2% of non-Hispanic whites [11].

HA should not be considered a homogeneous group. There are large differences, which exist between the various subgroups regarding the type and frequency of medical care sought and the type and amount of healthcare coverage. For example, Mexican Americans tend to use folk remedies as opposed to conventional medical care more than other HA subgroups [13]. A survey of HA patients in West Texas revealed that folk medicine was used by half of the families. Regarding medical care expenditures, there are considerable differences. Cubans tend to utilize private insurance much more than the other four categories of HA, whereas Puerto Ricans are twice as likely as Mexican Americans and over four times more likely than Cuban Americans to be covered by Medicaid. Puerto Ricans tend to spend more money on healthcare than other HA subgroups [14].

Regarding health insurance, HA as a group has a higher rate of non-coverage than whites and AA, regardless of income level. About 35% of HA adults are uninsured for medical care, compared with 21% of AA and 14% of whites [15]. HA are less likely than AA and whites to visit a physician’s office. For example, during 1994–1995, 17% of HA adults with a medical problem had not seen a doctor in the past year, as compared with 13% of AA and 11% of whites. The rates of no physician contact were highest for HA regardless of income level. However, it should be
clear that healthcare for HA is affected to a great extent by socioeconomic status. The National Longitudinal and Mortality Study [16] revealed that 24% and 34% of HA men and women, respectively, earned less than US$10,000/year, as compared with 12% and 18% of white men and women, respectively. In this study, it was apparent that there was an inverse relationship between income and mortality for both ethnic groups.

To summarize the health status of HA, it is important to recognize that not only is this group beset by serious diseases leading to high rates of morbidity and mortality, but they are also placed at inordinate risk for developing such diseases because of the deep penetration of risk factors among them such as obesity, cigarette smoking, and improper diet. Their entire health status picture is further affected by poverty, lack of access to healthcare, and the language barrier. Almost all of the factors that can be cited as causes of healthcare problems among HA are either preventable or remediable. This is where the major thrust needs to occur in the new century to eliminate health disparities in this increasingly growing minority group.

**African Americans**

The US census of 1990 reported that there were about 30 million AA in this country, representing about 12% of the total population, increasing to 12.3% by the census of 2000, and increasing further to 13.5% as of 2008, with 41 million people, according to US Census Bureau data (see Fig. 4.3). This makes AA the second largest...
minority group in America behind Hispanics. AA have been studied more than any other minority group in this country, and therefore relatively more data are available regarding their health status. Health statistics regarding morbidity and mortality have almost always shown that blacks lag behind whites in virtually every category of disease and illness, that is, death, incidence, prevalence, and complication rates are higher for AA and recovery rates tend to be lower. Overall life expectancy, which improved for all sectors of the population in the twentieth century, remains lowest for AA well into the twenty-first century (Fig. 4.4) [17]. For example, if one compares life expectancy figures for whites and blacks, the following statistics were observed in 1992: white males, 73.2 years; black males, 65 years; white females, 79.8 years; and black females, 73.9 years. This discrepancy phenomenon, which continues today, is one of the most striking disparities in vital statistics and is an example of what the author terms the “death gap.” There are numerous other examples, such as the fact that the infant mortality rate for AA is twice as high as for whites. In fact, when mortality from specific diseases is analyzed, it is seen that blacks have worse statistics than whites in almost all major categories [18].

Despite the great barriers to survival imposed by disease and premature death, the growth of the AA population is expected to rise appreciably in the twenty-first

![Graph](image-url)  
**Fig. 4.4** Life expectancy at birth and at 65 years of age, by race and sex: United States, 1970–2006
century, and it is predicted that by the year 2015, AA will increase to almost 23% of the total population [19]. This is largely because of the youth of the black population and to its high fertility rate. The median age of blacks in 1994 was 28 years, which is 7 years younger and 3 years older than the white and Latino groups, respectively. The fertility rate for AA women is 70.6 compared with 79.6 for HA, 59.2 for whites, and 58.9 for Asian Americans and Pacific Islanders (AAPI) [20].

AA consists of a heterogeneous group, which is a genetic mixture of several ethnic origins primarily of African, Caucasian, Native American, and Caribbean sources. The most recent additions to the AA population in recent years have come from immigrants from Caribbean nations such as Jamaica, with 506,000 immigrants, and Haiti, with about 400,000 immigrants in this country as of 1996. Immigration from Africa has been much smaller; legal immigration from Africa from 1994 to 1997 totaled 169,307. AA are heavily concentrated in the southern part of the United States, but the greatest amounts are found in the four most populous states in the union, California, New York, Texas, and Florida.

Poverty remains an important issue for AA. The poverty rate for this group is 31%, disproportionately high when compared with the 8% rate for whites. Although some gains have been made in the past decade, the high poverty rate experienced by AA continues to have a devastating effect on their health status. This is particularly true in large metropolitan areas. One study by McCord and Freeman [21] reported that the health status of blacks in Harlem in New York City was worse than that of the residents of Bangladesh, which is one of the poorest countries in the world. Much of the poverty seen among AA is because of the extremely high rate of unemployment suffered by this group; 13% of AA are unemployed compared with 6% of white Americans, and in some areas of the country, the differential is much greater.

Possession of health insurance is another indicator of a group’s capability of achieving a high standard of healthcare. According to Health, United States, 1995, only 28% of AA had private health insurance, compared with 71% of whites [22]. The federal government has officially expressed concerns about the impact of racism on black health status. In the landmark 1985 publication, the Report of the Secretary’s Task Force on Black and Minority Health [23], Secretary of Health and Human Services Margaret Heckler described the disproportionate burden carried by AA, which leads to inferior health status, and indicated that unequal healthcare access had caused 60,000 excess deaths of blacks over whites (this estimate of excess black deaths is now believed to be more than 80,000 lives lost per year). This was further corroboration that a “death gap” does exist between whites and blacks, and that one of the root causes is racism [24]. A study by University of Michigan researchers [25] also indicated a strong relationship between perceptions of racism and the physical and mental health of AA. This report was based on data accumulated over a 13-year span from the National Survey of Black Americans. A report from Harvard [25] reflecting the impact of racism on access to healthcare for AA showed a significant deficit in access between blacks and whites, which exists at all levels of income among AA. Part of the differences observed might be because of underutilization of health services by blacks, which in turn might be partly attributed to separate cultural traditions and beliefs.
Another factor contributing to underutilization is distrust of doctors and of the healthcare system in general. The memory of the Tuskegee syphilis experiments on black males in the 1940s [26] is still vivid in the minds of many in the AA community, and many who become ill are afraid to seek medical attention fearing that they too might become subjects of experiments. Many blacks also believe that AIDS is a disease that was deliberately spread among them to annihilate the black race, and some think that doctors, hospitals, and the government are involved together in a genocidal plot to infect and eliminate them. Such attitudes should not be regarded lightly, but instead should be taken under very serious consideration by healthcare providers, whether or not they are thought to be fact or fiction.

The major diseases affecting AA include CVD such as hypertension, coronary heart disease (CHD), and congestive heart failure (CHF); cancer; cerebrovascular disease or stroke; diabetes mellitus (DM); renal disease; respiratory disorders including asthma, pneumonia, sarcoidosis, and influenza; and infectious diseases such as HIV/AIDS and tuberculosis. Contributing to the poor health status suffered by AA are several lifestyle abnormalities, which precipitate or aggravate many of the disease problems cited. These include obesity, cigarette smoking, inadequate physical activity, stress, unhealthy environmental living and working conditions, high alcohol consumption, improper dietary habits, and risky sexual behavior. Overall, AA experience fewer years of healthy life than Caucasians, Hispanics, and Asians, and their total life expectancy is shorter than that of any other racial or ethnic group in the United States. The greatest killer of AA is CVD, not violence or HIV/AIDS. In fact, CVD is responsible for more than a third of the annual deaths of AA, and the percentage of deaths in AA is higher than the percentage in whites. According to the National Heart, Lung, and Blood Institute of the National Institutes of Health, in 1995 the death rate for AA from CVD was 154/100,000; for whites it was 114/100,000 [27]. American Heart Association statistics reveal that 44.6% of black men and 46.9% of black women over age 20 are affected by CVD. In 2006, the overall death rate from CVD for the entire population was 262.5/100,000; it was 422.8/100,000 and 292.2/100,000 for black men and women, respectively. In 2006, 47,956 black males and 50,798 black females died of CVD. African American women are at exceptional risk for various types of CVD. Incidence, prevalence, and mortality figures are all higher for black women than for white women for CAD, stroke, hypertension, and congestive heart failure (CHF). The mortality rate for CAD in black women is 69% higher; the mortality rate for stroke is 54% higher; the death rate for hypertension is 352% higher; and the age-adjusted mortality rate for CHF is 113.4 versus 97.5 /100,000 for black and white women, respectively [28].

Coronary Heart Disease (CHD) in African Americans

Non-Hispanic blacks are severely affected by CHD. Among the various categories of CVD, CHD is the largest single cause of death in the American population. When AA are compared with whites in this category, it is seen that blacks have a higher
death rate in the younger age groups but a lower rate at older ages. According to 2009 statistics from the Centers for Disease Control and Prevention, African Americans are diagnosed with coronary heart disease less than Caucasians but are more likely to die of it (see Tables 4.2 and 4.3). CHD death rates in 1995 for black males were 133.1/1,000 compared with 124.4/1,000 for white males, or 7% higher in blacks; the rates for black women were more than 35% higher than for white women (81.6 vs. 60.3/1,000, respectively). It is interesting that if one analyzes risk for CHD, it varies by gender as well as by race. Heart attack event rates are higher for nonblack men aged 65–74, but the rate is almost twice as high for black as compared with white women in that same age group. New and recurrent heart attacks occur more frequently in AA men than in white men only in the 75–84 age category; in younger as well as in older age groups, white men have more heart attacks than do AA men [29].

In addition, Gillum [29] analyzed data from NHANES I and found that the age-adjusted risk for CHD in persons with no baseline history of the disease was higher for AA women than for white women aged 25–74 but was lower for AA men than for white men at all ages. As risk factor levels tend to be higher in AA, reduction of these multiple risk factors in this group could lead to very dramatic reductions in CHD incidence if the risks were reduced only to the levels present in whites. This fact represents one of the most hopeful areas in disease management; as CHD age-adjusted fatality rates remain higher for AA than for whites, the major killer of AA can be significantly controlled through limitation of risk factors such as hypertension, diabetes, and cigarette smoking. Reduction of CHD risk factors in AA men and women just to the levels seen in whites should result in a considerable saving of lives and represents one of the best possible payoffs to public health efforts [30].

The number of studies of CHD in AA remains sparse, and except for a few longitudinal epidemiological studies, over the past two decades, randomized cardiovascular research investigations providing data on CHD morbidity and mortality have included

### Table 4.2 Diagnosed cases of coronary heart disease

<table>
<thead>
<tr>
<th>Non-Hispanic black</th>
<th>Non-Hispanic white</th>
<th>Non-Hispanic black/non-Hispanic white ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.9</td>
<td>6.2</td>
<td>1.0</td>
</tr>
</tbody>
</table>


### Table 4.3 Age-adjusted heart disease death rates per 100,000 (2006)

<table>
<thead>
<tr>
<th></th>
<th>African American</th>
<th>Non-Hispanic white</th>
<th>African American/non-Hispanic white ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>326.5</td>
<td>250.0</td>
<td>1.3</td>
</tr>
<tr>
<td>Women</td>
<td>216.1</td>
<td>160.9</td>
<td>1.3</td>
</tr>
<tr>
<td>Total</td>
<td>262.3</td>
<td>200.3</td>
<td>1.3</td>
</tr>
</tbody>
</table>

only 2–9% AA patients in their study populations. Recently, the National Heart, Lung, and Blood Institute and the Office of Research on Minority Health initiated the Jackson Heart Study in an effort to overcome the severe information deficit, which persists regarding information on CVD in blacks. Considered a black Framingham study, the Jackson Heart Study was built on its predecessor, the Atherosclerosis Risk in Communities Study (ARIC), which was carried out in Jackson, Mississippi for 13 years, based at the University of Mississippi Medical Center. One of the principal goals of the Jackson Heart Study is to “identify Risk factors for development and progression of CHD, with emphasis on manifestations related to hypertension (left ventricular hypertrophy [LVH], CHF, CHD, and stroke) and renovascular disease in AA” [31]. This appears to be the type of study needed to define the characteristics of CVD in AA. Its results will be awaited with great interest.

Other investigations that have shed more light on CVD in AA are the Antihypertensive and Lipid-Lowering Treatment to Prevent Heart Attack Trial (ALLHAT), the African American Study of Kidney Disease (AASK), and the African American Heart Failure Trial (A-HeFT). Significantly, the percentage of black participants in antihypertensive and lipid-lowering treatment to prevent heart attack trial (ALLHAT) was very large, and the African American Study of Kidney Disease (AASK) as well as A-HeFT were uniformly black.

Obesity, defined as a body mass index (BMI) of >30 kg/m², is a risk factor and contributor to the problem of CHD in blacks, especially among black women. Tables 4.4 and 4.5 demonstrate this fact. Four out of five African American women

<table>
<thead>
<tr>
<th>Table 4.4</th>
<th>Age-adjusted percentage of persons 20 years of age and over who are overweight or obese, 2003–2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic black</td>
<td>Non-Hispanic white</td>
</tr>
<tr>
<td>Men</td>
<td>71.6</td>
</tr>
<tr>
<td>Women</td>
<td>79.8</td>
</tr>
</tbody>
</table>

Persons are considered overweight if they have a Body Mass Index [BMI] of 25 or greater
National Health and Nutrition Examination Survey (NHANES)

<table>
<thead>
<tr>
<th>Table 4.5</th>
<th>Age-adjusted percentage of overweight persons 20 years of age and over who are obese, 2003–2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic black</td>
<td>Non-Hispanic white</td>
</tr>
<tr>
<td>Men</td>
<td>35.7</td>
</tr>
<tr>
<td>Women</td>
<td>53.4</td>
</tr>
</tbody>
</table>

Persons are considered obese if they have a Body Mass Index [BMI] of 30 or greater
National Health and Nutrition Examination Survey (NHANES)
are overweight or obese, and in 2007, they were 1.4 times more likely to be obese than non-Hispanic whites. In addition, black children ages 6–17 are 1.3 times more likely to be overweight than their white counterparts.

Hypertension in AA

A recent study by Egan et al. [32] indicates that prevalence of hypertension increased over time in blacks and whites but not Hispanics between 1988 and 2008, and was most prevalent in blacks. Significantly, control of hypertension increased in all groups and reached control levels in an estimated 50.1% of patients studied in the National Health and Nutrition Examination Survey (NHANES) 2007–2008 [33]. This demonstrates that great strides are being made in the management of this disease and that progress is being made towards the Healthy People 2010 goal of controlling blood pressure (defined as systolic blood pressure of <140 mmHg systolic and diastolic blood pressure of <90 mmHg), but much work still remains for all groups, especially African Americans, to decrease prevalence. It should be noted that recent studies have found that only 29.9% of non-Hispanic black men and 36% of black women have their blood pressures properly controlled, according to John M. Flack, M.D., professor of medicine and physiology and chairman of the department of medicine at Wayne State University, Detroit.

Some salient points regarding this disease in AA need to be reviewed herein. These points are as follows:

- AA have a much higher prevalence of hypertension in any decade of life than do all other Americans. For AA males and females, the overall prevalence is 35% and 34.2%, respectively, as compared with 24.4% and 19.3% for white males and females, respectively. Blacks are 1.5 times more likely to have hypertension than whites, according to 2007 CDC data (see Tables 4.6 and 4.7).
- Death rates from hypertension for AA males and females are 355% and 352% higher, respectively, than for their white counterparts.
- Compared with whites, hypertension is diagnosed later and is less well controlled.
- AA have higher risks of serious complications from hypertension such as end-stage renal disease (ESRD), CHF, LVH, and stroke compared with whites. Hypertension is the second most common cause of ESRD, after DM.

<table>
<thead>
<tr>
<th></th>
<th>Non-Hispanic black</th>
<th>Non-Hispanic white</th>
<th>Non-Hispanic black/ non-Hispanic white ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>26.5</td>
<td>17.4</td>
<td>1.5</td>
</tr>
<tr>
<td>Women</td>
<td>23.9</td>
<td>15.9</td>
<td>1.5</td>
</tr>
</tbody>
</table>

Table 4.6 Age-adjusted percentage of persons 20 years of age and over who have high blood pressure, 2003–2006

National Health and Nutrition Examination Survey (NHANES)
Complications of hypertension in AA have an earlier age of onset and a later age of detection than in their white counterparts.

AA tend to have pathophysiological characteristics including salt sensitivity, altered vascular reactivity, and low-renin status, which influence the occurrence and/or aggravate the effects of hypertension more than is the case in whites.

The treatment of hypertension in blacks is a matter of great debate, conjecture, and evolution. The forthcoming guidelines of the International Society on Hypertension in Blacks (ISHIB) recommend that treatment for hypertensive African Americans should begin at a blood pressure of 135/85 mmHg as opposed to 140/90 mmHg as was previously recommended. ISHIB also recommends that chlorthalidone, the thiazide-like diuretic used in the ALLHAT study, should be used as the diuretic agent of choice in blacks instead of hydrochlorothiazide, and that the initial dose of chlorthalidone should be 25 mg/day rather than the previously recommended 12 mg/day. ISHIB guidelines also stratify black patients into primary and secondary prevention groups. For primary prevention, where blood pressure is at least 135/85 mmHg without target-organ damage, or CVD, two-drug therapy should be initiated if the patient’s blood pressure is more than 15/10 above goal (compared to 20/10 as recommended for all hypertensive patients by the American Society of Hypertension (ASH)). The preferred combinations are either a calcium channel blocker and a RAS blocker or a thiazide and RAS blocker. Alternatives are a thiazide/beta blocker combination or a thiazide/calcium channel blocker combination. Secondary prevention applies to patients with a blood pressure of at least 130/80 mmHg who have evidence of target-organ damage or CVD. In these patients with blood pressure that is greater than 15/10 over goal, combination therapy employing drugs with compelling indications should be used. For secondary prevention in patients with blood pressure that is less than 15/10 above goal, a single agent with a compelling indication such as a diuretic or a calcium channel blocker is preferred, with a RAS blocker as an alternative and a beta blocker as an optional choice. It seems wise to advise that African Americans be treated early and vigorously to forestall the development of complications such as renal disease, which seem to occur earlier in black than in white patients. Choice of drug therapy should be made on an individualized basis. Recent data indicate that vasodilating beta blockers may be effective for the treatment of hypertensive blacks [33], and there are several reports of the effectiveness of combination therapy. Safety and avoidance of side effects and adverse events should be optimized.
Heart Failure in AA

Heart failure (HF) affects almost five million Americans, with about 500,000 new cases reported each year. The estimated yearly cost to the nation is US$10 billion. There are substantial differences between blacks and whites with HF regarding age, incidence, etiology, hospitalization rates, LVH, left ventricular function, clinical follow-up, and mortality. Although the data concerning black–white differences is not voluminous, there have been some studies performed, which help to shed light on these disparities and their impact on patient survival. For example, one study [34] showed that AA under age 65 with HF have 2.5 times the mortality experienced by whites of the same ages. When patients older than 65 were considered, the age-adjusted death rate in 1990 for HF was 143.9 for AA men compared with 117.8 for white men, and 113.4 for AA women compared with white females [35]. Medicare data have also demonstrated higher rates of admission [36] and discharge diagnoses of HF [37] for blacks.

A very startling and disturbing study of black–white differences in incident heart failure performed by Bibbins-Domingo et al. [38] clearly delineates the extraordinary aspects of the heart failure problem in African Americans and illustrates how wide the gap is between these two racial groups. In this study, black individuals under 30 years of age had 20 times the likelihood of developing heart failure in the next 20 years compared to whites.

The etiology of heart failure in different racial groups has been a matter of speculation. It has been stated often that AA have a greater prevalence of hypertensive heart disease as opposed to ischemic heart disease as the underlying etiology of their CHF, and that whites have the reverse situation. These beliefs are borne out in the Study of Left Ventricular Dysfunction (SOLVD) trial, in which blacks with HF had a higher prevalence of hypertensive heart disease and a lower prevalence of ischemic heart disease [39]. In addition, Mathew [40], in a prospective analysis of 301 AA HF patients, found that the underlying cause for the HF in the majority of the cases was systemic hypertension. Changes in the left ventricle caused by hypertension include increase in the collagen matrix and myocyte cell hypertrophy; when untreated, LVH might result. LVH might be associated with increased morbidity and mortality and is one of the reasons for the relatively poor prognosis in AA who have CHF [41].

A new treatment paradigm for AA with HF was proposed based on the African American Heart Failure Trial (A-HeFT) [42]. This study, which was carried out in conjunction with the Association of Black Cardiologists, involved 1,050 all-black patients, most of whom had New York Heart Association class III HF. A-HeFT was a randomized, double-blind, placebo-controlled multicenter study involving 169 sites. It tested a hypothesis, generated from earlier trials, that a fixed-dose combination of hydralazine and isosorbide dinitrate, two drugs that had been used for years with little impact on whites, would work successfully in blacks. As a result of a dramatic reduction (43%) in mortality in the drug-treated cohort and other positive end points such as a 39% decrease in first hospitalizations and a great improvement in quality of life, the study was terminated prematurely for ethical reasons, and the
impressive outcomes convinced the Food and Drug Administration (FDA) to approve the combination drug for treatment of HF in AA. The mechanism proposed for this unique benefit conferred by the combination drug is endothelial protection through increased levels of nitric oxide, which has a greater effect in black than in white patients. Isosorbide dinitrate is believed to donate nitric oxide and hydralazine is said to decrease nitric oxide degradation. The leaders of the study suggested that blacks have less natural bioavailability of nitric oxide, and they cited evidence of less robust endothelial function in blacks presumably under the condition of oxidative stress, which the drug combination is believed to ameliorate. Thus, the combination therapy was expected to slow the progression of HF, decrease hospitalizations for exacerbations of HF, and increase survival in AA. The long-term results of this therapeutic intervention are still awaited. The application of a therapy based on polymorphisms and perceived genetic differences is perhaps a portent for future pharmacotherapeutics.

It has been demonstrated that the dire heart failure statistics seen in blacks can be ameliorated and their health status can be improved by the implementation of higher quality healthcare delivery. One of the best current examples of this is the Robert Wood Johnson Foundation’s Expecting Success program [43], which shows that focusing on the provision of high quality care leads to improved outcomes, with the greatest improvement seen in those in the highest risk groups.

Diabetes Mellitus (DM) in AA

DM is the fourth leading cause of death in AA. African Americans are twice as likely to be diagnosed with diabetes as whites and are 2.2 times more likely than they are to die of the disease. According to the American Diabetes Association, about 2.3 million (10.8%) of AA in the United States have this disease. This might be an underestimation; it is believed that half of those who meet diagnostic criteria for DM are undiagnosed. Although the age-adjusted death rates in 1995 were 117% higher for black men and 167% higher for black women than for their respective white counterparts, the prevalence of CVD in blacks with DM appears to be lower than in whites. Overall, however, when one considers Type II or maturity-onset (noninsulin-dependent) DM, the prevalence in the 45–64 years age group is 51% higher for blacks than for whites. In addition, AA diabetics are characterized by the following features:

- A higher prevalence of microalbuminuria, which is a marker for kidney involvement; the presence of renal insufficiency in DM is indicated by microalbumin levels in excess of 200 g/L.
- DM is an independent risk factor for CHD. When hypertension is also present, the risk is doubled.
- Greater body-mass index (BMI) with earlier onset of overweight and obesity and higher rates of centralized obesity is seen in diabetics, which correlates more with CHD. DM is almost three times more prevalent in obese than in nonobese persons.
- More concomitant hypertension is seen in black diabetics.
Higher rates of amputation of the lower extremities occur in AA (1.5–2.5 times more common than in whites).

AA have twice the rate of blindness due to diabetic retinopathy as do whites.

Babies born to black mothers with DM are at higher mortality risk than whites.

ESRD might be up to 17 times more prevalent in AA than in whites.

### Cerebrovascular Disease in AA

Stroke is the third leading cause of death in the United States after CHD and cancer. There are about 500,000 strokes each year of which 150,000 are fatal. Stroke is also a major cause of physical impairment and the cost of acute and chronic care exceeds $30 billion/year in this country. A so-called stroke belt exists in the Southeastern part of the country, where almost 60% of the AA population resides. Even though stroke is generally thought of as a disorder affecting the elderly, it should be recognized that 28% of the victims are under age 65. AA have a stroke mortality rate that is twice that for whites. Although the rate of decline for stroke mortality has increased since the 1970s, there has been a recent slowdown in this decline. This has been especially true for AA, and some recent reports indicate that stroke mortality in this group may actually be increasing.

Because it is very difficult to treat stroke once the process has been initiated, much of the focus has been on primary prevention. Hypertension is the most powerful predictor of stroke, and is found to be a factor in 70% of the cases. Therefore, control of hypertension represents the best strategy to prevent stroke, and in fact a meta-analysis [42] showed that in all studies combined of the association between treating to lower blood pressure and stroke, there was a 42% reduction in the incidence of stroke and a 45% reduction in fatal stroke when diastolic blood pressure was reduced by 5–6 mmHg [44]. This meta-analysis is particularly important because it contains studies of mild-to-moderate hypertension as well as studies involving higher levels of blood pressure; it showed that treatment of all levels is likely to be beneficial.

In addition, the Systolic Hypertension in the Elderly Program (SHEP) demonstrated that a 36% decrease in stroke risk resulted from mean blood pressure reductions of 11/3.4 mmHg. This benefit was seen at all ages studied and in both sexes. This evidence and other data support the need for vigorous drug therapy of hypertension for the primary prevention of stroke at all levels of blood pressure, at all ages, in both sexes, and especially in AA patients. This might be going a step farther than the Joint National Committee on Hypertension, which has heretofore advocated a more conservative, nonpharmacological initiation of therapy for lower levels of hypertension when there are no other risk factors [45]. Another approach to prevention of stroke is through carotid endarterectomy in patients with high-grade carotid artery stenosis, which often leads to ischemic stroke. Although the latter condition occurs more commonly in AA than in whites, AA are one-third to one-fourth less likely than whites to receive carotid angiography to detect stenosis. This is an area
that qualifies as denial of access based on race. It deserves further study and a change in selection patterns for carotid endarterectomy procedures may result in a lowering of the stroke rate among blacks [46].

**End-Stage Renal Disease (ESRD) in AA**

Much has already been stated in this chapter about this very important disease, which has been on the increase in the past two decades despite the efforts to control hypertension. The following points summarize the salient features of ESRD relative to AA patients:

- Although the principal cause of ESRD nationally is DM, in the Southeastern part of the United States the number one cause is hypertension [47].
- The rate of diabetic renal disease is accelerated when hypertension is also present. Control of blood pressure and glucose might slow the rate of progression.
- ESRD has been growing exponentially since the early 1980s, despite efforts to control hypertension. This is particularly true for AA patients.
- The most common lesion resulting in renal failure in hypertension is nephrosclerosis, caused by elevated systemic blood pressure, which leads to vasoconstriction of the afferent arteriole of the glomerulus. This activates the renin-angiotensin-aldosterone system within the kidney, which in turn leads to a sequence of events resulting in elevated efferent glomerular arteriolar resistance. Ultimately, glomerular hyperfiltration occurs as intraglomerular pressure increases, and glomerular injury with mesangial cell hypertrophy results, as evidenced by the appearance of proteinuria.
- Blood pressure in patients with renal insufficiency should be controlled to 130/85 mmHg with any antihypertensive agent or therapy that is effective. In patients with proteinuria exceeding 1 g/day, and in AA with renal insufficiency, a goal of 125/75 mmHg should be sought [48].
- Angiotensin-converting enzyme inhibitors have been found to reduce proteinuria and to slow progression of renal insufficiency. These drugs are deemed to be renoprotective and therefore are the drugs of choice in treating these patients, although other drugs such as loop diuretics and calcium channel blockers may also be beneficial. Angiotensin-receptor blocking agents might also be effective in preventing the development and progression of renal failure [49].

**Asian/Pacific Islander Americans**

Although it is not the largest minority group in America, APIA represent the fastest-growing group in this country, with an increase in population from 3.5 to 10 million people in just 17 years, from 1980 to 1997. Currently, APIA represent about 4% of the total US population. They have the greatest longevity of any ethnic or
racial group in the United States, 85.8 years, according to 2008 US Census Bureau data. Most of the group has emigrated to the United States since 1965, as a result of elimination of quotas designed to restrict the numbers of non-European immigrants. APIA consist of a large number of subgroups. The largest, Filipinos, number about two million people. Other subgroups are Japanese, Chinese, and Koreans; the South Asians (East Indians, Sri Lankans, Pakistanis, Nepalese, and Burmese); the Pacific Islanders (native Hawaiians, Samoans, Tongans, Tahitians, Guamanians, Fijians, and Palauans); the Southeast Asians (Vietnamese, Thai, Cambodians, Laotians, Hmong, and Mien); Indonesians; and Malaysians.

Nearly 40% of the APIA reside in California. Other states with large APIA populations are Alaska, New York, New Jersey, Texas, Illinois, and Washington. The cities with the largest APIA populations are Honolulu, 63%; San Francisco/Oakland, 25%; San Jose, 20%; Stockton, 24%; Fresno, 13%; and Los Angeles, 11%. Some of the APIA arrived in this country decades ago, and many are recent arrivals. The earliest to immigrate here were the Chinese “coolies,” who were transported here to work on building railroads and on other projects in the nineteenth century as a source of cheap labor. Japanese, the third largest APIA group after Chinese and Filipinos, have been in this country for about five generations: the issei (first) were born in Japan and married in the United States between 1907 and 1924; the nisei (second) were born here between 1910 and 1940; the sansei (third), born here between 1940 and 1965; the yonsei (fourth), born here after 1965; and the gonsei (fifth), born here or in any country outside of Japan with at least one yonsei parent. Japanese are the most assimilated of the APIA because more were born in the United States than any other Asian American group, more than 70% of the total number, which far exceeds all others [50].

Thus, each APIA subgroup has distinctive characteristics, which have special health implications. These special aspects are accentuated in the Chinatowns, Little Tokyos, Koreatowns, Little Saigons, and Pnom Penhs, which are now seen in various cities around the country. From a public health standpoint, this means that one should focus attention on the principal medical problems that beset each subgroup, which is a very complicated task. No effort can be made in this chapter to address all of these issues. Instead, the main health problems of APIA will be highlighted.

**Principal Health Problems of AAPI**

**Cancer**

Although CVD is the leading cause of death for APIA in general, as is true for all Americans, there are differences when specific groups are analyzed. For Vietnamese and Chinese, cancer is the leading cause of death. Cancer of the liver is the most common form in Vietnamese, whereas stomach cancer predominates in Koreans and is five times higher than the national rate [51]. The high prevalence of the hepatitis B virus (HBV) among APIA appears responsible for the increased incidence of liver cancer in this group, as it is well established that HBV predisposes to
hepatic carcinoma [52]. Chinese American males have the highest rate, 9.8/100,000, compared with other APIA subgroups.

Colorectal cancer rates for the three major APIA subgroups, Chinese, Japanese, and Filipinos, are generally lower than for whites, according to data from the Surveillance, Epidemiology, and End Results (SEER) statistics [53]. However, with increased adoption of the American diet, these rates for APIA appear to be increasing. Lung cancer rates for AAPI are lower than for the white population, as are rates for prostate cancer. Nasopharyngeal cancer is a rare tumor but it predominates in Chinese and is thought to be tied to the custom of eating Chinese salted fish during infancy and later in life, as well as the presence of the Epstein-Barr virus, and perhaps unique hereditary factors [54]. About 32% of all cancer in the city of Canton (Guangzhou) in China are of this type [55].

Other cancers prevalent in APIA include gastric cancer, which is particularly high in Korean males (44.8 vs. 8.6/100,000 for white males in Los Angeles County) [56].

**Tuberculosis**

The incidence of tuberculosis is five times higher in APIA than in the rest of the population and in 2007, the tuberculosis rate was 24 times higher than that for whites. In addition, this disease is increasing among AAPI whereas it is decreasing for others. In the time period from 1988 to 1995, the tuberculosis rate rose almost 8% among APIA, from 36.3 to 45.9/100,000 [57].

**Hepatitis B**

This disease has shown a decrease in incidence from 1987 to 1995, but APIA children still have rates that are more than twice as high as in the general population [58].

**Cardiovascular Disease**

As stated earlier, CVD is the leading cause of death for most APIA, although they are 50% less likely to die of heart disease than Caucasians. Hypertension is a major risk factor for this group, although its prevalence is lower than in most other minority groups. For example, hypertension prevalence for Chinese is 15.7%, for Japanese, 12.5%, and for Filipinos 24.5%, compared with 26% for blacks and 20.2% for whites [59].

A study conducted in 1986–1988 to compare rates of hypertension in Japanese in Hiroshima, Hawaii, and Los Angeles showed a gradient of increase for the disease from Hiroshima (29%) to Los Angeles (37.2%) to Hawaii (42.6%). As all study participants were born in Japan, the data have been interpreted as demonstrating the impact of environmental, dietary, and other nongenetic factors on disease causation [60]. In addition, Kagan et al. [61] performed a study in 1974, which also
showed that the relative immunity to ischemic heart disease enjoyed by Japanese in Japan is progressively lost as migration is analyzed from Japan to Hawaii to San Francisco, which also correlates with a progressive rise in serum cholesterol levels (the Ni-Hon-San Study) CHD in particular varies greatly among AAPI subgroups. Chinese, Japanese, Koreans, Vietnamese, Cambodians, Thai, Laotians, Asian Indians, and native Hawaiians all have CHD death rates, which are lower than for whites. Conversely, the rates for Guamanians and American Samoans are much higher than for whites.

**Stroke**

An analysis of cerebrovascular disease in California [62] showed that American Samoans have the highest age-adjusted death rate from stroke of all ethnic and racial minorities (137.6/100,000), which is five times higher than that for the white population (28/100,000). This rate compares with 106.8 for Cambodians, 62.7 for Laotians, 35.2 for Vietnamese, Koreans 29.2, Filipinos 28.1, Chinese 24.0, Japanese 22.9, and Asian Indians 21.2.

**Diabetes Mellitus**

Type 1 diabetes is rare in APIA, whereas Type 2 is common. Among the four largest subgroups of APIA, Filipinos have the highest rate, 21.8/1,000 for total cases and 15.5/1,000 for new cases of diabetes; Chinese have the lowest prevalence rates [63]. For Japanese Americans, the prevalence of diabetes is higher than that found in Japan. In fact, the prevalence of Type 2 diabetes in Nisei (second-generation) men has been found to be 20%, or almost twice as high as in the white American population (12%) and about four times higher than in Japanese men of similar age in Tokyo (5%). In general, APIA in all major subgroups have a higher prevalence of noninsulin-dependent DM than their counterparts in their countries of origin.

**Overall Mortality**

In general, it is evident from most data sources that although there are serious disease problems from specific causes among APIA, which require focused attention from a public health standpoint, the mortality figures are better for this group than for all other minorities and for whites. In fact, according to two major studies, the National Health Interview Survey (conducted from 1986 to 1994) and the National Longitudinal Mortality Study, the overall age-standardized mortality was lower in APIA than in all other major ethnic groups and the risk of death was 40% lower than that for whites [64]. Significantly, there were fewer deaths from CHD than from cancer among APIA, although CVD in general is the greatest killer in both groups.
American Indians/Alaskan Natives

Included in this population category are a number of tribes of American Indians as well as Alaska Natives (Eskimos) and those native to the Aleutian Islands. According to the US census of 1990, 0.7% of the American population were AIAN, and this figure remained about the same in the 2000 census. This means that AIAN will have experienced a loss relative to other minority groups whose percentages have increased in the past decade. In general, native Americans have experienced severe health problems, but in the last half of the twentieth century there was an improvement of their health status. The period 1940–1980 witnessed a dramatic increase in life expectancy for American Indians, from 51 years in 1940 to 71.1 years in 1980. Also during that time period, the principal causes of disease and death changed, from gastroenteritis and infectious diseases such as tuberculosis in the early years to diabetes and injuries in more recent years [65].

AIAN are an extremely heterogeneous group with great intergroup variability in health status. Thus, it is difficult to make generalizations about their health problems or to make blanket recommendations, which would be appropriate for all members. The Federal government has recognized about 500 tribes in the United States, which have been placed under the authority of the Indian Health Service in 12 national service areas. This has allowed collection of some data in an organized manner although underreporting is common. Attention has been focused on seven health problem areas in which disparities are known to exist with the intent of reducing these problems through preventive strategies and health promotion initiatives. These seven areas of greatest concern are alcoholism and substance abuse, child abuse and family violence, diabetes, women’s health, the health of the elderly, maternal and child health, and injuries. Another indicator of health status is the Years of Potential Life Lost (YPLL), which is a measure of premature death utilized by the Centers for Disease Control and the National Center for Health Statistics. Age 75 is used as a reference point for all races, and YPLL-75 indicates the YPLL before that age per 100,000 persons. Thus, a child who dies at the age of 1 year has lost 74 years of potential life. For the years 1990–1992, the age-adjusted YPLL for the nation as a whole was 8,384/100,000; for AA the comparative figure was 15,468 and for AIAN it was 11,875. These figures highlight the disparities that exist for these two racial groups. For AIAN, the causes can be found in higher rates of infant mortality, injury deaths, homicide, and suicide.

Some of these problems could be prevented by appropriate attention to healthcare access discrepancies. For instance, American Indians had a rate of first-trimester care in pregnancy in 1991, which was about 60%; this was the lowest rate in the nation, compared with about 80% for whites [66]. A higher rate of prenatal care would almost certainly lower the neonatal mortality rate for American Indians.

Obesity is a common problem among AIAN and is frequently linked with adult-onset DM [67]. Regarding hypertension, the Strong Heart Study [68], which was a longitudinal investigation of CVD and attendant risk factors in over 1,500 participants from 13 tribes in Arizona, the Dakotas, and Oklahoma, showed that despite a high prevalence of diabetes and obesity, there was no more hypertension in
American Indians than in the general population. The suggestion has been made, based on these data, that obesity and hyperinsulinemia do not affect blood pressure in this group to the same extent as with AA. However, hypertension still must be aggressively treated and controlled in them because of its known role as a precursor of morbidity and mortality in CVD and diabetes. Although heart disease is the leading cause of death in this population, it contributes less to all-cause mortality than is the case with other minority groups, and mortality from heart disease in this group is about half of that for the general population. However, when one analyzes data for them under 35 years of age, the heart disease death rate is about twice as high for them as for all other ethnic groups; but as the death rate from heart disease rises less steeply with age compared with other groups, rates are ultimately lower for American Indians over the age of 44 [69].

Much more information is needed and more research must be conducted on American Indians so that better health profiles can be drawn of this population. Accordingly, on February 15, 1995, the Public Health Service conducted a Healthy People 2000 progress review, which focused on their health needs [70]. Determining that data sources in use were inadequate, the Public Health Service decided that reservation states would no longer be used as a unit of analysis. Instead, the Indian Health Service and the National Center for Health Statistics will collaborate with other appropriate agencies within the Public Health Service so that appropriate representation of AIAN in national health surveys will be accomplished. In addition, local sources of health information are now being utilized to supplement data from reservations, especially as it is now recognized that most AIAN no longer live on reservations. In addition, objectives drafted by the Federal government for improving the health of Native Americans must be tailored to particular communities. The Cherokee Nation and the Indian Health Board of Minneapolis are groups that have accomplished this. These types of revisions in data collection are necessary before appropriate solutions for the myriad medical problems of AIAN are proposed. Meanwhile, physicians should try to focus on the unique cultural aspects and special needs of these patients in attempting to treat this very complex group.

Conclusion

This presentation on cultural diversity in medicine has centered on statistics and information regarding the principal diseases affecting the largest minority groups in the United States. The intent is for this data to be used by medical practitioners to be more culturally sensitive to the unique characteristics of these people, and in so doing, to deliver a higher standard of healthcare to them. Although all diseases in each group could not be covered within the scope of this chapter, it is hoped that those who read it will be inspired to investigate such problems further. Each healthcare provider should ideally become a student of cultural differences and should become proficient in cultural competency. As the author indicated in the introduction above, every echelon of healthcare provision, from the primary care provider to the
physician working in the managed care setting to the medical administrator in a
government healthcare agency, should be trained in the skills of cultural competency,
and all have a moral and ethical obligation to learn these skills and to apply them.

It should be obvious from the foregoing that much more information is needed
on all racial minorities and that future iterations of investigations such as NHANES
must be broadened to cover minority groups such as AIAN and must be more
focused at the same time, out of consideration for the special features of the disease
process from group to group. In addition, this society has an obligation to train
more minority physicians and other health professionals, especially as it has
been amply demonstrated that they are the ones who devote more time to caring
for patients in minority communities. One must also assure these most needy of
patients in the United States that they will have all of their healthcare disparities
eliminated, and that they will be provided complete access to expert medical atten-
tion, which is their right to have. Cultural diversity is a huge reality in American
society, and the field of medicine is already delinquent in adjusting to this reality.
The time to grasp cultural diversity in medicine is now.

Glossary

**Culture**  The shared values, norms, traditions, customs, arts, history, folklore, and institu-
tions of a group of people.

**Cultural competence**  A set of academic and interpersonal skills that allow individuals to
increase their understanding and appreciation of cultural differences and similarities
within, among, and between groups. This requires a willingness and ability to draw on
community-based values, traditions, and customs and to work with knowledgeable persons
of and from the community in developing focused interventions, communications, and
other supports.

**Cultural diversity**  Differences in race, ethnicity, language, nationality, or religion among
various groups within a community, organization, or nation. A city is said to be culturally
diverse if its residents include members of different groups.

**Cultural sensitivity**  An awareness of the nuances of one’s own and other cultures.

**Culturally appropriate**  Demonstrating both sensitivity to cultural differences and simi-
larities and effectiveness in using cultural symbols to communicate a message.

**Ethnic**  Belonging to a common group – often linked by race, nationality, and language –
with a common cultural heritage and/or derivation.

**Language**  The form or pattern of speech – spoken or written – used by residents or
descendants of a particular nation or geographic area or by any large body of people.
Language can be formal or informal and includes dialect, idiomatic speech, and slang.

**Mainstream**  A term that is often used to describe the “general market,” usually refers to
a broad population that is primarily white and middle class.
Multicultural  Designed for or pertaining to two or more distinctive cultures.

Nationality  The country where a person lives and/or one that he or she identifies as a homeland.

Race  A socially defined population that is derived from distinguishable physical characteristics that are genetically transmitted.

Religion  A system of worship, traditions, and belief in a higher power or powers – often called God – that has evolved over time, linking people together in a commonality of reverence and devotion [71].

References

29. Gillum RF, loc cit.


Part II
Current Problems
Chapter 5  
Perspective: Health Care and the Politics of Race

M. Gregg Bloche

Abstract  Straw men are large players in the debate over racial disparity in American medicine. Most have been deployed by the disparities-denying right, but progressives intent on “outing” racism have sent forth their share. In this chapter, I devote some effort to flushing them out. But my larger aim is to understand the competing moral premises that drive the politics of healthcare disparity. At the end of the chapter, I contend that arguments about the scope of disparity and discrimination in medical care are disputes about the appropriate scope of personal responsibility for life circumstances. Further research into the factors that correlate with racial differences in health care can shed light on the circumstances that bring about these differences. But whether these circumstances, once understood, should be deemed acceptable is a moral and political matter. Sharp disagreements over the scope of personal and public responsibility for these circumstances are inevitable. These disagreements make it harder to pursue common ground solutions to racial and other inequities in health care.

The Institute of Medicine’s (IOM) report on racial disparity in health care (IOM 2003) has become the subject of much sound and fury. Critics on the right have attacked the authors’ motives, condemned them for being too quick to diagnosis discrimination, and insisted that racial disparity in health care remains unproven. Prominent conservative scholar Richard Epstein has characterized the report as both a “genteel-guilt trip” and “a determined effort to make things appear worse than they really are”. Some on the left, meanwhile, have criticized the IOM for papering over pervasive racism in American medicine. Since the politics of race is

1I was a member of the IOM committee responsible for the report and was one of the principal drafters of the chapters that assessed the mechanisms by which racial disparities arise.

M.G. Bloche (✉)  
Professor of Law, Georgetown University, Senior Fellow, The Brookings Institution, Adjunct Professor, Bloomberg School of Public Health, Johns Hopkins University, Washington, DC, USA  
e-mail: bloche.law@georgetown.edu
hardly genteel (and since I was a coconspirator in the IOM report1), I shall take Epstein’s remark as a compliment. But rather than bemoaning the ideological fuss, I shall try in this chapter to glimpse what lies behind it, with an eye toward possibilities for common ground in the pursuit of healthcare equity.

That the politics of healthcare disparities has at times been testy is clear. Allegations of racism attract attention, and the charge that America’s physicians are biased against blacks and Latinos has drawn considerable press coverage. Disparities-denying conservatives, on the other hand, have found welcoming audiences in high places. In 2003, top officials at the Department of Health and Human Services ordered HHS researchers to strike the term disparity from a congressionally mandated annual report on “healthcare disparities”. Officials told the researchers to delete their conclusion that racial disparities are “pervasive in our healthcare system” and to remove findings of disparity in care for cancer, cardiac disease, AIDS, asthma, and other illnesses. The researchers complied. Two days before Christmas of 2003, HHS secretary Tommy Thompson released a neutered rewrite, one that rejected the IOM’s findings of racial disparity and dismissed the “implication” that racial “differences” in care “result in adverse health outcomes” or “imply moral error … in any way.”

Unhappy HHS officials then leaked earlier versions of the report. Irate House and Senate Democrats insisted that Thompson retract the rewrite and issue the researchers’ suppressed version in its stead. In February 2004, Thompson did so, telling a Congressional hearing that the rewrite had been a “mistake.” This, in turn, disappointed disparities-deniers, who chided Thompson for failing to maintain a stand against political correctness.

All sides in this debate have deployed straw men, though the disparities-denying right has assembled them in greater numbers. I devote some effort in this chapter to flushing them out. But my larger aim is to understand the ire. To this end, I search for the competing moral premises that inspire conflict over whether racial disparities in health care are a problem and what the state should do about them. Further research into the factors that correlate with group differences in health care can shed light on the circumstances that bring about these differences. But whether these circumstances, once understood, should be treated as unjust or inevitable (or even as a matter of just dessert) is a moral and political matter. Those wedded to an ethic of individual responsibility and self-reliance, unleavened by sensitivity to unlucky life circumstances differ sharply from those more concerned with fair distribution of life’s possibilities and misfortunes.

Keywords Hueristics • Stereotypes • Kabuki • Doctor-patient communication • Universal medical coverage • Racism • Discrimination • Richard Epstein • Sally Satel • Jonathan Klick
Straw Men

Straw men are fixtures in right-wing criticism of the IOM report, in op-ed pages, opinion magazines, and scholarly fora. Sally Satel and Jonathan Klick, among others, have deployed them in multiple venues, from the *Weekly Standard* to academic journals and conferences. Some examples follow.

Insurance Coverage and Ability to Pay

Satel and Klick [1] portray the IOM report as emphasizing “discrimination” and underplaying access to quality care as a cause of racial disparities. Richard Epstein has done the same. But the IOM report begins by noting that access, in the form of insurance coverage, is the main determinant of racial differences in care, since the quality and extent of coverage vary by race [2]. The IOM committee on racial and ethnic disparities directed its attention elsewhere at congress’s request. The legislation that created the committee (and led to its report) instructed the IOM to “[a]ssess the extent of racial and ethnic differences in healthcare that are not otherwise attributable to known factors such as access to care (e.g., ability to pay or insurance coverage)” (emphasis added), and to “[e]valuate potential sources of racial and ethnic disparities in healthcare, including the role of bias, discrimination, and stereotyping at the individual (provider and patient), institutional, and health system levels.”

Thus, the committee sought to factor out differences in insurance coverage, income, wealth, and other access-related influences, and to focus on racial and ethnic disparities among patients with similar coverage and ability to pay. The committee recognized that these disparities, although substantial, are small in comparison with differences between the care that insured and uninsured Americans receive. The panel also noted that health *status* – as opposed to health care – disparities mostly reflect differences in behavioral risks, social and economic circumstances, and environmental conditions. Medical care by itself has surprisingly small effects on population-wide health.

Uncertainty and Discretion

Epstein, Satel, and Klick misportray the IOM committee’s explanation for racial disparities in care that persist after insurance and other access-related factors are taken into account. Epstein writes that the committee’s report “lumps together the questions of clinical uncertainty and communication breakdown with bias and
prejudice,” and evinces “eagerness to find (illicit) discrimination as the source of the various difficulties.” Satel and Klick make similar claims. They thereby fail to engage, let alone rebut, the committee’s explanation.

The committee’s explanation invokes two kinds of uncertainty: that arising from incomplete information about diagnostic and therapeutic alternatives and that stemming from shortcomings in doctor–patient communication [3]. The first, in my view, is the most important. Clinical judgment is beset by pervasive uncertainty about diagnosis and prognosis, the efficacy of tests and treatments, and patient preferences [4]. More often than not, medical decisions do not rest solidly on scientific evidence, and more often than not, physicians choose from among multiple clinical alternatives. Wide variations in medical practice ensue, leaving doctors with a great deal of clinical discretion. To the extent that physicians exercise this discretion in ways that vary by race or ethnicity in the aggregate, racial and ethnic differences in healthcare ensue. Among the many factors that can influence the exercise of discretion are race-linked heuristics, attitudes, and levels of empathy. The cognitive psychology literature contains ample proof that race-linked heuristics, attitudes, and differences in empathy persist. To be sure, as John Wennberg and others note, other influences, including geography, affect the exercise of discretion [5]. But some of these influences may themselves be race-linked: patterns of housing segregation, for example, mean that the effects of geography and race can be correlated, mutually reinforcing, and difficult to disentangle.

Epstein, Satel, and Klick heap invective on this line of reasoning instead of probing its recesses. They might have posed questions, not addressed in the IOM’s report, about when race-linked heuristics should merit deference (on clinical or other grounds) and when they should be rejected as offensive or inaccurate stereotypes. They also might have explored the trade-offs between gains from reducing clinical discretion (and group disparities in care) by imposing rules and the clinical advantages of bedside discretion. In addition, they could have examined the role of patients – their expressed preferences and levels of trust – in shaping physicians’ clinical judgments.

Uncertainty stemming from shortcomings in doctor–patient communication gets more sympathetic treatment from Epstein (though not from Satel and Klick). Epstein is open to the possibility that communication failure matters and that cultural and linguistic gaps make it more likely. Satel and Klick speak scornfully of a “cultural competence training industry,” and they misportray the IOM’s discussion of linguistic and cultural gaps as a diatribe against racial bias. The IOM’s hypothesis concerning shortcomings in doctor–patient communication is, in essence, this: (1) communication is imperfect (due to time limits, economic constraints, and ambiguities in the meaning of language and other cues); (2) communication across racial and ethnic lines is especially prone to errors and uncertainty because of language and cultural gaps; (3) physicians are therefore more uncertain about minority group members’ medical needs and concerns; and (4) physicians are therefore less inclined to offer at least some high-intensity, high-cost treatments to minority group members. As a corollary, patients separated from their doctors by language and cultural gaps are more uncertain about the quality and reliability of their doctors’ recommendations. Faced with this greater uncertainty, these patients are (on rational grounds) less inclined to agree to recommended treatments or to seek medical consultation in the first place.
This account of physician–patient communication explains racial disparity, to some degree, at least, without invoking racial bias. Satel and Klick refuse to acknowledge this; Epstein allows for this possibility but does not pursue its policy implications. These implications are straightforward. Approaches that Satel and Klick ridicule, including cultural competence-building and better representation of disadvantaged minority groups in the health professions, hold out great potential to shrink race- and ethnicity-related gaps in doctor–patient communication. So does physician payment reform that better rewards effort spent talking and listening to patients. Even skeptics about the import of racial bias have reason to support these approaches as part of an effort to ameliorate healthcare disparities. For some on the right, however, ideological blinders get in the way.

**Variations in Clinical Circumstances**

Yet another straw man, proffered by Epstein, Satel, Klick, and others, is the claim that the IOM committee failed to acknowledge that legitimate, race-related differences in care can arise from variations in clinical circumstances. Differences in disease incidence, drug metabolism, treatment efficacy, patient preferences, and family support systems sometimes correlate with race [6]. Good, patient-centered, clinical decision making should take such factors into account, even if they result in race-related variation. The IOM report took note of this.

Conservatives (and others) could push the discussion forward in this sphere by challenging the IOM and others to do better at distinguishing between clinical differences that do and do not justify racially disparate treatment. There are gray zones in this realm, worthy of further exploration. One is patient preferences. Conventional bioethics thinking holds that the choices of mentally competent patients merit great deference. But it is well known that these choices are greatly influenced by how doctors frame and portray clinical alternatives. They are also shaped by patients’ social circumstances, including community-wide levels of trust. To the extent that these influences themselves reflect race-related unfairness, formulaic deference to patient choice cannot be the whole answer. But how should health policy – and the law – address disparities that arise from these influences? The role of family support systems raises similar issues. To the extent that weaker social support systems in minority communities ensue from historical injustice, medical decision making that takes account of available social support may be both clinically appropriate and morally problematic. This conundrum of health policy and social justice merits deeper exploration.

**Minority Physicians’ Beliefs and Attitudes**

Epstein, Satel, and Klick also err by assuming that minority physicians are not influenced by stereotypes or bias when they care for patients who belong to their own racial or ethnic group. This premise plays a key role in their critique: based on it, they contend that proof of racial bias in clinical decision making requires a showing
that white and minority physicians treat minority patients differently. This assumption is understandable – the notion that black or Latino doctors can hold negative stereotypes or biased attitudes toward their compatriots is counterintuitive. But evidence from cognitive psychology studies shows that members of minority groups often hold unfavorable beliefs and biases toward fellow group members. A variety of mechanisms for this have been proposed, including incorporation of ideas and attitudes that prevail in the wider society and identification with members of favored groups (and with their beliefs and biases). Both of these mechanisms may be especially relevant for minority physicians anxious about their social status and eager for acceptance by their white peers. If minority physicians share their white peers’ beliefs and biases toward minority group members, then requiring proof that they treat minority (or white) patients differently than do white physicians makes no sense.

**Discrimination and Racism**

The claim that healthcare disparities are the product of pervasive racism is a caricature promoted, for the purpose of ridicule, by the disparities-denying right. Some, though, have invoked the IOM report as proof of pervasive racism in medicine, and a few press reports have characterized the IOM’s conclusions in such terms. In fact, the IOM report avoided the word *racism*, and many have criticized this omission as a failure to fully acknowledge racial injustice and its causes. Overt racism – apartheid beliefs (consciously experienced and acted upon) about the relative respect and regard owed to whites and to racial minority groups – is part of the healthcare disparities story: it persists on the fringes in American life. But it is not the main plotline.

There is little evidence that American physicians, as a group, openly harbor and act upon race-based hatred or contempt. There are outlier cases of crude bigotry, but preoccupation with these distracts attention from the larger story. Clinical uncertainty and discretion, race-related heuristics and attitudes, and communication failures across cultural and linguistic lines interact in complex ways to create disparity. The word *racism* is a conversation-stopper – an epithet that delivers a harsh judgment. Harsh judgment is at times warranted: calling a bigot a bigot achieves a measure of corrective justice and affirms the dignity of those who are objects of the bigot’s contempt. But wielding the “r-word” against race-related heuristics, attitudes, and differences in empathy that are both widespread and subliminal, even unconscious, is more likely to arouse ire than to encourage self-scrutiny and inspire change. To ameliorate disparities, consciousness-raising scrutiny of causal mechanisms will be essential. Facile resort to the “r-word” makes such scrutiny less likely.
Subsidies and Morals: When Are Racial Differences Wrong?

The chief pity of the right’s resort to straw men is that they divert attention from conservatives’ more potent challenge to policies aimed at ameliorating racial disparities in care. Part of the foundation for the conclusion that disparities are widespread is the large number of studies that find disparities after controlling for insurance status, income, education levels, and other confounding factors. Epstein, Satel, and Klick attack this foundation by pointing to potential confounding influences that go unobserved (and uncorrected for) in these studies. Racial disparities, they note, appear to narrow as additional confounding variables are identified and factored out. They extrapolate from this argument to the conclusion that unobserved variables, associated with race, explain all apparent racial disparities. Decisions by doctors and patients, Epstein argues, take myriad unobserved costs and benefits into account. Because some of these correlate with race, race-related differences in care ensue.

For Epstein, all racial differences in care that result from differential costs and benefits are legitimate per se. Some accuse him of thereby countenancing racism. His response is that markets select against racial prejudice to the point of extinguishing it. Racist sellers charge more than non-racists to serve members of the racial out-group, since racist sellers seek compensation for the affront to their bigoted tastes. But this price difference, Epstein holds, is the racists’ undoing, since it channels patrons to cheaper, non-racist sellers. Well-functioning markets, Epstein says, provide immunity against racial animus, and in medicine, markets function well enough. Excessive government regulation, not bigotry, keeps markets from fulfilling their antiracist potential.

This is an appealing story. The American way, with a few right turns, prevails over the bigots in the end. Dismissing this account as racist, as some do, is a resort to epithet, not reason. Epstein’s story, though, sidesteps an anomaly at the outset. This anomaly points the way to a deeper problem, unacknowledged by those at either pole of the disparities debate. The anomaly is that open racism – segregation, exclusion, and race-based contempt – was pervasive in American life at a time of comparative laissez faire. Racial segregation and exclusion in economic life, including medicine [7], was a matter of choice, not just Jim Crow law. Sellers of myriad goods and services, including health care, chose to sacrifice profits in order to discriminate openly. The emergence of antidiscrimination laws and antiracist social norms during the 1960s and 1970s coincided with the intensification of economic and health and environmental regulation more generally. This is not to say

---

2 One might argue that some sellers were not in fact sacrificing profits by discriminating, since failure to exclude victimized racial groups might have led to backlash and boycotts by white purchasers. This argument underscores the insufficiency of laissez faire as a remedy for discrimination based on racial animus.
that such regulation accounts for the fade of overt racism since the 1950s; it is merely to note that markets made room for racial animus for much of our history.

Does this disprove Epstein’s account? No – to the contrary, it shows that Epstein has not pushed his story far enough. His central claim is that race-related differences in behavior, including healthcare disparities, result from race-related differentials in costs and benefits. But he hesitates to treat bigotry itself as a basis for cost – that is, he hesitates to count the psychic cost bigots experience when they serve members of disfavored social groups. Epstein is not a racist, and he treats bigotry as an illegitimate preference; this buttresses his wishful thinking about the ability of markets to extinguish bigoted behavior. By not “counting” bigoted preferences – and the psychic costs of violating them – he clears a path for his claim that racial disparities are legitimate market outcomes that reflect race-related cost differences.

This is a provocative proposition as it stands, but it would turn offensive were Epstein to “count” racial animus as a preference and to therefore treat bigoted behavior as the legitimate product of differential costs. To avoid doing so, he distinguishes (implicitly) between differential costs that do and do not count. For Epstein, overt bigotry does not count, but, it seems, virtually every other race-associated factor does. The problem with this approach is that it fails to explain how lines are to be drawn between the factors, or costs, that do and do not count. Indeed, Epstein does not acknowledge the need to draw such lines; instead, he merely ignores the psychic costs suffered by disappointed bigots whom markets (or law) will not let discriminate. But surely these costs are real for the bigots. Deciding not to count them is a moral and political judgment – one that virtually all of us would agree upon, but a political choice nonetheless. Likewise, deciding to count other race-related factors, as Epstein does, and to treat the racial disparities that result from them as legitimate, is a political judgment.

Others may and do disagree with this judgment. Many different costs, or variables, can contribute to racially disparate outcomes by influencing people’s market choices. Some, as Epstein, Satel, and Klick note, are difficult to observe and probably have not been accounted for in studies of healthcare disparities. Epstein could and should have pushed his story further by explaining all racially disparate results as products of differential costs, then noting the need for political choices between acceptable and illegitimate differentials in cost.

Had Epstein done so, he would have had to acknowledge that differential costs do not make disparate outcomes legitimate per se. Discovery that a previously unrecognized differential cost, or unobserved variable, contributes to racial disparity does not in itself shrink the problem of disparity: it sets up the need for a political and moral judgment as to whether the newly recognized factor should be accepted as a given or targeted for amelioration. This judgment is often easy to make. For example, nearly all would agree that a physician’s race-related empathy or dislike is cause for objection and reason for action.3 Likewise, nearly all would

---

3 There might, however, be disagreement over the proper scope and content of government intervention – for example, over whether government should pursue primarily punitive, educational, or other approaches.
hold that race-correlated differences in disease presentation and drug metabolism can justify differences in diagnostic and therapeutic strategies. Other factors, however, are politically and morally contested. Should race-correlated differences in social support, patient trust, and therapeutic compliance be tolerated or treated as morally unacceptable? Answers to such questions depend on views about social justice. Do past ill treatment of minorities and present social, cultural, and economic differences create moral duties to address gaps in family structure and social capital? How deeply should government intrude into the private sphere in order to tackle such problems, and how much economic redistribution should the state impose? Are trust and compliance, and their psychological determinants, a state responsibility, perhaps because of past government failures to address abuses of trust?

Other politically contested factors reflect the differential abilities of white and disadvantaged minority populations, in the aggregate, to pursue their needs and wants within healthcare systems. There is evidence that African Americans are less inclined to press their concerns, to complain, and to sue when health plans and providers disappoint them. The resulting cost differentials for payers and providers create incentives to deliver more intensive services to whites. It is, of course, not the case that all whites are more assertive or demanding than all blacks: these cost differentials represent population-wide trends. These trends, though, are enough to instill expectations in heuristic fashion, and to make it economically rational for payers and providers to act on these heuristics by delivering lower levels of care to African Americans. Should the healthcare disparities that result be dismissed as matters of personal preference, not public responsibility? Or should government intervene, in the face of cost differentials, either to push payers and providers to compensate for African American reticence or to encourage black patients to more vigorously pursue their needs?

Epstein does not acknowledge, let alone address, these and other political questions about the morality of disparity. He sidesteps such questions by adopting the principle of actuarial fairness, the premise that differential costs justify healthcare disparities per se. He avoids embarrassment by making an exception for the psychic costs that bigots experience on encountering members of groups they do not like, but he does not explain his basis for this exception. Epstein’s embrace of actuarial fairness sets up his most far-reaching claim: that government action to ameliorate disparities entails coerced cross-subsidies. Antidiscrimination laws triggered by disparate racial impact are his paradigmatic case. To comply with these laws, Epstein notes, actors must incur costs that they otherwise would not. For example, applying a disparate impact standard to health plans would press them to ignore the

---

*It is frequently suggested that physicians are more reluctant to prescribe onerous courses of treatment for patients with weaker home and family support systems. In addition, the IOM report pointed to racial and ethnic differences in patient preferences (influenced in part by patient trust and manifested in part by patient compliance) as part of the explanation for racial and ethnic differences in care.*
cost differentials (and business opportunities) created by race-related differences in patient assertiveness. To the extent that antidiscrimination law causes plans to act differently than they would were they free to respond to race-related cost differentials, it creates a cross-subsidy, from less assertive to more assertive racial groups.

From an actuarial fairness perspective, such cross-subsidies are wrong: differential costs should be taken as given, not shifted between groups. But other conceptions of fairness yield different verdicts on inter-group subsidies. Moral objection to pervasive, race-related disadvantage, in health and other spheres, leads to refusal to take race-linked cost differentials as given — and to insistence on cross-subsidies that arouse Epstein’s ire. Objection to racial disparity in rescue efforts leads to insistence on equity in healthcare provision even when disparities in care do not yield differences in clinical outcomes. Objections to socioeconomic disparity in health or in rescue efforts give rise to calls for other inter-group subsidy schemes — schemes that overlap considerably but not completely with programs aimed at racial inequity.

Epstein does not make the case for preferring actuarial fairness to these other grounds for judging cross-subsidy schemes, nor does he acknowledge the case against it. The case for actuarial fairness is tied to the value of allowing differential costs to remain with the groups that incur them. Doing so has value when group members and others can respond meaningfully to these cost signals by adjusting their behavior in socially desirable fashion. Auto insurance is the paradigmatic example: different rates for drivers with different safety records encourage drivers to take care. Actuarial fairness has another, non-instrumental value: the morality of reciprocity supports leaving higher costs with those who voluntarily create them. In the healthcare disparities context, actuarial fairness yields little of either of these forms of value. Providing disparate levels of care to people with different levels of social support, trust and assertiveness, expected likelihoods of compliance with treatment, and ease of communication with clinical caretakers is unlikely to spur improvements in social support, trust and assertiveness, or these other things. And the morality of reciprocity hardly supports “punishing” disadvantaged minorities for their deficits (actual or perceived) in these areas by giving them lower levels of medical care. In the healthcare disparities realm, actuarial fairness is a principle unmoored from its rationale.

Yet Epstein’s core insight — that racial disparities in care reflect differential costs — retains its power. If Epstein has not taken the next step, toward a way to distinguish

---

Footnotes:

5 Epstein assumes that the measure of medical care’s value is its impact on health: the number of lives or life-years saved (perhaps adjusted for quality of life) per dollar spent or organ transplanted. But given the reality that medicine has relatively little effect on population-wide health in comparison with lifestyle, socioeconomic influences, and other environmental factors, it is implausible to understand social spending on medical care solely in terms of its impact on health. Medical care matters at least as much because people and societies ascribe independent value to attempted rescue. Rescue, daringly conceived and courageously executed, affirms the individual’s dignity and import for society, even when rescue fails.  

6 More precisely, these costs are spread, but within separate groups, without cross-subsidies between groups.
between acceptable cost differentials and those that merit intervention to ameliorate disparities, neither have activists in the campaign against disparities. Some supporters of robust remedial measures treat the disparities that remain, after income and insurance status are factored out, as wrongful, race-based discrimination. To do so is to avoid the task of identifying the mechanisms that contribute to disparity and making political and moral judgments about the acceptability of disparities arising from each.

Consider, for example, physician reliance on stereotypes, a pejorative term for heuristics. Heuristic reasoning is unavoidable in all endeavors characterized by uncertainty and by complexity that exceeds limited information processing capacity [10]. Medical practice surely qualifies [9]. Heuristics can be wrong, but they are often remarkably accurate – that is, they yield results close to those produced by more systematic, comprehensive reasoning processes. To the extent that race-related differences in patient assertiveness, treatment compliance, family support systems, and other clinical variables exist, heuristics that reflect them will be accurate. This makes categorical rejection of racial stereotypes problematic, something civil rights–oriented progressives (including me) do not like to think about.7 Saying no to inaccurate racial stereotypes is a simple matter. Rejecting a valid heuristic makes no sense unless its use – or its result – so offends that the cost of invoking it outweighs the cognitive efficiencies it yields.

To reject all race-based heuristics as cases of wrongful discrimination is to take the categorical position that all carry costs greater than their efficiency gains. This forecloses nuanced consideration of what to do when a stereotype is both noxious and valid.8 Acknowledging this possibility – and the quandary it presents – does more than open the way for reluctant use of a stereotype that may have value under particular decision-making constraints. It also clears a path for candid exploration of the factors that lend validity to the stereotype. Better understanding of these factors can, in turn, aid efforts to ameliorate inequities that lie behind the stereotype.

An illustration is the stereotype that African American patients have more fragmented family support systems than whites, and are therefore less able to sustain the stresses of intensive and disabling medical treatments. This stereotype may well be incorrect, and even if it is accurate on a population-wide basis, reliance on it may be inefficient: a modest effort to learn something about each patient’s home life might improve patients’ social support at minimal cost. To the extent, though, that it is accurate, it highlights the importance of paying attention to black patients’

7A high-visibility example of this problem is the debate over profiling for airline security purposes. Rejection of profiling policies that are based on inaccurate thinking as to which nationalities are high-risk is easy; objections to the profiling of, say, young Saudi men, who are more likely than grandmothers from Iowa to be hijackers, are less compelling. Subjecting grandmothers from Iowa to the same security precautions as Saudi men will raise costs (with little security payoff), unless equity is achieved by reducing the precautions taken for Saudi men (which would reduce security).

8In criticizing “political correctness” in medicine, Satel and Klick have made this point, albeit in more polarizing fashion than I think is helpful, given this topic’s sensitivity.
The availability of social support is relevant to the decision to begin a disabling or agonizing course of treatment – even if taking social support into account yields racially disparate decisions. And sensitivity to weaknesses in African American family support systems can help clinical caretakers to take “affirmative action,” case by case, to fill gaps in family support so all can benefit from vigorous therapies. Beyond this, awareness of the consequences of family breakdown in the medical setting can fuel efforts to strengthen families through educational opportunity, job creation, high-quality child care and preschool, and other proven strategies [11].

Other sources of racial disparity likewise merit closer scrutiny so that we can (1) learn more about causal mechanisms and (2) decide which causes of disparity do and do not merit remedial action. Americans are bound to differ over how to make these decisions, since we disagree about the proper scope of personal responsibility and the extent of society’s obligation to address historical and institutional inequities. But we should have that debate, and it is unhelpful to dismiss those who take a broad view of personal responsibility and a narrow view of public obligation as racists or apologists for discrimination. Those, like me, who hold that racial and other inequities of opportunity are society’s concern should go about the work of winning over our fellow citizens (especially those who vote) without suggesting that those who see things differently are apologists for bigotry.

**Toward Common Ground Solutions**

Meanwhile, progress on disparities is possible through programs built on common ground. There is wide agreement that universal medical coverage would go most of the way toward eliminating racial disparities in care. Health insurance, like auto insurance, should be a personal obligation, though public subsidies will be needed to make it affordable to all [12]. Required coverage, moreover, should include services shown to promote health as well as early detection and treatment of disease. Framing the problem of healthcare disparities as more a quality-of-care matter than a civil rights issue could reduce political polarization. It might also make health plans and providers less defensive. Clinical outcomes research and state-of-the-art quality measurement and management methods can and should target disparities. In the years ahead, market and political pressures will push plans and providers to do so, as America’s workforce and electorate become increasingly multiracial. The same pressures are also likely to encourage more vigorous efforts to bridge cultural and language barriers to communication and to effective use of health systems by disadvantaged Americans [13].

---

9 It is, of course, also important to pay attention to other patients’ support systems. But if this stereotype is accurate, there will be a higher “yield” from inquiring into African American patients’ support systems.
Yet a key pathology of American politics will remain an obstacle to progress. Since 1968, the right has fallen into the habit of seeking votes by stoking working-class racial and cultural resentment. Success at the polls has been addictive. In national elections, millions of working-class whites vote against their own and their families’ economic interests, in favor of candidates hostile to federal health, education, and other opportunity-creating programs. This electoral alchemy has aligned economically distressed whites with well-off Americans intent on tax cuts – and against disadvantaged minorities who benefit from programs these candidates aim to cut.

Were this alliance to fray, tax-slashing politicians (and their wealthy beneficiaries) would fare less well at the polls. Race and culture are the ties that bind, by dividing. Hard-pressed whites bitter over black and Latino advantages, real or perceived, blind themselves to the concerns they and minorities share. From the right’s perspective, keeping this bitterness alive is important. Opposing affirmative action, disputing claims of race-based disadvantage, and objecting to vigorous antidiscrimination laws send the desired political signals. Caricaturing concerns about racial disparities in health care and ridiculing proposed solutions are consistent with this approach. Dispensing with caricatures in order to search for common ground would depart sharply from it.10

Liberals participate in this polarizing dynamic. Common ground solutions, especially universal coverage, will require the well-off to sacrifice. For privileged Americans with progressive politics, it is easier – and certainly cheaper – to take the side of the “good guys” by speaking out against racial discrimination than it is to campaign for the redistribution (through taxes) that universal coverage would require. For many baby boomer progressives, being liberal on social and cultural issues (including race) but tight-fisted on fiscal matters has become a point of pride. This means, in practice, strong support for affirmative action and antidiscrimination law enforcement – and desultory effort, at best, on behalf of universal coverage and other initiatives that target core inequalities of opportunity in American life.11 This stance takes on the “bad guys,” and polarizes debate, on racial matters while insulating economic privilege against redistributive politics.

The American debate over racial inequity thus has a Kabuki quality. In health as in other policy spheres, ritualized struggle over the scope of discrimination and the propriety of race-conscious remedies masks a shared aversion to more basic,

---

10 This is not to say that commentators and scholars who dispute claims of racial injustice are consciously pursuing a political strategy. It is doubted that most are. Conservative think tanks, media outlets, and other institutions with the power to influence public perceptions play the key strategic role, by bestowing opportunities on commentators and scholars who effectively articulate the preferred message.

11 Examples of other such initiatives include equalization of resources per pupil across rich and poor public school districts (current struggles between liberals and conservatives over such matters as vouchers and school choice obscure this larger inequality); universal, high-quality preschool; and intensive mentoring and tutoring programs for children from disadvantaged neighborhoods.
opportunity-creating change. Polarization protects privilege, in part by setting working-class Americans against each other. There is need and possibility for a new progressive politics – a politics that highlights financially stressed Americans’ shared needs and tackles inequities of opportunity, yet respects personal success. Such a politics can yield common ground solutions that go most of the way toward ending racial disparity in medical care. But the Kabuki politics of racial polarization will be a daunting obstacle to overcome.

References

2. IOM 2003.
Chapter 6
Perspective: The Spectrum of Health-care Disparities in the USA

Thomas A. LaVeist

Abstract In 2002, the Institute of Medicine (IOM) issued Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare, a report on disparities in quality of care within health-care settings. This landmark report succeeded at placing the issue of health disparities squarely on the nation’s health policy agenda, leading to increased attention and resources devoted to understanding and ultimately solving this long-standing and vexing problem.

Unequal Treatment (The IOM Report) focused on health-care disparities, which are to be distinguished from health status disparities (which are covered in another section of this book). While health status disparities relate to disparities in the pattern of morbidity, mortality, and disability, health-care disparities relate to disparities within the health-care system: access to and utilization of health services, and quality of care received. The objective of this review is to summarize the recent literature on health-care disparities. Specifically, this review examines racial/ethnic discrimination within health-care settings. In selecting articles for inclusion in this review, we established a set of criteria to focus on the scope of the project. To be included in this review, articles had to meet the following criteria: (1) based on a US population; (2) published in English in a peer-reviewed journal, book, or government or other report; (3) topic of the article is racial/ethnic differences in health services or racial discrimination or racism in the health-care setting. Studies of discrimination outside of the health-care setting are not included.

We searched the National Library of Medicine PubMed database, which combines the Medline and Pre-Medline databases. PubMed includes bibliographic listings from more than 4,000 biomedical journals published in the United States and 70 other countries. It contains over ten million citations dating from 1966 to the present. PubMed is the most widely used computerized search tool for medical information
and is very comprehensive. In addition to articles selected via PubMed, we searched the reference list from each article that met our criteria to search for additional articles that were not detected in the PubMed searches. This included book chapters and other papers that were not published in peer-reviewed scientific journals.

After the elimination of duplicates, this procedure resulted in a total of 496 articles that met the inclusion criteria. Each article was summarized with respect to its study objectives, data sources used in the study (administrative data, vital data, medical records, questionnaire, and others), the specific measure(s) of discrimination used in the study, and the study’s key findings.

**Keywords** Unequal treatment • Healthcare dissimilarities • Healthcare disparities • Coronary angiography • Percutaneous transluminal coronary angioplasty • Coronary bypass surgery • Lower extremity amputations • Total knee arthroplasty • Patient/provider interaction • Discrimination • Racial concordance • IOM • Access • VA system • Medical home

**Conceptual Model of Disparities in Healthcare**

The Institute of Medicine’s (IOM) conceptual model of health-care disparities is outlined in Fig. 6.1. The model shows a simulation of racial disparities in health-care quality. The differences between the quality of care received by minorities and nonminorities fall into two broad groupings: (1) health-care disparities and (2) health-care dissimilarities. Health-care disparities are racial/ethnic differences in the outcomes or quality of care that are indicative of injustice within the health-care system or in the behavior of health-care providers. Health-care dissimilarities refer to racial/ethnic differences that are not caused by underlying inequities. For example, there are differences in care that can be attributed to patient cultural preferences or patient choice. Thus, not all differences in health-care quality can necessarily be attributed to inequity.

The IOM described the scope of the report as follows: “... racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical need, preferences and appropriateness of interventions” [1]. By design, the analytic model used in *Unequal Treatment* does not consider access to care and utilization of health services. Both are major problems in the USA and obvious contributors to health-care disparities. By including these issues in the present review, we expand beyond the scope of *Unequal Treatment*.

In the sections that follow, we review the state of the research literature on health-care disparities within the context of the conceptual model outlined in Fig. 6.1. Specifically, the review will focus on disparities in access/utilization of health-care services, disparities in the management of conditions, disparities resulting from patient/provider interaction, and patients’ assessment of discrimination.
Racial Differences in Access to and Utilization of Health-care Services

Racial and ethnic differences in access and utilization of health services comprise the largest category of studies demonstrating discrimination. Health insurance status is perhaps the largest contributor to disparities in access and utilization. For example, some studies have found that although health insurance and health status reduced race differences in physician office visits, unmet health-care needs, unmet preventive care needs, and usual source of care, substantial differences still exist [2–6].

After controlling for numerous individual factors, Shi showed that minority populations were 1.46 times as likely to identify their usual source of care as a facility rather than a person [7]. In addition, minorities, especially Hispanics, were less likely than whites to indicate that their usual source of care providers listened to them. One study examined the emergency department (ED) as a source of routine health care and reported that neither race nor ethnicity remained a strong predictor of routine ED use after controlling for insurance status, income, employment status, and education [8]. Shi found substantial differences by race/ethnicity in health insurance status and having a usual source of care [9]. Blendon et al. found that racial differences in access to care were present across all income groups and demonstrated severe underuse of services among African Americans [10]. Gregory et al. found that this underuse is caused, at least in part, by racial differences in the medical care resources available at the facilities where white and African American patients receive care [11]. Health-care disparities are also
affected by decreased access to medical resources or increased exposure to health risks in minority communities. Examples are studies showing less availability of opioid analgesics in predominantly nonwhite communities [12] and studies showing greater availability of substances that are harmful to health, such as alcohol [13] and cocaine [14].

Racial Differences in the Medical Management of Conditions

In reviewing studies describing physician practices with regard to the surgical management of disease, we found these studies to be a diverse amalgam of studies evaluating such things as surgical procedures in general and knee replacement surgery in particular. Racial differences in the surgical and medical management of heart disease are perhaps the most studied medical practices [15–18].

A large literature has demonstrated that white patients are about twice as likely to receive coronary angiography and three times more likely to receive percutaneous transluminal coronary angioplasty (PTCA) and coronary bypass surgery (CABG) compared with African American patients [19–33].

Similar findings have been demonstrated with other conditions as well. For example, differences in screening and/or treatment have been found in cancer [34–36], asthma [37], participation in AIDS clinical trials [38], access to kidney transplantation [39], renal allograft survival [40], inflammatory bowel disease [41, 42], and long-term care [43, 44]. Marsh et al. found that physicians were twice as likely to recommend hormone replacement therapy for white patients compared with blacks [45]. Studies have demonstrated racial differences in access to care among the elderly [46–48]. In addition, several studies have simultaneously examined multiple conditions and procedures [49–51].

Huber et al. examined surgical management practices of peripheral artery occlusive disease (PAOD), a form of cardiovascular disease that affects primarily the lower extremities [52]. Using a retrospective analysis of hospital discharge abstracts, he examined a total of 51,819 procedures during the study period. Of these procedures, 15,579 were lower-extremity amputations and 36,240 were limb-saving revascularization procedures. His analysis found that the incidence of amputations was twice as high and the incidence of revascularization procedures was 44% lower among African Americans than whites. Further analysis revealed African Americans were significantly more likely (odds ratio 3.79; 95% [CI] 3.34–4.30) than whites to undergo amputation as opposed to revascularization procedures.

Wilson et al. examined the rates of total knee arthroplasty and found that blacks have markedly lower rates of total knee arthroplasty for osteoarthritis of the knee than do whites [53]. Further, these differential rates could not be explained by disease prevalence and were apparent at all patient income levels. Controlling for the use of competing procedures and age at first operation did not alter these disparities.
Todd et al. demonstrated that African American and Hispanic patients with extremity fractures at two different hospitals were more likely to go untreated for pain compared with white patients with similar fractures [54, 55]. It can be concluded from studies of racial and ethnic differences in access and utilization of health services that racial and ethnic minorities often face the prospect of seeking care in facilities with fewer resources. Also, when they obtain access to similar facilities, they often receive less optimal treatment than nonminorities. Interesting exceptions to this pattern are studies conducted in health-care systems used by active military personnel, which find no racial/ethnic differences [56]. However, it should be noted that discrimination has been documented in the VA system, which is used by retired military personnel [57].

**Racial Differences in Patient/Provider Interaction**

In a review of the literature on emergency care, Richardson et al. found that stereotyping, biases, and uncertainty on the part of health-care providers all contributed to racial and ethnic disparities in the provision of emergency care [58]. Similar conclusions have been reached in other clinical settings.

Flaherty and Meagher conducted a retrospective chart review of 66 Black and 36 White male schizophrenic patients. They found that African American patients spent less time in the hospital, obtained a lower privilege level, and were less likely to receive recreation and occupational therapy. African American patients were also more likely to be placed in seclusion, and restraints were more likely to be used [59].

Among the most commonly stated solutions to racial discrimination in health care have been suggestions to increase the number of minority health-care providers. The underlying hypothesis is that more minority providers will increase the number of minority patients who will have physicians of their own racial/ethnic group, and when the race/ethnicity of the patient and provider is concordant, the patient will receive better care. Although quite popular, this hypothesis has not been thoroughly tested. There have only been a few studies of the effect of race matching between the patient and provider on quality of care and patient satisfaction. However, these studies have found mixed results. Although one study found that African American and Hispanic patients are more likely to report having a minority physician [59], another study found that minority patients tend to report not having a racial preference for their physician [60]. LaVeist and Nuru-Jeter [61] found that among survey respondents to the Commonwealth Minority Health Survey patients, those who reported having a choice in selecting a health-care provider were more likely to select a regular doctor of the same race/ethnicity [61]. While some studies have found support for the hypothesis that patients perceive better care from minority physicians [62, 63], others have found that patients are more likely to perceive better quality care from nonminority physicians [64]. LaVeist and Nuru-Jeter found
that patients of all racial/ethnic groups were more likely to report being satisfied with the quality of care if their health-care provider was of the same race/ethnicity [61]. In a subsequent analysis, LaVeist et al. found that patients whose regular doctor was of a different race/ethnicity than theirs were more likely to fail to use health-care services even when the patient perceived they had a need [65].

An additional aspect of patient/provider interaction is bias in diagnosis. Loring and Powell presented African American and white male and female psychiatrists with a set of cases that were identical with regard to clinical characteristics, but varied by race and gender of patient. They found that psychiatrists were more likely to diagnose the case correctly if the patient was the same race and sex as the psychiatrist or if race and sex were not indicated [66]. In another study, race was found to influence physicians’ recommendations significantly for coronary artery bypass surgery. Physicians’ perceptions of patients’ education and physical activity preferences were significant predictors of their recommendations, independent of clinical factors, appropriateness, payer, and physician characteristics [67].

Patients’ Assessment of Discrimination

A handful of studies have examined the patient’s assessment of discrimination within health-care systems. This concept is distinguished from studies of broad societal discrimination, such as those reviewed in Broman [68]. Diala et al. examined the predictors of patients’ perception of discrimination in the health-care setting. Their analysis found an association between patient/provider racial concordance and patient’s perception of discriminatory treatment. Patients who were race concordant with their provider were less likely to report experiencing discrimination. However, even after adjusting for patient/provider racial concordance, African American and Latino patients were more likely to report discrimination compared with white patients [69]. Murray-Garcia et al. examined racial differences in patient satisfaction and physician primary care performance among patients in a large HMO population. Asians rated physician performance less favorably than whites. Latino patients rated physicians’ accessibility less favorably than whites. African Americans rated physicians’ psychosocial and lifestyle health promotion practices higher than did whites [70].

Discussion

Race has played a central role in nearly every aspect of the formation and evolution of the USA, and health care has not been immune from its influence. Race has been used and misused in health care since the earliest days of the nation’s history [71, 72], through the tumult of the civil rights movement [73], and today as well [74].
Racial and ethnic disparities in health care have been a persistent feature of the US health-care system. It has been difficult at times to determine if these disparities are the result of socioeconomic status or access to care. This had led some to conclude that research on disparities should focus less on race/ethnicity and more on socioeconomic status [75, 76]. But, while continued attention to socioeconomic status in health care is clearly warranted, overwhelming evidence across a wide variety of health conditions, procedures, and health-care settings demonstrates that even after adjusting for socioeconomic status there are substantial racial/ethnic disparities in health-care access, utilization, and quality of care received. Thus, while socioeconomic status disparities in health care represents a significant problem, racial disparities in health care are a related, but independent, problem.

The etiology of racial disparities in health care may not be as obvious as one might think. It is not likely a simple matter of health-care providers discriminating against racial minorities. While the actions of individuals surely can affect individual health outcomes, health-care disparities are likely to emanate from systemic factors which require system change. Merely changing individual actors seems unlikely to lead to significant change.

Patients of all race/ethnic groups prefer to have a health-care provider of their same race/ethnicity, and when patients are race concordant with their doctor, they report more satisfaction and are less likely to underutilize services [61, 65]. However, the rate of production of minority health-care providers is not sufficient to keep pace with the increasing demand that will likely be created by the rapidly diversifying nation. Moreover, there is little evidence that race concordance leads to better health outcomes. Only one study attempted to address this issue [77]. That study found that disparities in referral for coronary angiography were similar for African American and white physicians. However, this study had several significant methodological limitations which call its conclusions into question. Thus, race matching of patients and health-care providers is an unlikely solution. Training health-care providers to serve a culturally diverse population will be increasingly necessary in the coming decades.

While there is much that we know about health-care disparities, much remains to be learned. There is a need for comprehensive research on the effects of doctor/patient race concordance on quality of care and outcomes of health care. There is also a need for more research on racial segregation. That is, it is not clear to what extent racial differences in health-care quality is a function of the different health-care settings in which members of various race groups receive care. Much of the research on this question suggests that disparities exist even within health-care settings, but the degree to which disparities reported at the national level is a function of segregation in health-care settings has not yet been clearly outlined. Finally, there is a need for more direct empirical tests of interventions to address health-care disparities. While there have been ample descriptions of disparities in health care, there have been only a few reports on interventions and their outcomes. A recent report from the Commonwealth Fund is notable exception [78]. The report found no racial differences in quality of care among patients who had a “medical home.” But, in spite of this promising finding, there are few empirically tested interventions to address health-care disparities.
References


2. Cook BL. Effect of Medicaid Managed Care on racial disparities in health care access. Health Serv Res. 2007;42(1 Pt 1):124–45.


Abstract  Over the last 200 years, the USA has experienced dramatic improvements in overall health and life expectancy largely due to initiatives in public health, health promotion, and disease prevention. Nevertheless, despite interventions that have improved the overall health of the majority of Americans, racial and ethnic minorities have benefited significantly less from these advances. National data indicates that minority Americans have poorer health outcomes (compared to whites) from preventable and treatable conditions such as cardiovascular disease, diabetes, asthma, cancer, and HIV/AIDS, among others (The 2008 National Health Care Disparities Report. Rockville: Agency for Health Care Research and Quality, 2009; Eliminating Racial and Ethnic Disparities in Health. Prepared by co-sponsors Grantmakers in Health for the DHHS conference: “Call to Action: Eliminating Racial and Ethnic Disparities in Health.” Potomac, MD, 11 Sept 1998).

Multiple factors contribute to these “racial and ethnic disparities in health.” First and foremost, research has demonstrated that social determinants such as lower levels of education, overall lower socioeconomic status, inadequate and unsafe housing, racism, and living in proximity to environmental hazards disproportionately impact minority populations and thus contribute to their poorer health outcomes (Williams, Soc Psych 53:81–89, 1990; Pincus et al., Ann Intern Med 129(5):406–411, 1998; Hinkle et al., Science 161(838):238–246, 1968; Antonovsky, J Chronic Dis 21(2):65–106, 1968; Pincus and Callahan, Advances 11:4–36, 1995). One poignant example of the impact of social determinants is the fact that three of the five largest landfills in the country are in African American and Latino communities, thus contributing to some of the highest rates of pediatric asthma among these populations (Flores et al., JAMA 288(1):82–90, 2002). Second, lack of access
to care also takes a significant toll, as uninsured individuals are less likely to have a regular source of care, are more likely to report delaying seeking care, and are more likely to report that they have not received needed care – all resulting in avoidable hospitalizations, emergency hospital care, and adverse health outcomes (Andrulis, Ann Intern Med 129(5):412–416, 1998; Health care Rx: access for all. Barriers to health care for racial and ethnic minorities: access, Workforce diversity and cultural competence. Boston, MA: Department of Health and Human Services and The Health Resources and Services Administration, July, 1998; No health insurance? It’s enough to make you sick. Philadelphia, PA: American College of Physicians-American Society of Internal Medicine (ACP-ASIM), 2000). This is especially important for minority populations who are more likely to be uninsured than their white counterparts. Data from the US Census Bureau demonstrating that between 2004 and 2006, 33% of Hispanics, 31% of American Indians and Alaska Native, and 19% of African Americans were uninsured, compared to only 15% of whites (DeNavas-Walt et al., Income, poverty, and health insurance coverage in the United States: 2006. Washington, DC: U.S. Census Bureau, U.S. Government Printing Office, 2007).

**Keywords** Social determinants • Quality of care • Racial and ethnic disparities • Clinical decision-making • Limited English proficiency • Heuristics • Stereotypes • Prejudice • Evidence-based guidelines • Crosscultural education • Mistrust, prejudice

In the last 20 years, literature has emerged that highlights the fact that in addition to existence of racial and ethnic disparities in health, there is also evidence of racial and ethnic disparities in quality of care for those with access to the health-care system, in fact, contribute to the larger issue of racial and ethnic disparities in health. Research in this area has shown that minorities receive a lower quality of care when they are in the health-care system, even when controlling for social determinants and insurance status. For instance, disparities have been shown to exist in the utilization of cardiac diagnostic and therapeutic procedures (African Americans being referred less than whites for cardiac catheterization and bypass grafting); blacks hospitalized with acute myocardial infarction (AMI) are less likely to receive revascularization when compared to whites with similar health insurance); [1–8] prescription of analgesia for pain control (African Americans and Latinos receiving less pain medication than whites for long bone fractures and cancer) [9–13], and the treatment of lung cancer (blacks 34% less likely to receive timely surgery, chemotherapy, or radiation for stage III non-small-cell lung cancer relative to whites); African Americans receiving less curative surgery than whites for non-small-cell lung cancer) [14, 15]. Disparities have also been seen in referral for renal transplantation (African Americans with end-stage renal disease referred less to the transplant list than whites) [16], treatment of pneumonia and congestive heart failure (African Americans receiving less optimal care than whites when hospitalized for these conditions) [17], utilization of general services covered by Medicare (i.e., immunizations
and mammograms) [18], and the administration of influenza and pneumococcal vaccinations (blacks less likely than whites to receive influenza and pneumococcal vaccinations despite similar insurance coverage and the presence of a usual physician) [19]. Again, perhaps the most important issue that should be noted about all of these studies is that disparities occurred even when variations in such factors such as insurance status, income, age, comorbid conditions, and symptom expression are taken into account. Whereas racial/ethnic disparities in health are unacceptable, yet understandable given the persistent racial and socioeconomic inequalities in the USA today (which include minorities, on the whole, having lower levels of education and less annual income than whites) [20], research highlighting racial/ethnic disparities in health care sheds light on a heretofore less visible crisis that has up until recently been given little national attention.

As a result of this work, the US Congress commissioned the Institute of Medicine (IOM) in 1999 to further study the issue of racial/ethnic disparities in the health-care system. The IOM, part of the National Academy of Sciences and chartered by Congress to advise the Federal Government on issues of health policy, medical care, research, and education, was asked to:

- Assess the extent of racial/ethnic differences in health care that are not otherwise attributable to known factors such as access to care (e.g., ability to pay or insurance coverage)
- Evaluate potential sources of racial and ethnic disparities in health care, including the role of bias, discrimination, and stereotyping at the individual (provider and patient), institutional, and health systems level
- Provide recommendations regarding interventions to eliminate health-care disparities

**The IOM Report: “Unequal Treatment”**

To study this issue, the IOM convened a committee of academicians, medical educators, health service researchers, health policy makers, economists, social psychologists, social scientists, lawyers, practicing physicians, and nurses – some with experience and knowledge in the area of disparities, and others with expertise and proven leadership in other aspects of health-care delivery and research. This approach is consistent with the goal of the IOM to assemble an objective and open-minded group of committee members who can effectively evaluate the evidence and come up with findings and recommendations. Given that the charge of the committee was limited to disparities in health care (versus the larger issue of health outcomes) once access had been achieved, specific areas of exploration included health system factors (financial and institutional arrangements, structural processes of care, etc.), provider factors (communication in the medical encounter, the effect of race/ethnicity on clinical decision-making, etc.), and consumer factors (patient preferences). To carry out its responsibilities over the 18 months of the study, the committee reviewed a significant amount of evidence from five main streams, including a
literature review (with strict inclusion and exclusion criteria), commissioned papers (on topics ranging from an exploration of health disparities to the economic, ethical, and legal ramifications of disparities in health), expert testimony, focus groups of patients and providers, and a public workshop. The final report, entitled “Unequal Treatment: Confronting Racial/Ethnic Disparities in Healthcare” [21], was released on March 20, 2002. The major findings stated that:

- Racial and ethnic disparities in health care exist and because they are associated with worse health outcomes are unacceptable.
- Racial and ethnic disparities in health care occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.
- Many sources – including health systems, health-care providers, patients, and utilization managers – may contribute to racial and ethnic disparities in health care.
- Bias, stereotyping, prejudice, and clinical uncertainty on the part of health-care providers may contribute to racial and ethnic disparities in health care.
- A small number of studies suggest that certain patients may be more likely to refuse treatments, yet these refusal rates are generally small and do not fully explain health-care disparities.

Key Clinical Lessons from the IOM Report, “Unequal Treatment”

During the course of research for “Unequal Treatment,” in addition to exploring health system factors, we explored all aspects of clinical practice that might lead to racial/ethnic disparities in health care. Three in particular – provider–patient communication, clinical decision-making, and mistrust – stood out. Here we explain their clinical relevance, and how they contribute to racial/ethnic disparities in health care.

Provider–Patient Communication

There is a growing literature that delineates the impact of sociocultural factors, race, ethnicity, and limited-English proficiency on health and clinical care [22]. Health-care professionals are not shielded from diversity, as patients present varied perspectives, values, beliefs, and behaviors regarding health and well-being. These include variations in recognition of symptoms, thresholds for seeking care, comprehension of management strategies, expectations of care (including preferences for or against diagnostic and therapeutic procedures), and adherence to preventive measures and medications. These sociocultural differences between patient and
provider influence communication and clinical decision-making, and are especially pertinent given the evidence that links provider–patient communication to patient satisfaction, adherence, and subsequently, health outcomes [23, 24]. Thus, when sociocultural differences between patient and provider are not appreciated, explored, understood, or communicated effectively in the medical encounter, patient dissatisfaction, poor adherence, poorer health outcomes, and racial/ethnic disparities in care may result [25].

A 2001 telephone survey of 6,722 Americans 18 years of age and over commissioned by the Commonwealth Fund shed additional light on this issue, and was particularly relevant given the important link between provider–patient communication and health outcomes [26]. White, African American, Hispanic, and Asian-Americans who had a medical visit in the last 2 years were asked whether they had trouble understanding their doctor, whether they felt the doctor did not listen, and whether they had medical questions they were afraid to ask. The survey found that 19% of all patients experienced one or more of these problems, yet whites experienced them 16% of the time, compared to 23% of the time for African Americans, 33% for Hispanics, and 27% for Asian-Americans. More recently, a 2007 survey of 4,334 US adults compared perceptions of physician care of 14 racial and ethnic groups with those of whites [27]. When asked if they ever had a problem communicating with a health-care provider because of language or cultural differences, eight minority groups were more likely than whites to report that this happened. Compared to 13% of whites, 34% of Korean Americans, 29% of Vietnamese Americans, and 27% of Central/South Americans said that they had a communication problem with their physician [27].

Provider–patient communication without an interpreter, in the setting of even a minimal language barrier, is recognized as a major challenge to effective health-care delivery [28–32]. Research in this area has shown that Spanish-speaking patients discharged from the emergency room are less likely than their English-speaking counterparts to understand their diagnosis, prescribed medications, special instructions, and plans for follow-up care [33] and inner-city asthmatics with limited-English proficiency (LEP) have significantly poorer asthma control, higher rates of resource utilization, and a lower quality of life [34]. Furthermore, limited-English proficient patients are less likely to have a usual source of care [35], less likely to receive recommended health care services [31], less likely to be satisfied with their care or willing to return if they had a problem, more likely to report problems with their care [36, 37], and less satisfied with the patient–provider relationship [36]. Hispanic patients with language-discordant physicians are more likely to omit medication, miss office appointments, and visit the emergency room for care [38]. Patients with limited-English proficiency and racial/ethnic minorities are more likely than their English-speaking white counterparts to suffer from adverse events, and these adverse events tend to have greater clinical consequences [39–41]. These patients also have longer hospital stays for some common medical and surgical conditions (unstable coronary syndromes and chest pain, coronary artery bypass grafting, stroke, craniotomy procedures, diabetes mellitus, major intestinal and rectal procedures, and elective hip replacement) than their white
counterparts [42]. On the other hand, limited-English proficient patients with access to interpretation services during their medical visit report their quality of care to be similar to those with language-concordant providers [43, 44]. In addition, physicians who have access to trained interpreters report a significantly higher quality of patient–physician communication than physicians who used other methods [45–47]. Given the importance of effective communication in the clinical encounter and the link to health outcomes, it becomes obvious that this issue disproportionately affects minorities and likely contributes to racial/ethnic disparities in health care.

**Clinical Decision-Making**

Over the course of medical education, doctors are taught the “prescriptive theory of clinical decision-making.” Simply put, this theory states that clinical decisions should rely on the detailed exploration of two variables: the presentation of symptoms and the probability of disease (through the application of Bayes’ theorem) [48]. Simultaneously, doctors are taught a set of heuristics or “clinical gestalts” with the premise that there are certain “hallmark” symptoms for conditions. These heuristics then become shortcuts for clinical decision-making (e.g., cough and fever likely equals bronchitis or pneumonia). Although this runs counter to what we are taught about generating a detailed review of symptoms and a broad differential diagnosis, as we practice under greater stress and time pressure we become more susceptible to using these “shortcuts” in our clinical decision-making. Finally, doctors are taught that their own personal background, and the characteristics of the patient and the clinical setting, should be excluded from consideration in the formulation of clinical decisions. This is central to both the “prescriptive theory of decision-making” and the science of Bayes’ theorem.

Our explorations revealed, however, that many nonmedical factors, ranging from the patient’s physical appearance to the organizational setting in which medical care is delivered, may have as much influence on clinical decisions as the actual signs and symptoms of disease [48, 49]. Our decisions, in addition to being shaped by symptoms and probability of disease, are shaped by characteristics of the patient (including patient age, gender, socioeconomic status, race/ethnicity, language proficiency, and insurance status), characteristics of the doctor (including the specialty, level of training, clinical experience, age, gender, and race/ethnicity), and features of the practice setting (including location, organization of practice, form of compensation, performance expectations, and incentives) [5, 23, 50–58].

The literature on social cognitive theory has also brought to our attention the ways in which natural tendencies to stereotype might influence clinical decision-making. Every day, we are faced with enormous amounts of information that we must sift through in order to make decisions. As a result, we all share the subconscious strategy of attempting to simplify our decision-making process and lessen our cognitive effort by using “categories” or “stereotypes” in which we apply
beliefs and expectations about groups of people to individuals from that group [59–61]. Interestingly, we may not be aware of our attitudes or consciously endorse stereotyping. Nevertheless, when individuals are mentally assigned to a particular class or group, the characteristics assigned to that group are subconsciously and automatically applied to the individual. It should be emphasized that this is a normal, functional, adaptive cognitive process that is oftentimes automatic, and most likely centered on (in rank order) race, gender, and age – characteristics that manifest visually [59]. Most importantly, we tend to activate stereotypes most when we are stressed, multitasking, and under time pressure – the hallmarks of the clinical encounter.

It is important to differentiate stereotyping from prejudice and discrimination, both conscious processes. Prejudice is a conscious, knowledgeable prejudgment of individuals that may lead to disparate treatment; discrimination is conscious and intentional disparate treatment [59]. We all stereotype naturally and oftentimes subconsciously, despite our best intentions to treat every patient equitably, and as an individual. The challenge is that if left unchecked, stereotyping has a detrimental clinical effect on certain groups who fall into specific categories deemed as less worthy of diagnostic or therapeutic procedures or resources [62, 63].

Several processes may contribute to the development of stereotypes, even among those who consider themselves well intentioned and egalitarian. Based on our training or practice location, we may develop certain perceptions about race/ethnicity, culture, and class that may evolve into stereotypes [64]. For example, many medical students and residents are often trained — and minorities cared for — in academic health centers or public hospitals located in socioeconomically disadvantaged areas. As a result, doctors may begin to equate certain races and ethnicities with specific health beliefs and behaviors (i.e., “these patients” engage in risky behaviors, or “those patients” tend to be noncompliant) that are more associated with the social environment (poverty, etc.) than patient’s racial/ethnic background or cultural traditions. This “conditioning” phenomenon may also occur if doctors are faced with certain racial/ethnic patient groups who do not frequently choose aggressive forms of diagnostic or therapeutic interventions. The result over time may be that doctors begin to believe that “these patients” do not like invasive procedures, and thus they may not offer them as options very ardently, if at all. In the case of African Americans, for example, one could understand how this interaction can become a cyclical and self-fulfilling prophecy. As described previously, based on historical factors of segregation and medical experimentation, African Americans have been shown to be more mistrustful of the health-care system than any other racial or ethnic group (with Latinos not far behind) [65]. This mistrust may contribute to weariness in accepting or following recommendations, undergoing invasive procedures, or participating in clinical research. This in turn may lead doctors to continually believe that the African American population is less adherent or less interested in aggressive treatments.

Emerging evidence is demonstrating a role for provider bias in clinical decision-making. A recent study found that when physicians who reported no explicit preference for white versus black patients were given the Implicit Association Test (IAT),
they demonstrated a preference for white Americans and implicit stereotypes of black Americans as less cooperative with medical procedures and less cooperative in general [66]. This is the first study to demonstrate evidence of race-based unconscious bias among physicians. Green et al. found that as physicians’ pro-white implicit bias increased, so did their likelihood of treating white patients and not treating black patients with thrombolysis [66]. In another study, blacks were more likely than whites to have their asthma severity underestimated, which was associated with less daily use of inhaled corticosteroids, less physician instruction on management of asthma flare-ups, and lower ratings of asthma care and physician communication [67]. Although stereotyping is natural and expected, evidence is demonstrating its affect on clinical decision-making and racial and ethnic disparities in health care.

**Mistrust**

Mistrust has become a major concern for many institutions today. Frequent scandals in social groups, and financial, political, and health-care institutions have led to deteriorating levels of trust among members of the general public. The Institute of Medicine Reports, “To Err is Human: Building a Safer Health System” which documented alarming rates of medical errors [68], and “Unequal Treatment” made patients feel vulnerable and the public less trusting of the US health-care system. The increased publication of medical errors and poor quality care has also clearly diminished trust in doctors and nurses [69]. The media has played a significant role in the public’s mistrust of health-care providers with headlines such as “Nursing Mistakes Kill, Injure Thousands” [70] and “How Hospitals are Gambling with your Life” [71] perpetuating mistrust among patients and prompting second thoughts about seeking medical attention.

Trust is a crucial element in the therapeutic alliance between patient and health-care provider. It facilitates open communication and is directly correlated with adherence to physician recommendations and patient satisfaction [3]. Patients who mistrust their health-care providers are less satisfied with the care they receive [72] and mistrust of the health-care system greatly affects patients’ use of services. This lack of confidence in physicians also results in inconsistent care, doctor shopping, self-medicating, and an increased demand for referrals and diagnostic tests by patients [73].

Based on historical factors of discrimination, segregation, and medical experimentation, African Americans in particular may be especially mistrustful of providers [74]. The exploitation by the US Public Health Service during the Tuskegee study left a legacy of mistrust that persists even today among this population [75, 76]. A national telephone survey conducted by the Kaiser Family Foundation in 2000 found that there is significant mistrust for the health-care system among minority populations. Of the 3,884 individuals surveyed, 36% of Hispanics and 35% of African Americans (compared to 15% of whites) felt they were treated unfairly in
the health-care system in the past based on their race and ethnicity. Perhaps even more alarming – 65% of African Americans and 58% of Hispanics (compared to 22% of whites) were afraid of being treated unfairly in the future based on their race/ethnicity [77]. In contrast, a similar national mail survey of 2,608 physicians (whose primary activity is patient care) conducted by the Kaiser Family Foundation in 2001 found that the majority of those surveyed (mainly white) said that the health-care system “never” (14%) or “rarely” (55%) treats people unfairly based on race/ethnicity [78]. This mistrust also has an impact on research and clinical trials. In a recent national survey on participation in clinical research among African American and white respondents, researchers found that African Americans were most likely than whites not to trust that their physicians would fully explain research participation [79]. African Americans report less trust in their health-care providers and are more likely to perceive discrimination in health care [80, 81]. This lack of trust can result in inconsistent care, doctor shopping, self-medicating, and an increased demand for referrals and diagnostic tests by patients [73]. Any effort to eliminate barriers that contribute to disparities in clinical practice will surely have to take into account the importance of addressing mistrust – and building trust – in the medical encounter.

Unequal Treatment: Recommendations and Programs to Date

The IOM Report “Unequal Treatment” provided a series of recommendations to address racial and ethnic disparities in health care targeted to a broad set of stakeholders (the executive summary and full IOM Report can be found at www.nap.edu under the search heading “Unequal Treatment”). Several of the recommendations are targeted directly at addressing barriers that contribute to disparities emerging from clinical practice.

Increase Awareness of Racial/Ethnic Disparities in Health Care

As described above, recent surveys have shown that physicians, health-care leadership, and patients are not fully aware of the extent of racial and ethnic disparities nationally and are even less inclined to acknowledge the existence of disparities within their organization and among their patients. For example, a survey of providers found that while 88% acknowledged the existence of racial disparities in diabetes care within the US health system, only 40% reported their presence among patients they personally treated [82]. In addition, results from an organizational assessment survey distributed to approximately 150–200 executives, physicians, and hospital management at 10 hospitals across the country found that only 3% of executives agreed or strongly agreed that disparities in health care were a major problem in their hospital and 85% disagreed or strongly disagreed that disparities were a major
problem (12% were neutral; McAlearney AS, 2006, Personal Communication). Increasing the awareness of racial and ethnic disparities among health-care leaders and professionals is an important first step in addressing disparities in health care. Strategies to increase awareness and education regarding health disparities can occur through several venues – including through Grand Rounds, public relations campaigns, and newsletters, as part of ongoing curricula, etc. [78].

Collect and Report Health-Care Access and Utilization Data by Patient’s Race/Ethnicity

One of the foremost challenges in the effort to eliminate racial/ethnic disparities in health care is the ability to detect these differences when they are present. Many of the findings in “Unequal Treatment” were based on national studies or regional studies that utilized data that was readily available (i.e., hospital discharge data) yet not designed to capture health-care disparities based on race and ethnicity. As a result, the report is unable to give a local “snapshot” of the issues facing a particular health-care system or hospital. This is further confounded by the fact that race and ethnicity data collection systems – when present, such as in Medicare databases – have just until recently begun to collect data on patient groups outside the standard categories of “white,” “black,” and “other” [83]. Consequently, not only do we lack the appropriate systems to track and monitor racial and ethnic disparities in health care, we also know little about the disparities that other minority groups (Hispanics, Asian-Americans, Pacific Islanders, Native Americans, and Alaska Natives) may be experiencing. In sum, standardized data on racial and ethnic disparities in care are generally unavailable. Federal, private, and state-supported data collection efforts are scattered and unsystematic, and many health-care systems, hospitals, and health plans, with a few notable exceptions, do not collect data on patients’ or enrollees’ race, ethnicity, or primary language.

Recent efforts by health-care organizations and governing bodies are supporting the collection of race, ethnicity, and language data in health-care organizations. The Institute of Medicine in 2009 released “Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement.” The report recommends the collection of the ethnicity and language of patients according to national standards and to OMB race and Hispanic ethnicity categories. Some states have begun mandating the collection of patient information such as Massachusetts which requires all acute care hospitals to collect and report race and ethnicity data. On a federal level, the Patient Protection and Affordable Care Act signed by President Obama in 2010 adds to the Public Health Service Act to ensure that federally supported health-care programs, activities, and surveys collect and report data on race, ethnicity, sex, primary language, and disability status while also standardizing Medicaid and CHIP collection requirements. These efforts are important initial steps in ensuring the implementation of standard race, ethnicity, and language data collection systems.
It is clear that our ability to track and eliminate racial and ethnic disparities centers on our ability to collect race and ethnicity data in a systematic and standardized fashion. Only then can we effectively identify disparities locally, and then implement strategies to monitor and eliminate them as part of quality improvement and performance measurement efforts. This leads us directly into our next recommendation.

Encourage the Use of Evidence-Based Guidelines and Quality Improvement

“Unequal Treatment” highlights the subjectivity of clinical decision-making as a potential cause of racial and ethnic disparities in health care by describing how clinicians may offer different diagnostic and treatment options to different patients (conscious and unconscious) based on their race or ethnicity, even in the presence of well-delineated practice guidelines. As such, the broad adoption and implementation of evidence-based guidelines is a major recommendation to eliminate disparities. For instance, there now exist evidence-based guidelines for the management of diabetes, HIV/AIDS, cancer screening and management, and asthma – all areas where significant disparities exist. As part of ongoing quality improvement efforts, particular attention should be paid to the implementation of evidence-based guidelines for all patients, regardless of their race and ethnicity – and to monitor progress accordingly.

Quality improvement interventions and programs use evidence-based guidelines to ensure that all patients are getting the highest quality of care, regardless of their race, ethnicity, culture, or class. Evidence is showing the positive impact evidence-based interventions have on improving care for all and in reducing racial and ethnic disparities [84–86]. A program that monitored patient outcomes, provided feedback of performance data, and provided clinician education was implemented for 58,700 hemodialysis patients [84]. At the end of the 7-year intervention period, adequate hemodialysis dose increased twofold for patients and the initial gap between white and black patients decreased from 10% to 3% [84]. The improvements in health care demonstrated in these studies underscore the importance of providers and health systems in addressing and eliminating disparities. Quality improvement will become especially important as the Patient Protection and Affordable Care Act will facilitate these efforts to address disparities. For example, the Act will establish a national strategy for quality improvement; support quality measurement development by improving, updating, or expanding quality measures; require the Center for Medicare and Medicaid Innovation (CMI) to test innovative payment and service delivery models to reduce program expenditures and to improve the coordination, quality, and efficiency of health care services; and support community-based, patient-centered medical homes.
Support the Use of Language Interpretation Services in the Clinical Setting

As described previously, when a health-care system lacks interpreter services, it can lead to patient dissatisfaction, poor comprehension and compliance, and ineffective/lower quality care for patients with limited-English proficiency [28–30, 33, 36, 38, 45, 87]. The report’s recommendation to support the use of interpreter services has clear implications for health care delivery. Doctor–patient communication without an interpreter, in the setting of even a minimal language barrier, is recognized as a major challenge to effective health-care delivery [28–32]. The use of trained interpreters positively affects quality of care and outcomes [44, 47]. Furthermore, innovative interpreter modalities such as telephonic interpreter services and remote simultaneous medical interpreting are becoming available at health-care organizations. These modalities improve patient satisfaction [88, 89], improve patient understanding of discharge diagnosis [90], and result in fewer medical errors [91] among limited-English proficient patients.

Increase the Proportion of Underrepresented Minorities in the Health-Care Workforce

Recent data available from the American Medical Association indicate that of US physicians whose race and ethnicity is known, Hispanics make up 5%, African Americans 3.5%, and American Indian and Alaska Natives less than 0.2%, respectively. Minority physicians are also poorly represented in specialties such as cardiology, surgery, and radiation oncology [92]. Data regarding the racial/ethnic composition of medical school faculty is no different, with minorities composing only 8% nationally [93]. It should be further noted that underrepresented minorities make up approximately only 4.5% and 6.7% of the nation’s professors and associate professors respectfully [94]. As it relates to the future health-care workforce, despite comprising 30% of the population, underrepresented minority students accounted for approximately 14.8% of medical school graduates in 2007 [93]. African Americans had the highest representation (6.8% of total graduates), followed by Mexican Americans (2.3%), other Hispanics (2.3%), and Puerto Ricans (1.8%). American Indians/Alaska Natives still remain greatly underrepresented, accounting for 0.8% of total medical school graduates in 2007 [93]. These percentages have remained relatively unchanged since 1995 [93].

In sum, given the important role academic health centers play in training our future health care workforce, it is increasingly important that recruitment, retention, and promotion of minorities at all levels of the academic ladder become a mainstream admission and promotion policy. The goal of this recommendation is to develop a diverse health-care workforce that can meet the needs of an increasingly diverse population, not only from the standpoint of direct clinical care, but also from the standpoint of leadership, health system design, and research.
Integrate Cross-Cultural Education into the Training of All Health-Care Professionals

The goal of cross-cultural education is to improve providers’ ability to understand, communicate with, and care for patients from diverse backgrounds. Training in this area focuses on enhancing awareness of sociocultural influences on health beliefs and behaviors, and providing skills to understand, and manage these factors in the medical encounter. Given the findings of “Unequal Treatment” and the description of how stereotyping by health-care providers might lead to disparate treatment based on a patient’s race or ethnicity, it is now felt that that cross-cultural curricula should be expanded to explore the role of race, ethnicity, and culture on clinical decision-making. The Liaison Council on Medical Education, a major accrediting body of US medical schools, states “cultural sensitivity must be a part of the educational experiences of every student,” and now has standards requiring cross-cultural curricula as part of undergraduate and graduate medical education [95]. The state of New Jersey requires all medical schools to provide cultural competency training to undergraduate medical students and to offer cultural competency training for CME credits. Other states such as Washington, California, and Ohio have developed similar laws for cultural competency training.

Cross-cultural curricula should provide an overview of health-care disparities, a framework for understanding the clinical decision-making process (including strategies to avoid stereotyping), skills on how to use an interpreter, and tools to effectively build trust and communicate and negotiate across cultures. These can be incorporated into all health professions training for doctors, nurses, residents, and medical and nursing students, among other staff.

Medical schools have begun implementing such programs in their institutions. For example, at Harvard Medical School (HMS) third year students, are required to complete “Quality Interactions: A Patient-Based Approach to Cross-Cultural Care” (www.qualityinteractions.org). This is an interactive, case-based, e-learning program that takes a patient-based approach to cross-cultural care [96]. Since the program is available online, all students receive the same curriculum regardless of where they complete their rotation, and can complete the course at any time. This program was also used to train close to 1,000 physicians at Massachusetts General Hospital in the third quarter of 2009 [97].

Conclusion

The Institute of Medicine Report “Unequal Treatment” provides the first detailed, systematic examination of racial/ethnic disparities in health care. From this exploration emerge three particular barriers that contribute to disparities in clinical practice – poor provider–patient communication, stereotyping in the clinical decision-making process, and patient mistrust. Although the recommendations in “Unequal Treatment” are broad in scope, they provide a blueprint for how to address them,
and they have direct implications for clinical practice. Interventions such as those that affect health systems (e.g., race/ethnicity data collection, quality improvement through the use of evidence-based guidelines, interpreter services) as well as those related to health-care professionals (e.g., increasing awareness, providing cross-cultural education, and minority recruitment) should help address disparities that arise from the clinical encounter. The last few years have seen significant progress in multiple areas, including new standards and measures by the National Committee of Quality Assurance, which accredits health plans [98], the Joint Commission, which accredits hospitals and other health-care organizations [99], and the National Quality Forum [100], to name a few. Most notably, the passage of health-care reform, which will insure 32 million uninsured Americans, and also will address disparities through a series of important provisions, will certainly make an important difference. Ultimately, the strategies presented here will improve the care of all patients, not just those who are racial and ethnic minorities. No longer should eliminating disparities be considered a marginal or “add-on” issue; instead, it must be a critical part of the mission of all health-care providers. Ultimately, we can ill afford to have patients sustain complications of long-term, treatable chronic conditions because we are not able to provide the highest quality of care to all patients we see, regardless of their race, ethnicity, culture, class, or language proficiency.

References


71. Rock A. How hospitals are gambling with your life. Read Dig. 2001;2001:151–68.
94. U.S. Medical School Faculty. Association of American Medical Colleges; 2009.
Abstract The Promise of Evidence-Based Medicine. The spectacular ascent of medical science at the dawn of the twenty-first century trumpets a new era in US health care and great possibilities for preserving human health. At the same time, it poses serious challenges for policymakers who must make crucial decisions about the safety, efficacy, and affordability of medical technologies. One of the most difficult and contentious matters confronting decision-makers is the question of how to ensure the delivery of lifesaving technologies to low-income and minority patient populations, whereas simultaneously controlling ever-rising health-care costs. In theory, the increasingly popular concept of evidence-based medicine (EBM) suggests a potential tool for both cost containment and the reduction of severe racial and ethnic disparities in health-care delivery. Drawn from systematic reviews of studies that use rigorous research methods, particularly the randomized controlled trial, the “evidence” guiding EBM protocols informs treatment decisions made by physicians, as well as policy decisions regarding the allocation of health technologies at the population level.

Operating largely out of the “average” American’s view, EBM protocols are policy devices that set the rules for who gets what medical care and on what terms. The foremost claim of some advocates of EBM is that it serves this function well by providing the best available “evidence” about therapeutic interventions, thereby enhancing the capacity of policymakers and physicians to make sound, defensible decisions. At least in theory, the use of EBM should lead invariably to rational decisions so that patients with the same illnesses and clinical indications receive appropriate interventions regardless of race or ethnicity. Again in theory, policy decisions made within EBM frameworks should lead to evenhandedness in the allocation of therapeutic interventions at the population level. Thus, EBM offers the “implicit promise of greater fairness than previously existed” (Poolsup et al., J Clin Pharm Ther 25:197–220, 2000; Taylor et al., N Engl J Med 351:2049–2057, 2004; Yancy, J Card Fail 6:183–186, 2000; Rogers, J Med Ethics 30(2):141–145, 2004).
Keywords  Evidence-based medicine • Cost containment • Clinical trials • External validity • Efficacy • Safety • Gold standard • Cherry-picking • Preferred drug lists • Clinical judgment • Fragmentation • Comparative-effectiveness research

The National Dilemma of Racial Health Disparities

This latter promise – the assurance of greater fairness, and, by logical extension, a reduction in health-care disparities – should not be accepted without critique. Health inequality represents one of the most persistent, ubiquitous, and troubling phenomena in the US health system. Evidence of racial disparities in health status long predates the Civil Rights era [1], with systematic studies that document these disparities appearing in the literature at least as early as 1899 [2]. Clayton and Byrd have richly documented a continuous pattern of systemic racial inequality in health care dating back to at least the seventeenth century and persisting, significantly unabated, into the present millennium [3, 4].

Over the past two decades, at least 600 journal articles and 8 major reviews – most notably, the 2002 report by the Institute of Medicine (IOM), Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare – have verified deep racial inequities in health care [5, 6]. Systematically reviewing over 100 studies conducted between 1992 and 2002, the landmark IOM report found that racial gaps persist in the delivery of evidence-based interventions even when researchers take into account such factors as insurance coverage, disease severity, and expression of symptoms. These disparities span an alarming array of major diseases, including heart disease, diabetes, end-stage renal disease, and AIDS. Racial disparities manifest across numerous diagnostic and therapeutic procedures, including cardiac procedures, renal transplantation, and the delivery of pharmaceuticals. Most significantly, it is consistently documented that racial inequities in health-care delivery result in higher morbidity and mortality for minority populations.

Furthermore, there is strong evidence that in recent years, the nation has made only the slightest progress in correcting this problem. A recent issue of the New England Journal Medicine reported on three studies examining national progress over the past decade in closing the racial gap in health care [7–9]. Accounting for key variables such as age, sex, socioeconomic status, and health plan, the studies analyzed health-care delivery patterns for both high-cost and low-cost evidence-based medical interventions. In one study, in an investigation of care for elderly Medicare beneficiaries in 183 managed care plans from 1997 to 2003, researchers found a “significant reduction” in racial disparities in seven out of nine low-cost interventions, including cholesterol testing, blood glucose screening, eye examination, and mammography [7].

The other two studies, which investigated high-cost procedures, found no such progress. A study of nearly 600,000 patients hospitalized with myocardial infarction between 1994 and 2002 showed that blacks were significantly less likely than whites to receive reperfusion therapy and coronary angiography, and were more
likely to die. This study found “no evidence” that racial disparities have narrowed in recent years [8]. The third study examined racial trends in the use of nine major surgical procedures for Medicare beneficiaries between 1992 and 2001, including cardiac procedures, total hip replacement, back surgery, and appendectomy. Rates of procedures performed were greater among whites for all nine procedures, and the racial gap widened even further for five of the procedures. Researchers found “no evidence, nationally or locally, that efforts to eliminate racial disparities in the use of high-cost surgical procedures were successful” [9]. These new data represent clear and troubling signs that the corrective actions taken to date to eliminate severe racial inequities in the delivery of evidence-based interventions are woefully inadequate.

**EBM and Minority Health**

It is within this context that the promise of evidence-based medicine (EBM) to promote “greater fairness” in health-care delivery is so critical and that its conceptual framework requires greater attention. In 2002, the IOM recommended the use of EBM protocols to promote “consistency and equity of care” for racial and ethnic minority patients [5]. Although there should be little doubt that well-designed, evidence-based treatment guidelines for clinicians or drug coverage protocols for policymakers can be a useful tool for enhancing the delivery of high-quality medicine, several aspects of the prevailing EBM model raise concerns about its actual capacity to improve (or diminish) minority access to emerging, new, or existing medical technologies.

First, state policymakers under budgetary pressures have increasingly adopted EBM as a cost-containment device, subjugating the clinical priority of health outcomes to the political mandate of cost control. Accordingly, policymakers have integrated the cost-focused EBM model into drug coverage decision-making processes, including the development of restrictive formularies and preferred drug lists (PDLs) for public insurance programs in which minority groups tend to be over-represented. The mechanism by which – or evidence of how – restrictive formularies/PDLs will reduce health-care costs while improving (or even sustaining) current levels of minority access is disturbingly unclear. Second, whereas supporters welcome the empirical consultation offered by EBM protocols, critics warn that the cost-focused framework can diminish the clinical flexibility and clinical judgment of physicians, and impose the guiding hand of an “invisible clinician” who is deaf to the peculiarities of patient–provider relationships. This drawback compromises the optimal goal of individualized care.

Third, and perhaps most important, the historically low participation of minority subjects in clinical trials raises fundamental questions about the relevance, or external validity, of EBM “evidence” to minority populations. Concurrently, the ongoing national shortage of minority researchers appears to constrain any possibility of advancing more culturally competent research designs and analyses that might
improve the quality of the EBM evidence base. Despite these significant concerns, there has been no meaningful public dialog in the medical research community about the capacity of the popular EBM model to fulfill the IOM recommendation for promoting “equity” in health care, or its ability to advance the larger national goal, set by the Healthy People 2010 program, to eliminate racial and ethnic health disparities. To address these concerns, a discussion intended to generate greater dialog about the actual potential of EBM to improve minority access to medical technologies, specifically lifesaving pharmaceuticals, is put forth.

First, the quality of EBM “evidence” and its external validity among minority populations is discussed. Second, given the known limitations of this evidence base, the growing utilization of EBM frameworks in drug reviews and health-care coverage decision-making, and the implications of this trend for minority access to lifesaving medications are discussed. Third, to explore the capacity (and potential) of EBM to reduce (or exacerbate) health-care disparities, health system fragmentation is discussed in brief – a key system-level factor identified by IOM that contributes to health-care disparities – and how this factor fits into the prevailing EBM framework is considered. Last, key policy recommendations are put forth that suggest a more explicit and functional role for EBM in the growing national effort to eliminate racial and ethnic health disparities.

Missing Evidence of EBM

**Key Decision-Making Considerations of EBM**

The practice of medicine requires careful, ongoing, and multidimensional decision-making about crucial aspects of clinical care, including which diagnostic tests to order and when to order them; how to interpret these tests and synthesize the results with other information, including patient histories and physical examinations; and what therapeutic intervention is most appropriate for a given patient at a given point in time. EBM clinical guidelines provide physicians with an “evidence-based” protocol designed to facilitate, manage, or, in some way, guide the clinicians’ decision-making process. EBM drug reviews provide policymakers and health-care managers with an “evidence-based” framework to appraise drug efficacy, safety, and cost, and to make subsequent determinations about health coverage. The quantity and quality of the evidence used within these frameworks is central to the question of how useful or appropriate these protocols are when applied to decision-making processes that affect a given population.

Although the mere claim or label of “evidence-based” tends to convey a degree of assumed credibility, there are, in fact, potentially significant uncertainties inherent in the EBM evidence base that may confound the analysis, thereby limiting its capacity for decision-making [10]. In the context of group decision-making, researchers, policymakers, and practitioners alike face the challenge of summarizing and interpreting bodies of evidence in a way that addresses key caveats, such as
statistical uncertainty, information gaps, conflicting evidence, and the application of the evidence to “real” (nonexperimental) environments [11, 12].

Appreciating the importance of these uncertainties, especially as they pertain to minority populations, requires an understanding of the fundamental nature of evidence derived from systematic study reviews. In general, evaluating a body of evidence involves gathering, evaluating, synthesizing, and interpreting the available data [10]. Steinberg and Luce [10] note that evaluators must take into account at least three considerations. First, the unavailability of evidence about a particular intervention does not necessarily mean that the therapy is unsafe or ineffective. Thus, evaluators must be careful not to allow information gaps – or “missing evidence” – to lead to unsupportable judgments resulting in policies that withhold potentially lifesaving therapeutic interventions or that mandate untested interventions as clinical standards.

The second consideration is that ratings on the strength of evidence for a given intervention do not describe the magnitude of effectiveness for the intervention. For example, a particular technology may show strong evidence of safety and efficacy, although having little impact on patient outcome (e.g., a new antihypertensive may show strong evidence of blood pressure control and minimal side effects, but no evidence of improving mortality). Conversely, it may generate only weak evidence despite an apparently strong impact on patient outcome.

The third consideration, which receives strikingly scant attention given its centrality to the decision-making process, is external validity, or the degree to which the available evidence actually relates to a specific patient or population in need of care. A known and serious limitation of the EBM model is that it relies on evidence that may not be relevant to all individuals or groups [11]. Evidence is deemed relevant, or externally valid, if the following conditions are met: “(1) the patients enrolled in the study are similar in terms of demographic (age, sex, and race) and clinical characteristics (severity of primary disease and number and types of comorbidities) to those to whom the healthcare intervention might be applied and (2) the real-life setting approximates that tested in the research setting” [10]. Thus, the relevance of evidence to a particular individual or group is largely a function of study design and the demographic and environmental peculiarities in which the evidence is applied [10].

**External Validity: The Elephant in the Room**

External validity poses perhaps the greatest challenge to the integrity and utility of EBM. This challenge is known but routinely unacknowledged – at least when it comes to EBM decisions affecting minority populations. Still, most EBM protocols suffer from the following key deficiencies that can compromise external validity:

1. Inclusion and exclusion criteria are not retained as elements of the “evidence” even though the prevalence rates of these criteria may vary across populations.
2. Characterization of the final study population is rarely considered in the creation of protocol recommendations.

3. Recruitment and retention biases are rarely retained as important components of generalized recommendations.

It is within this decisional environment that the national shortage of therapeutic trial evidence for minority groups poses a systemic problem for external validity and calls into question the current use of EBM protocols for decision-making that affects minority populations. Whereas EBM clinical guidelines and drug review protocols draw their evidence from the most reputable study design – the randomized clinical trial (RCT) – the problem of data availability arises from traditionally low minority participation in RCTs and from the failure of researchers to account for key variables in studies that draw data from diverse study populations [13–15]. The absence of trial data for minority subgroups is quite alarming and is evident even in studies pertaining to diseases with the most severe racial disparities [16]. For example, although African Americans account for over half of HIV-related deaths and a growing share of AIDS diagnoses (doubling from 25% of cases in 1985 to 49% in 2003) [17], only 11.3% of subjects in AIDS-related National Institutes of Health clinical studies are African American.

Indeed, one of the most striking research paradoxes in the USA is that scientists have copiously reported racial and ethnic health-care disparities across an impressive array of diseases, while simultaneously underreporting on therapeutic safety and efficacy for minority populations. Although there are credible explanations for this research gap, including distrust and inadequate recruitment efforts, the critical concern for this article is that the homogeneous (predominately Caucasian) demography of the EBM evidence base creates an empirical “blind spot” because the generality of the evidence is limited to people who are sufficiently similar to trial participants. Consequently, for racial and ethnic minority populations, data on the true efficacy and safety of innumerable therapeutic interventions is substantially nonexistent [16].

The lack of minority trial data constitutes a significant information gap for medical research. There are two main ways that racial and ethnic differentials may be important in determining whether evidence obtained from demographically homogeneous trials is applicable to different populations. First, in contrast to whites, minority groups are more likely to experience a disproportionate share of certain comorbidities – a variable known to confound the research design. Second, there is strong and increasing evidence of racial and ethnic variance in responses to some drug treatments. Whereas scientific evidence of reportedly innate racial differences has been unscrupulously used to rationalize social inequality as the inevitable outcome of natural differences [18], compelling evidence does exist to support the more reasonable claim that racial or ethnocultural differences in pharmacodynamics may warrant the use of safeguards to protect minority access to needed medications.

Cardiovascular, psychotropic, and central nervous system drugs are among the many classes of drugs known to have such differential effects between racial and
ethnic groups [19]. Examples include (1) the increased sensitivity of Asians to antidepressants; (2) the marked effectiveness of certain nitric oxide-based heart medication for African Americans with congestive heart failure; and (3) the paradoxical outcomes for patients with hypertension and left ventricular hypertrophy, with non-African Americans showing a better response to β-blockers.

Given the known racial and ethnic differences in therapeutic responses, it can be reasonably inferred that the dearth of minority-specific data compromises external validity and calls into question the use of EBM frameworks as the “gold standard” for health-care access decisions affecting minority populations. A perverse consequence of this clinical reality is that those who care for minority populations and rely on observed clinical experiences instead of following EBM guidelines (which regulators often convert to standards) [20] are at risk for regulatory profiling, despite the lack of evidence to counter these clinical experiences. This leads to “cherry-picking” – “high-risk” patients are excluded from care to improve health-care report cards – thereby exacerbating disparities [21]. This has important implications for pay-for-performance programs.

The lack of therapeutic trial data for minority populations arises, at least in part, from the lack of diversity among researchers [5, 6]. Key clinical trial activities, including study design, data analysis, and data reporting, are carried out by “small groups of specially trained people, usually sponsored by an organization” [22]. As with other professions tied to medicine (e.g., physicians and medical school faculty and administrators), a common demographic feature of clinical trials and systematic reviews is that minority researchers are severely underrepresented [6].

The cultural skill sets and social orientation of physicians and medical researchers who design studies, create data, and interpret findings are important to the process of medical research and can vary significantly. Consider the exceptional and well-observed role of minority physicians in the clinical and policy environments. Minority patients report greater levels of trust and patient satisfaction with minority physicians [23]. Minority physicians tend to show greater cultural affinity with minority patients, and are more likely to practice in minority populations and to be aware of and responsive to health policy issues affecting respective minority populations [6]. Thus, it is likely that African American physician researchers have a more nuanced awareness and greater appreciation of qualitative issues, including social, cultural, and psychological factors, which might enhance study design and analysis. For example, although the literature often ties African American distrust in the health-care system to the notorious Tuskegee Syphilis Study, African American researchers are well represented among the few scientists who have traced this distrust to its much deeper roots in slavery, Jim Crow, and the more longstanding experiences of racial oppression [24–27]. This awareness and sensitivity may prove beneficial to the recruitment and retention aspects of study design.

In addition, many have noted the systemic lack of attention given to cultural and sociohistorical analyses of African American health and health disparities. Given their greater sensitivity to the cultural and sociohistorical dimensions of health,
including their historic exclusion from the nation’s health-care workforce, African American physicians may bring different viewpoints to the prioritization of research projects, such as the recognition of population-sensitive variables in research design, the interpretation of research findings, and the application of findings to the clinical setting and policy sector.

More fundamentally, minority physicians and researchers may also be more likely to challenge the efficacy of new or longstanding paradigms for improving minority health and reducing racial and ethnic health disparities. For example, Airhihenbuwa [28] has noted that African American researchers have consistently challenged durable theoretical frameworks in public health that tend to be drawn from the white population and that evidently have been inadequate for health promotion and disease prevention in African American communities. Increasing the number of African American researchers and subjects suggests a meaningful step toward the development of a more culturally competent conceptualization of EBM. In 2003, the Sullivan Commission on Diversity in the Healthcare Workforce released a report that provided 37 national recommendations for increasing diversity and cultural competence at all levels of the health-care system [6]. The EBM work of the medical research community would significantly benefit from the advancement of these national efforts.

Application of EBM to Drug Reviews and Health Coverage Policy

Expansion of EBM to Drug Reviews

The application of EBM to drug reviews and health coverage decision-making is clear evidence that the accepted utility of EBM has expanded far beyond its commonly cited role as “the conscientious, explicit, and judicious use of the current best evidence in making decisions about the care of individual patients” [29]. A largely unchecked use of EBM is its application to drug review processes that control access to lifesaving medications for publicly insured populations with heavy minority concentrations. A significant and growing trend among state Medicaid offices faced with severe budgetary constraints is the adoption of EBM-based protocols for drug coverage decision-making programs, including the use of restrictive formularies and preferred drug lists (PDLs). As of 2004, nine state Medicaid offices were following the Practitioner-Managed Prescription Drug Plan, a formulary designed by researchers at the Evidence-based Practice Center (EPC) at the Oregon Health and Science University [30] and more recently, several other states have adopted this pattern.

Drawing from methods used by the EPCs (established in 1997) designated by the Agency for Healthcare Research and Quality, researchers at the Oregon EPC
determine the “best” therapies in a given class based on evidence culled from clinical studies, published comparative analyses, and manufacturer dossiers. When evidence is inconclusive, the selection process defaults to the cheapest drug. As of 2004, state Medicaid offices subscribing to the Oregon EBM formulary included Idaho, Kansas, Missouri, New York, Nebraska, Oregon, Washington, Wisconsin, and Wyoming. State health-care administrators use this cost-focused EBM model in different ways. Most state administrators use this model to set policy for Medicaid drug coverage by establishing PDLs, whereas some states use it to guide decisions about public employees’ drug coverage and workers’ compensation coverage decisions. In Wyoming, the state’s Prescription Drug Resource Center provides online consumer access to drug reviews. By September 2004, the Oregon EPC had completed 12 reviews, with an additional 10 reviews in the pipeline and 3 newly selected drug classes (Table 8.1).

Table 8.1 Classes of drugs reviewed by the Oregon EPC as of September 2004

<table>
<thead>
<tr>
<th>Class</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angiotensin-converting enzyme inhibitors</td>
</tr>
<tr>
<td>Angiotensin-II receptor antagonists</td>
</tr>
<tr>
<td>Antidepressants (second generation)</td>
</tr>
<tr>
<td>β-adrenergic blockers</td>
</tr>
<tr>
<td>Calcium-channel blockers</td>
</tr>
<tr>
<td>Estrogens</td>
</tr>
<tr>
<td>Inhaled corticosteroids</td>
</tr>
<tr>
<td>Opioids (long acting)</td>
</tr>
<tr>
<td>Nonsteroidal anti-inflammatory drugs</td>
</tr>
<tr>
<td>Oral hypoglycemics</td>
</tr>
<tr>
<td>Proton pump inhibitors</td>
</tr>
<tr>
<td>Skeletal muscle relaxants</td>
</tr>
<tr>
<td>Statins</td>
</tr>
<tr>
<td>Triptans</td>
</tr>
<tr>
<td>Urinary incontinence drugs</td>
</tr>
</tbody>
</table>
Inevitably, a common attribute of EBM drug reviews is that the “end product” is generic in that “it is intended to apply to a class or group of patients defined by some clinical criteria, rather than to an individual patient” [22]. The nonspecific “end product” is the direct outcome of a process in which EBM drug reviews act as an “invisible clinician” who guides, prompts, directs, or, in some way, compels the attending physician to deliver a preformulated therapeutic intervention to patients. In contrast to the actual physician, it is unavoidable that the “invisible clinician” acts with lesser awareness of variance in patient profiles and the significance of these variations. In the US health-care system, it is a reasonable expectation that patients, regardless of their insurance status, “expect their doctor to tailor care to their individual condition, incorporating their medical history and preferences, the doctor’s experience with similar patients, the most current research, and alternative therapies” [32]. Similarly, whereas physicians themselves recognize the importance of cost containment, they also believe that “only the physician and patient should decide the value of a treatment option” [32].

Consistent with the IOM report on patient-centered care, a recent monograph by the National Medical Association and the National Pharmaceutical Council calls attention to the need for individualized pharmaceutical treatment in view of the increasing body of evidence showing that drug therapy works best when tailored to the individual [33]. As reported in the monograph, research in pharmacogenetics has uncovered significant differences among population groups in the metabolism, clinical effectiveness, and side effect profiles of many important drugs. Gender, age, culture, and race-related genetic polymorphisms may influence a drug’s action by altering its pharmacokinetic or pharmacodynamic properties. Clinically, this may result in an increase or decrease in the intensity and duration of the expected drug effect, and substantial dosage adjustments may be necessary for individuals from different populations. The pathophysiology of disease may also differ among racial groups (e.g., hypertension) and thus some drugs and drug combinations will be more effective than other drugs in a given racial group.

In addition to the broadly nonspecific nature of the EBM drug review process, one notable impediment to individualized medicine is the reliance of EBM drug reviews on generic drug substitutions without regard to their therapeutic quality or efficacy, or the possible differential drug responses of minority populations. The clear evidence of drug response differentials discredits the increasingly outdated assumption that all generic drugs share “therapeutic equivalence” with brand name drugs. On the contrary, the evidence suggests that the substitution of drugs within the same class may place minority patients at greater risk because drug effectiveness and safety can vary among untested groups. There is also a distinct possibility of toxic effects among groups with slower metabolisms, or ineffective bioavailability among groups with faster metabolisms. These outcomes pose the potential risk of higher morbidity and mortality for untested racial and ethnic subgroups and increased health-care costs.
Restrictive Drug Formularies/PDLs Compromise Clinical Flexibility and Clinical Judgment

Whereas the IOM specifically recommends the use of evidence-based guidelines to promote “consistency and equity of care,” it also recommends that a “pragmatic balance must be sought between the advantages and limitations of evidence-based guidelines, such as the tension between the goal of standardization and the need for clinical flexibility” [5]. It is precisely here – at the precarious intersection between standardization of care and clinical flexibility – that the current momentum of EBM sharply swerves off course.

The propagation of EBM drug reviews signals a new level of encroachment on both clinical flexibility and clinical judgment. Flexibility refers to the elasticity of a clinician’s range of therapeutic options, whereas judgment refers to the physician’s capacity to evaluate and select a given option from a stipulated range of choices. Within the constraints imposed by the EBM framework, clinicians must navigate new hurdles, including restricted therapeutic choices and time-consuming appeal processes, in order to provide individualized treatment within the context of the patient’s specific characteristics, including, but not limited to, age, gender, race, and ethnicity. Ultimately, ensuring a “pragmatic balance” between the benefits and limitations of EBM frameworks and “the need for clinical flexibility” is precisely the recommendation of the IOM and is consistent with the mandate to address racial and ethnic disparities in health care. Furthermore, the emergence of new therapeutic paradigms that use combination therapy to gain greater treatment efficacy only reinforce the need for the EBM model to be broad and flexible enough to enable rational choices by clinicians on behalf of their patients.

Implications

In the face of expanded use of EBM in drug review protocols, correcting systemic deficiencies in the EBM evidence base must be accompanied by a number of other key steps to improve the usage of EBM in setting health coverage policy. First, there is a need to enhance EBM-based decision-making processes in a way that makes policymakers more sensitive to the quality of evidence and the limitations of the EBM model [34]. One promising effort is the grades of recommendations, assessment, development, and evaluation (GRADE) consortium, an initiative that enables decision-makers who use systematic reviews to assess the evidence and judgments behind recommendations. The GRADE approach to appraising the quality of systematic reviews includes the following considerations: (1) a review of which outcomes are critical to the decision, (2) the quality of the evidence across studies for each key outcome, (3) the overall quality of evidence across outcomes, (4) the trade-off between potential benefits and harm, and (5) the strength of the recommendations [35].

Helfand et al. [12] note that the strength of the GRADE approach is that it explicitly recognizes the role of important considerations in the decision-making
process other than the strength of the evidence and the magnitude of the effect. Three additional considerations would significantly enhance the GRADE approach, particularly regarding decision-making processes that have potentially adverse effects on access to care for minority populations. These considerations are: (1) racial and ethnic minority differentials in drug responses; (2) the lack of trial data for minority populations; and (3) the lack of minority scientist participation in research prioritizing, study design, analysis, and reporting.

Second, there is a need to ensure that EBM-based drug coverage policies include adequate provisions for safeguarding clinical flexibility and clinical judgment in order to preserve individualized medicine. Although cost containment is an important and necessary consideration in an era of soaring health-care costs and competing national priorities, improved health outcomes through individualized care must be the centerpiece of the EBM decisional framework if it is to serve the best interests of human health. The following provisions would help to ensure that EBM drug reviews and the judgments of “invisible clinicians” do not undermine individualized medicine or use cost containment as a rationale for denying care that is appropriate and medically necessary:

- Drug review managers should establish checks and balances to ensure that cost analysts do not conduct drug evaluations based solely or primarily on financial savings. For example, drug reviewers should carefully separate cost information from reviews of therapeutic efficacy and safety.
- Formularies/PDLs should not prevent access to medically necessary medications, and only treating physicians should make final determinations of medical necessity.
- Physicians should be able to prescribe nonformulary drugs without “prior authorization” mechanisms when the physician determines that the formulary drug is less efficacious or the patient has exhibited significant adverse effects from the formulary/PDL drugs, or when the patient has comorbidities that require use of nonformulary/PDL drugs.
- If a formulary/PDL only offers generic drugs, insurers must provide access to brand name medications when no generic medication exists.
- Clinicians should provide clear instructions to patients on how to access appeal processes and independent medical reviews for drug coverage decisions.
- Drug review managers should not rely solely on RCTs, especially regarding conditions for which limited trials exist or generality is questionable because of homogeneity in the evidence base.
- In decisions regarding drugs that are considered clinically equivalent, drug review managers should recognize that some patients may respond differently to one drug than to another and that patients suffering from life-threatening illnesses require access to expanded treatment options.
- To ensure access to newly approved drugs, formularies/PDLs should review new FDA approvals every 90 days.
- EBM-based “Pay for Performance” should be adjusted for key demographic and health infrastructure variables (which the EBM model may not recognize).
Application of EBM to Reducing Health-Care Disparities

**EBM as a Policy Tool**

In the policy arena, proponents of EBM often portray it as a counterbalance to an otherwise autonomous medical model based on impermeable authority, tradition, and the physician’s personal experience [36]. In this broader institutional context, the “invisible clinician” guides the discipline of medicine toward a presupposed higher ground of efficiency, prudence, and fairness. Although few would doubt that EBM, if used properly, plays a valuable role in “advancing” medicine, it is important to recognize that EBM bears its own political agenda. Today, policymakers use EBM as a system tool not only to ensure quality, safety, and affordability, but also to alter the balance of power among doctors, payors, and patients in accordance with preset objectives whose raison d’être is not likely to be better health outcomes or the reduction of racial and ethnic disparities in health-care delivery. Indeed, the paramount objective of cost-focused EBM is the reduction and/or containment of health-care costs, achieved through direct or indirect political control of the clinical environment.

Over the past half-century, legitimate concerns about health-care spending have given rise to a cost-management industry, which now seeks increasingly greater control of the health-care system. Managed care organizations have significantly shifted decision-making away from physicians and markedly altered the way in which doctors practice medicine. Today, “the interposition of managed care and thick layers of insurance bureaucracy displace the *house call doctor* of yesterday” [37]. New care management institutions have arisen, along with a new class of professionals who evaluate, oversee, and significantly influence medical practice and physician conduct.

This new and dynamic era of American medicine superimposes unprecedented mechanisms of political authority, such as EMB-based drug reviews, that are detached and distant from the patient care milieu and seemingly at odds with the national mandate to improve minority health-care access and eliminate racial health disparities by 2010. A new threshold of political will to cut spending on publicly funded health programs has led to the growing use of EBM as a policy tool to redefine standards of care and reset the rules for funding authorization, thereby allowing agencies to deny payment for medical services deemed medically unnecessary or ineffective under the cost-driven standards. Whether intended or not, this new policy arena poses the clear risk of perpetuating historic patterns of allocating “second-class” health care for minority populations. Furthermore, the potential for decreases in minority access with simultaneous increases in majority access suggests the unsettling possibility that, in an era of aggressive cost containment, services for disadvantaged groups “are being sacrificed to pay for new, evidence-based interventions that do not apply to the disadvantaged” [38].
Health-Care Disparities and Fragmentation

As a policy tool, the cost-focused EBM model suggests nothing in the way of supporting the national effort to eliminate racial and ethnic disparities in health-care delivery. Indeed, even if the EBM model existed in some ideal configuration, fully suited for use among minority populations, it would still be insufficient to shift the nation’s obdurate patterns of unequal treatment. To be sure, the massive and growing body of evidence on racial and ethnic health-care disparities reflects inequities in the delivery of evidence-based interventions. As one EBM observer has aptly noted, “perhaps the best evidence in the world is not enough to overcome deeply entrenched patterns of discrimination” [38].

According to the IOM, the conscious or subconscious decision by health-care providers or payors to withhold or not provide even evidence-based pharmaceuticals and services during the course of minority patient care is manifest in major areas, including cancer, cardiovascular disease, HIV/AIDS, mental disease, and pain management. In assessing potential sources of these inequities, the IOM committee identified several patient-level, provider-level, and system-level factors that might play a causal role in these disparities. Most notably, the report found that among system-level factors, “changes in the financing and delivery of health-care services – such as shifts brought by cost control efforts and the movement to managed care – may pose greater barriers to care for racial and ethnic minority patients than for nonminorities (emphasis added)” [5]. Minorities are “more likely than whites to be enrolled in lower end health plans, which are characterized by higher per capita resource constraints and stricter limits on covered services” [5]. For example, in 2003, 49% of Medicaid beneficiaries were racial and ethnic minorities [39].

This racial and socioeconomic “fragmentation” of health plans creates “segregated shelves” of medical and pharmaceutical services – a “bottom shelf” for poor, disproportionately minority populations that rely on public health plans, and a “top shelf” for the advantaged others. Under cost-cutting EBM frameworks, system managers allocate pharmaceutical and medical service from the “bottom shelf” in accordance with ever more stringent rules. The propagation of the cost-focused EBM model and its restrictive formularies clearly signals a movement away from the defragmentation of the health system recommended by the IOM as a health disparity intervention.

Healthy People 2010 and the Intent of EBM

It is an exceedingly remote possibility that the cost-focused EBM model, in its drug review adaptation, will somehow reduce health-care disparities. To the contrary, EBM’s greater fragmentation of health-care delivery will almost certainly worsen racial inequities in health-care delivery, increase morbidity and mortality among minority groups, and increase health-care costs associated with higher morbidity. As a policy tool, with its current cost-focused design, EBM will likely reinforce the
longstanding paradigm of second-class medicine for minority patients, and therefore is a liability, rather than an asset, to the national mandate to end health inequality [40].

This raises the essential question of what the purpose or intent of EBM is. EBM can mean different things and have different goals, depending on its politically prescribed intent. If properly applied in a cost-conscious environment, an EBM-based drug review designed with the *intent* to improve health outcomes and reduce racial and ethnic health disparities has the potential to enhance minority health, and overtime, reduce costs. However, the narrow and explicit intent of today’s proliferating EBM model is to cut costs on the chopping block of “EBM.” Given this unambiguous purpose, such frameworks operate not to improve health outcomes or reduce health-care disparities (unless these are secondary objectives), but to reduce costs. Nonetheless, the political priority of cost control, although itself an ostensibly reasonable one, does not relieve policymakers of the responsibility to ensure that EBM drug reviews are conducted in ways that protect access for minority populations. Failure to acknowledge or fulfill this responsibility represents a dubious application of science and a policy hazard for minority care.

**Implications**

Carol Easley Allen, former president of the American Public Health Association, is among those health professionals who have suggested that public researchers and practitioners incorporate issues of equality and justice in health promotion and disparity reduction programs [41]. There is an urgent need to incorporate these same transformational themes of equality and justice into the paradigm of EBM. Policymakers can help facilitate this paradigm shift by building a policy bridge between EBM protocols and the federal Healthy People 2010 program. Such a bridge should provide policies that promote the reduction of racial and ethnic disparities in health-care delivery. These anti-disparity policies should reside within the procedural frameworks that govern EBM-based systematic reviews and in the protocols derived from these reviews.

These policies should address three areas of potential impact. First, EBM models must adopt policies that provide checks and balances to protect health-care access for racial and ethnic minorities and other populations facing systemic access barriers to lifesaving medical intervention. A number of key provisions would meaningfully support the goal of *access protection* for highly vulnerable populations. EBM drug review policies should call for multifactorial decision-making processes that recognize the need for cautiously translating external validity into policy decisions that affect minority populations. For example, the level of certainty required to make efficacy judgments is set by decision-makers and stakeholders [42]. However, limits in data availability and external validity logically correspond to limits in policy-setting capacity, especially as it pertains to the denial of medications for highly vulnerable populations that have long been denied fair access and treatment in the US health system. Thus, in the interest of minority access protection,
EBM procedural policies could require the assessment of policy-setting capacity in the context of external validity and known racial and ethnic disparities. As aforementioned, the GRADE approach to evaluating decision-making capacity can serve as a useful tool when modified to incorporate key concerns about racial and ethnic minority populations.

EBM policies must also promote greater transparency of drug review projects. Consistent with recommendations from the IOM, efforts must be made to ensure that EBM protocols are subject to both “professional and consumer review” [5]. Public engagement should include active dialog between EBM administrators, consumer advocates, and community members about protocol design and development; policies for minority access protection and decision-making capacity assessments; and information about the demographic composition of sample populations, research teams, project management, and advisory committees. Transparency policies should also clearly identify the pathways provided to appeal denied services and to obtain nonformulary pharmaceuticals prescribed by a treating physician.

Second, anti-disparity policies must promote proactive efforts to identify, understand, and eliminate racism in EBM. Semmes [43] has explained that racism is an institutionalized phenomenon in the US health system, whereas Jones posits that racism exists at three distinct levels: individual, interpersonal, and institutional. Perhaps the most complex and obdurate form of racism in health-care today is that which exists institutionally through policies and practices that, intentionally or unintentionally, perpetuate measurable racial disparities. Historically, the institutional control of knowledge by scientists has been used to support particular political agendas [18]. These agendas have resulted in the persistence of well-marked patterns of racial inequality in health-care delivery.

Previous calls have been made to investigate and challenge the influence of racism in the health sciences and in health disparity interventions [44]. In the absence of policies that identify and eradicate this debilitating health system phenomenon, EBM reviews will likely advance along the well-trodden path of “scientific racism” in the health sciences [3, 4, 45]. Anti-disparity policies can serve as an important vehicle for countering this trend and ensuring a more equitable and responsive health-care system. In EBM, such policies should make provisions for tracking and publicly reporting data on the demographic compositions of trial populations, research teams, and project management, as well as the establishment and regular review of programs for promoting diversity and cultural competence among researchers and project managers. These policies should call for appraising the training and credentialing of EBM planners and evaluators, including training in cultural competence and awareness of the dynamics of racism and disparities in the health-care system. Anti-disparity provisions in EBM must be driven by an explicit policy commitment to support federal and state mandates to eliminate racial and ethnic disparities in health care. This overarching commitment should ensure that EBM projects take account of equity and justice in project design, data analysis, and health policy decision-making.

As the federal government moves forward in implementing health-care reform law, an important area where EBM should be appropriately involved is in
patient-centered or comparative-effectiveness research (CER). According to the Federal Coordinating Council for CER, “The purpose of CER is to improve health outcomes by developing and disseminating evidence-based information to patients, clinicians, and other decision-makers, responding to their expressed needs about which interventions are most effective for which patients under specific circumstances.” The Obama administration designated $1.1 billion as part of the American Recovery and Reinvestment Act of 2009 (ARRA) for CER through the federal Stimulus package, and an additional $1.26 billion from the General Treasury has been appropriated through the new law to support the newly created Patient-Centered Outcomes Research Trust Fund over the next 10 years. This means that funding is now available with additional support from the Patient Protection and Affordable Care Act (PPRACA) to conduct comparative testing of drugs, medical devices, etc., to ensure that safety, effectiveness, and appropriateness are maximized in the public interest. This is an opportunity wherein EBM can be used primarily to benefit the patient and to achieve equity, and it should help to assist CER in cost containment as well. This is an area that will be closely scrutinized. However, at present, there seems to be an absence of evidence that CER impact is being evaluated. Since evidence reviews will tell us what really works through the application of CER, this type of evaluation must become a national priority so that we can determine whether progress is being made by measuring CER’s effect on patient outcomes and clinical practice. In addition, a proper infrastructure for federally sponsored CER clinical trials needs to be built before implementation of such trials can occur. This will require coordination with insurers; at present, there is no mechanism established to cover drug-related costs associated with the trials. There needs to be collaboration between the insurance industry and the Federal Coordinating Council for Comparative Effectiveness Research in order to overcome the roadblocks to CER implementation [46].

**Conclusion**

As policymakers struggle with rising health-care costs, there is an urgent need to revisit the use of EBM and to assess its impact on delivering equitable health care to minority populations. Three intersecting challenges, largely unaddressed by the research community, have important implications for the national capacity to eliminate racial and ethnic disparities in health care. First, states have increasingly adopted EBM as a cost-containment device, subjugating health outcomes to cost control, further fragmenting the health-care system with delivery restrictions for public insurance programs in which minority groups tend to be overrepresented. Second, cost-focused EBM protocols tend to diminish clinical flexibility and clinical judgment for physicians, encumbering the goal of individualized care. Third, the underrepresentation of minorities in clinical trials – as both subjects and researchers – compromises the quality of the EBM evidence base, with especially serious implications for external validity.
The scientific nature of medicine, and the dynamic social, cultural, and political context in which the practice of medicine takes place, requires special attention to research validity, distributional fairness, and policy intent. This is especially true in the context of longstanding racial disparities in health-care delivery. The proliferating EBM model, with its cost-containment mission, takes inadequate account of validity, fairness, and intent. In the absence of fundamental alterations to this model – including the prioritization of individualized care and health outcomes, and the explicit inclusion of the goal to reduce disparities in health-care delivery – it is possible that EBM will worsen minority access to therapeutic interventions, exacerbate health status disparities, and increase associated spending. Implementation of comparative-effectiveness research (CER) provides the best current opportunity for EBM to be employed in the public interest and to help to eliminate health-care disparities.

Acknowledgments Special thanks to the Alliance of Minority Medical Associations and the Commission on Health, Genetics, and Human Variation. The authors acknowledge the assistance of Health Policy Analyst and Science Writer, John Sankofa, who contributed significantly to the development of this chapter.

References

Abstract  The term “health literacy” describes a certain set of skills stemming from global literacy that allows patients to obtain, understand, process, integrate, and utilize health information to make decisions about their health. Health literacy levels parallel those of global literacy; however, health literacy is more significant than education when examining health status. Surveys conducted by the National Center for Education Statistics (NCES) reveal that approximately 90 million Americans have inadequate literacy skills, which impacts their ability to interface with the healthcare system at many levels. Efforts should be made to ensure that health information and the healthcare system are usable and accessible to all, regardless of literacy level.

Keywords  Literacy • Health literacy • National Adult Literacy Survey • Numeracy • Prescription error • Health disparity • REALM (Rapid Estimate of Adult Literacy in Medicine) • S-TOFHLA (Shortened Test of Functional Health Literacy in Adults)

Introduction

As recently as the 1990s, the idea that literacy could negatively impact patient outcomes was a relatively new concept. In 1992, a survey, the National Adult Literacy Survey (NALS), was conducted through the National Center for Education Statistics (NCES) which reported that 40–44 million Americans (21–23%) functioned at the lowest level of literacy, and another 50 million functioned at the next lowest level where their skills were “quite limited.” Though the majority of participants in both levels perceived their abilities to read and write English as at least “well” and were able to function in their personal and occupational lives, they nevertheless had
“considerable difficulty performing tasks that required them to integrate or synthesize information from complex or lengthy texts or to perform quantitative tasks that involved two or more sequential operations and in which the individual had to set up the problem” [1]. Extrapolated into the healthcare setting, the statistics suggested that reading a prescription label or instructions to prepare for a diagnostic test presented a significant challenge for one in three Americans, a fact that could not be ignored [2]. Subsequent studies would show there is a high price to be paid for limited health literacy in both patient quality of life and utilization of healthcare dollars, an estimated $73 billion in 1998 [3]. In 2002, a panel of experts was formed by the Institute of Medicine (IOM) and was given a mandate of determining the scope of the health literacy problem in the USA. The panel’s report, titled Health Literacy: A Prescription to End Confusion, which concluded that “health literacy is fundamental to quality care,” according to committee chair Dr. David A. Kindig, was issued in 2004 by the IOM. This report has provided the impetus for the more recent interest in the subject and has propelled the efforts to reduce health illiteracy forward.

Current Status and Scope of Health Literacy

Today, health literacy has its own definition apart from generalized or global literacy, and is recognized as an important part of health care. Literacy is most often understood as the ability to read and write printed material [4]. The NALS defined literacy as “Using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential” [1]. This definition speaks of a skill set that determines in part how the individual integrates into his culture as well as of a sense of purpose and self-actualization. Health literacy as defined by the IOM is “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate decisions regarding their health” [5]. Health literacy, then, goes beyond just reading and writing, and requires the ability to analyze and then utilize the information, skills captured by the NALS. A critical part of health literacy that is often overlooked is that of numeracy, the ability to use numbers and mathematics [6]; this skill is vital when it comes to dosing from an over-the-counter bottle of pediatric cough syrup or drawing up the correct volume of insulin. Other researchers have included listening and oral communication as well, citing increased difficulty in expressive communication, understanding, and recall [7]. These five core skills of literacy – reading prose and documents, writing, numeracy, speaking, and listening [8] – are all skills required for health literacy as well. These might involve patient tasks such as being able to report symptoms, recognizing the importance of “family history,” asking questions about invasive testing, and navigating hospital labyrinths and signs to find strangely named places such as “Phlebotomy” and “Radiology.” Realizing that health literacy is a dynamic exchange between patient and caregiver, Rudd later proposes that
Health literacy must be understood as a dynamic characteristic that ebbs and flows in response to other factors, including health materials, communication skills of those delivering the message, changes in life experiences, education, and the presence of co-morbid conditions such as depression, mental illness, and functional status.

Objective 11-2: Improvement of Health Literacy

Communicating Health, USDHHS, 2003 [8]

Assessment of Health Literacy

Functional health literacy is most often measured by one of two tests, the Rapid Estimate of Adult Literacy in Medicine (REALM) or the Shortened Test of Functional Health Literacy in Adults (S-TOFHLA). In the REALM assessment, patients or subjects read a list of increasingly difficult and polysyllabic English medical words; the number of correct words is translated to a grade level estimate [9], sixth grade or less (fewer than 45 words pronounced correctly), seventh to eighth grade (fewer than 61), or ninth grade and above [10]. REALM requires only 3 min to administer, but it does not measure comprehension. However, it may be the preferred measure of health literacy, especially since it requires less time. In the Shortened Test of Functional Health Literacy in Adults (S-TOFHLA), patients read various passages with missing words, and must identify the correct word from a list of four. Patients may also be asked to interpret medicine bottle instructions and appointment slips, and are then scored accordingly [9]. There are also four items measuring numerical ability. This test takes 7–12 min to administer. The full TOFHLA is generally felt to be the most comprehensive reference standard and measures understanding of written instructions and numerical information, but it takes 22 min to administer. These tests are rarely administered clinically, but are often cited in studies evaluating literacy level of patients. Patients scoring below a threshold of literacy reference standards are described as having low, limited, or inadequate literacy.

The relationship between literacy and health literacy is not always clear. In one recent study, patients were assessed using REALM and then identified as having adequate, marginal, or low literacy levels. Forty-six percent of all patients misread at least one out of five prescription label instructions, with the number of errors increasing as literacy level decreased. Importantly, despite being able to read the instructions, “Take two tablets by mouth twice daily,” fewer patients – regardless of literacy level – were able to correctly demonstrate the number of pills to be taken [emphasis mine]. Errors increased with the varying numerical information such as “take one tablet by mouth twice daily for seven days,” again pointing to the importance of numeracy when dealing with pharmaceuticals related instructions. Increasing number of prescriptions taken by the patient also increased the likelihood of errors [10]. In a later study, Rudd reports that in general, those with stronger literacy skills will be more likely to have stronger health literacy skills [11].

In what is now a landmark report, the AMA Ad Hoc Committee on Health Literacy found that “when statistical adjustments were made for education and
other sociodemographic covariables, literacy level was the strongest correlate of health knowledge and disease skills.” Another study cited found that poor self-reported health was more prevalent among those with inadequate functional health literacy, and, “literacy was a stronger correlate of health status than education level and other sociodemographic variables. In fact, after adjustment for literacy, education level had no significant association with health status [12].”

When it comes to which patients are likely to be most affected, inadequate health literacy reflects a disparity seen in other areas of the healthcare system. Adults without high school diplomas, with health-related restrictions, with limited access to resources, members of minority population groups (such as African American and Hispanic American), and immigrants have poorer health literacy than those of the general population [11].

While there are reports that do not find a correlation between health literacy and health outcome, there are far more studies to support the contrary. Patients with limited reading skills are less likely to engage in screening and preventive behaviors, less likely to have chronic diseases under control, more likely to be hospitalized, more likely to report poor health, and more like to die early [13]. In a study comparing health literacy in an elderly population, individuals with inadequate and marginal health literacy as measured by the S-TOFH LA were more likely to die during the 67 month follow up than those assessed with adequate health literacy, 39.4%, 28.7%, and 18.9%, respectively [14]. Limited health literacy has also been associated with poorer glycemic control in diabetics, increased utilization of emergency room services, and increased severity of symptoms in children with asthma.

**Examples of Health Literacy Problems**

Quoting statistics and studies as done here is necessary and informative, but perhaps a few examples can better illustrate the impact of health literacy on the lives of patients that are too often unseen and may be unrecognized. The potential for confusion and error on the part of patients who do not possess health literacy should be evident.

1. A patient has been given a prescription analgesic to take after outpatient surgery. The prescription label reads, “Take one to two tablets every 4–6 hours as needed for pain.” She is also given an antibiotic that she needs to “Take one tablet four times daily for ten days.”

2. A patient with asthma must take twice daily oral medication preferably at measured intervals to maintain appropriate blood levels, know how to correctly use and interpret a peak flow meter that measures peak expiratory pressure, know the difference between the controller and the rescuer inhalers, recognize when to use a rescue inhaler and when to call for emergency assistance.

3. A patient with hypertension takes two medications each with a different time schedule, supplements with a diuretic “when needed,” takes and interprets self
blood pressure readings from a home or pharmacy sphygmomanometer, interprets whether the reading is high or low, and reads a nutrition label on a can of soup to determine if the serving size exceeds the recommended milligrams of salt for his particular diet.

4. A young woman who desires elective surgery for breast enlargement must read and sign a 12-page consent form for the procedure; if she desires silicone breast implants, she will need to sign a separate consent form and agree to be tracked for possible future notification.

5. An insulin-dependent diabetic patient uses a 1 cc syringe to measure and self-administer the appropriate units of long-acting and short-acting insulin from vials where it is recorded in “units/ml.” Throughout the day, she takes and interprets her blood glucose readings and adjusts her short-acting insulin or diet accordingly. Nutrition information regarding grams of carbohydrates and protein is not available on the cafeteria menu to assist in making dietary exchanges as recommended by her physician.

6. A patient with severe coronary artery disease who has undergone various testing is advised to undergo a bypass procedure commonly referred to as a “3-vessel cabbage.” After a lengthy consult, the patient is asked to read and sign a 4-page consent form where risks “include but are not limited to” stroke and death.

The above examples are neither extreme nor rare; by contrast, they occur in the lives of thousands – or more likely millions – of Americans every day. Each example above utilizes and assumes a certain level of health literacy and numeracy, some with potentially life-threatening consequences should errors occur. In a healthcare environment where patients are given increasing responsibility for their own care, where the complexities of modern medicine and the number of pharmaceuticals increase every year, where a system tosses about terms such as “providers,” “payors,” “third party payors,” “EOB (explanation of benefits),” “primary care,” “take on an empty stomach,” and “risk,” is the system really doing everything possible to provide the best care to all patients?

Proposed Legislative, Governmental and Organizational Remedies

In spring 2010, the Health Reform Bill (PPACA) was passed and signed into law. The importance of health literacy is recognized in the law by requirements that speak to the utilization of plain language, “language that the intended audience, including individuals with limited English proficiency, can readily understand and use because that language is concise, well-organized, and follows other best practices of plain language writing” (Amendment, section 1303). Furthermore, in regards to shared decision making between patient and caregivers, patient aids will be required “to reflect the varying needs of consumers and diverse levels of health literacy …” (Sec. 3506).
Health literacy is being increasingly recognized as yet another vital part of the healthcare puzzle. Figure 9.1 demonstrates how it plays a central role in the matrix involving the health system, culture and society, and the education system, and the potential impact on health outcomes and costs and points of potential intervention. Accurate communication between patient and provider is paramount to achieving optimal health outcomes. To that end, the use of “plain language” as defined above is helpful to patients functioning at any level of literacy. Administering a health literacy test such as REALM or S-TOFHLA is too time-consuming in most practices today to be practical as a screening tool, but it might be useful for high risk patients such as those with multiple illnesses taking multiple medications, or patients who repeatedly miss their appointments and have difficulty adhering to medical regimens. More practical, daily strategies include: patient-centered learning, focus on behaviors, not knowledge; repetition and reinforcement; focus on survival skills; and using a teach-back method [13]. Having patients repeat back instructions is helpful, but having them demonstrate or draw how to take their medicine or use a device is even more effective. Asking patients if they understand that what was said is good, but asking them if they understand a particular word or phrase (“on an empty stomach”) is better. Workplaces can assist patients by having people available in human resources to help fill out insurance forms and documents for new enrollees. Hospitals must be sensitive to the signs and placards patients must read to navigate the various departments.

Increased consumer and community-based initiatives are important sources of information. Suggested efforts include incorporation of health literacy into K-12 education, as well as encouraging health librarians to partner with other community sources such as senior citizen facilities, public libraries, and school and literacy groups [3].

The fact is that there is no place in the healthcare realm that cannot benefit from acknowledging the varying degrees of global and health literacy of the patients that are served, and working towards a more universally comprehensible environment.
It is important for physicians to stress clear communications with their patients and this can be accomplished through improvements in health literacy [16]. The American Medical Association (AMA) has long recognized this need and has developed a health literacy kit, *Health Literacy: Help Your Patients Understand*, which was designed for healthcare professionals and contains a 48-page manual, a videotape, and patient information (the kit is available at [http://www.amafoundation.org](http://www.amafoundation.org)).

To facilitate improvement of health literacy, the federal government released the National Plan to Improve Health Literacy on May 27, 2010. Promulgated by the US Department of Health and Human Services, this plan aims to make the language of healthcare more patient- and consumer-friendly by dispensing with the jargon that is used at the point of service. The dense verbiage used in patient handouts, medical forms, brochures, Web sites, etc., will be changed to a more culturally and linguistically appropriate form. An attempt will also be made to improve the literacy skills of health professionals. Assistant Secretary for Health Howard K. Koh, M.D., M.P.H., stated the following: “Basic health literacy is fundamental to the success of each interaction between health care professionals and patients – every prescription, every treatment, every recovery. Everyone has a right to health information that helps them make informed decisions. When people receive accurate, easy-to-use information about a health issue, they are better able to take action to protect and promote their health and wellness.” The Action Plan has seven objectives, each with a strategy pertaining to a component of the healthcare system including payers, the media, healthcare professionals, and government agencies. Emphasis is placed on building health literacy skills early in life and providing reinforcement of these skills by influencing learned behavior about health through the educational process. Resulting from a decade of work by the HHS-sponsored Health Literacy Workshop, which consists of public and private sector individuals, the Action Plan now points to the future by supporting the health literacy objective for Healthy People 2020. This is a demonstration of the federal government’s serious concern about this issue. It seems prudent to urge state and local governments to follow this lead.

### References

Part III
Approaches to Correcting the Problems
Chapter 10
The Good, the Bad, and the Ugly: Overview of the Health Reform Law and Its Impact on Health-Care Disparities

Richard Allen Williams

Abstract  The passage of the Patient Protection and Affordable Care Act (PPACA or ACA) on March 23, 2010 has been hailed as simultaneously being a wondrous blessing that promises to uplift the delivery of health care for all; as a lukewarm and incomplete approach to the prodigious medical problems of the United States; and as a downright mistake that will hamper rather than help us to overcome what nearly everyone acknowledges as a crisis in medical care. Of course, there has been much subjective conjecture on this topic, with one’s orientation being influenced by political status, personal experience, level of education, geographical factors, racial and ethnic group membership, exposure to the issues, and frank bias. There has been a great deal of debate about what provisions are best for the country that has ranged from vitriolic to vapid, with no unifying perspective having been enunciated as yet. Some pundits say that there is no possibility of unification and that the issue of what kind of health care is best will remain perpetually divisive.

There are ten major titles in the new national health-care reform program, each with its own separate agenda (The Patient Protection and Affordable Care Act, P.L. 111–148, 23 Mar 2010). They are as follows:

1. Title I: Quality, Affordable Health Care for all Americans
2. Title II: Role of Public Programs
3. Title III: Improving the Quality and Efficiency of Health Care
4. Title IV: Prevention of Chronic Disease and Improvement of Public Health
5. Title V: Health Care Workforce
6. Title VI: Transparency and Program Integrity
7. Title VII: Improving Access to Innovative Medical Therapies
8. Title VIII: Class Act
10. Title X: Strengthening Quality, Affordable Health Care for all Americans

R.A. Williams
Clinical Professor of Medicine, UCLA School of Medicine,
President/CEO, The Minority Health Institute, Inc., Founder,
The Association of Black Cardiologists, Inc., Chairman of the Board, Emeritus Institute for the Advancement of Multicultural and Minority Medicine, Washington, DC, USA
e-mail: mhinst@aol.com
As the nation moves forward in complying with what is now health-care reform law, it is important to look at what we are in for and how we are going to deal with it. We also need to understand that the law is not immutable, and that we will need to examine the impact of certain policies and provisions that have been promulgated in order to determine what changes need to be made down the road.

This gives us an opportunity to choose one particular entity, health-care disparities, to see how much has been included in the new law (or excluded from it) that might relate to this important area of health-care endeavor, and to examine it in an objective manner. None of the titles listed specifically aims at eliminating health-care disparities, although just about all of them contain sections that relate to this topic in one way or another. Some of these sections relating to ethnic and racial minorities and to disparities indicate an intent of beneficial action; others state mandated actions in the strongest terms, and many but not all list penalties for noncompliance as well as the level of appropriations to enable implementation. It appears useful, therefore, to put together a kind of road map that hopefully will help one to navigate through the complex waters of the new health-care reform law as it concerns health-care disparities and racial and ethnic minorities. Some of these will be discussed in detail, and others are presented in various chapters elsewhere in this book. They are not necessarily discussed in the order of importance or priority.

For this report, the entire 906 pages of the health-care bill have been scanned and will be analyzed regarding the presence (or absence) of key provisions for reducing or eliminating health-care disparities. In this manner, we will be able to ascertain the extent to which concern over health equity has been taken into account by Congress and the Obama Administration.

**Keywords** Healthcare reform • Disparities • Equity • Literacy • Data collection • Quality improvement • Health insurance coverage • Affordability • “Donut hole” • Wellness • Prevention • Cultural competency • Diversity • Medical home • “Public option” • Patient-centered research • Appropriations • Proposition 209 • Community empowerment

**Current “State of the Union” of Health-Care Disparities**

Disparities in health care primarily affect racial and ethnic minorities in the United States, who will probably be the majority of the population by the year 2050 (Table 10.1). In 2007, the US Census Bureau estimated that there were 38.8 million African Americans (12.9%), over 45.5 million Hispanics or Latinos (15.1%), almost 13.4 million Asians (4.4%), more than 2.9 million American Indians/Alaska Natives (AI/AN) (1.0%), and more than 0.5 million Native Hawaiian or Pacific Islanders (NHOPI) (0.2%). The current population of the United States, in 2010, is approximately 310 million.
Table 10.1  Some key health equity concerns

- Affordable health insurance
- Workforce diversity
- Health literacy
- Data collection by race and ethnicity
- Health-care quality improvement
- Equity of access to care
- Protection of children’s health
- Safety net availability
- Health information technology
- Cultural competence education and training
- Improvement of community health centers
- Implementation of the medical home model
- Comparative effectiveness research (CER)
- Community empowerment
- HIV/AIDS issues
- Wellness, health promotion, and disease prevention

At present, the recent National Health Disparities Report and National Health Quality Report (NHDR and NHQR) presented by the Agency for Healthcare Research and Quality (AHRQ) indicate that almost all of the measures of disparities either have not improved or have declined (gotten worse). This has been the case in each of the 7 years that the reports have been issued since 2003.

The Institute of Medicine (IOM) has formed the Future Directions Committee to address the incentive from AHRQ to provide a vision for NHDR and NHQR to advance the state of health-care quality for all citizens of the United States and to eliminate disparities. The objective is to close the gap between recommended standards of care and current performance levels. The Future Directions Committee has recommended the following actions:

1. Align the content of the reports with nationally recognized priority areas for quality improvement to help drive national actions.
2. Select measures that reflect health care attributes or processes that are deemed to have the greatest impact on population health.
3. Affirm through the contents of the reports that achieving equity is an essential part of quality improvement.
4. Increase the reach and usefulness of AHRQ’s family of report-related products.
5. Revamp the presentation of the reports to tell a more complete quality improvement story.
6. Identify measure and data needs to set a research and data collection agenda.

In addition, further proof that we are not making good progress in eliminating disparities may be found in the most recent update from Healthy People 2010, the three-decades-long CDC program advocated by former US Surgeon General Dr. David Satcher and Health and Human Services (HHS) Secretary Donna Shalala to provide an assessment of various health indicators. Its targets are subsumed within 28 focus areas, 955 objectives and subobjectives, and 31 leading health indicators (LHI). Its overarching
goals are to increase the quality and quantity of life, and to eliminate health-care disparities. In a recent article, the Assistant Secretary for Health at HHS states that although there have been some modest gains, with progression toward objectives in 52% and reaching the target in 19%, the goal of eliminating disparities remains unmet [1]. An example is obesity, for which the rates for blacks and Mexican Americans have steadily increased from 1998 to 2008. Another example is diabetes, a condition that predominates among racial and ethnic minorities, for which the age-adjusted prevalence in 2008 was 59 cases per 1,000 population, compared to the baseline prevalence in 1997 of 40 cases per 1,000 and far above the 2010 goal of 25 cases per 1,000.

Following the Money: The High Cost of Health-Care Disparities

Although we are first in the world in spending for health care, paying more than $2.5 trillion in 2006, and spending far more per capita than any other country ($7,290 per person in 2007, according to a Commonwealth Fund report), our performance on traditional measures of health-care delivery has been dismal. For instance, the United States ranks 39th for infant mortality, 43rd for adult female mortality, 42nd for adult male mortality, 36th for life expectancy, and 37th overall [2]. In addition, although we spend more and more annually, we are falling farther behind each year. From a cost-effective standpoint, we are not getting enough “bang for the buck.” Much of the deficiency in health-care delivery connoted by these statistics is due to health-care disparities, and racial and ethnic minorities have the worse performance statistics for most of the measures. Research conducted by the Joint Center for Political and Economic Studies indicates that between 2003 and 2006, the additional burden of disability and disease among racial and ethnic minority patients cost the nation at least $230 billion in direct health-care expenditures, and the total cost rises to $1.24 trillion when indirect costs such as lost wages and productivity are factored in [3]. The Joint Center also estimates that the annual cost of health-care disparities is $50 billion. If cost containment is considered to be a prime objective of fiscal policy in health-care reform, it should be obvious that elimination of health-care disparities must be given the highest priority for economic as well as compassionate reasons.

Identifying Minority-Related Areas of Concern in Health-Care Reform

The new health-care reform law has included several provisions related to the problem of equity for racial and ethnic minorities. Following is a detailed analysis of some of them, with an emphasis on the prospects that these provisions hold for bringing real change to the disparities problem, and the extent of funding support being supplied to effect that change (see Table 10.2):
### Table 10.2  Itemized provisions related to health-care disparities in Health Reform Law

<table>
<thead>
<tr>
<th>Item</th>
<th>Included in law</th>
<th>Authorized for funding</th>
<th>Funding appropriated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affordable health insurance</td>
<td>Yes</td>
<td>Yes</td>
<td>$5 billion to establish high-risk pools</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$250 million for State grants for insurance exchanges</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$5 billion for reinsurance for early retirees</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$30 million for health insurance consumer information data collection</td>
</tr>
<tr>
<td>Data collection by race/ethnicity</td>
<td>Yes</td>
<td>As needed</td>
<td>Appropriations as necessary. Another Act of Congress may be needed to allow appropriation of implementation funds</td>
</tr>
<tr>
<td>Improving health literacy</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Provisions for American Indians/Alaska natives</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes, but more is needed to prevent triaging of those receiving care because of severely limited resources</td>
</tr>
<tr>
<td>Community empowerment</td>
<td>Yes</td>
<td>Yes</td>
<td>$1.5 billion in 2014, increases to $2 billion in each year after</td>
</tr>
<tr>
<td>Provisions for higher education</td>
<td>Yes</td>
<td>Yes</td>
<td>$2 billion for community colleges</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$2.55 billion for HBCUs</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$36 billion/10 years to increase Pell Grants</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$750 million for college access/retention</td>
</tr>
<tr>
<td>Improving the health-care workforce</td>
<td>Yes</td>
<td>Yes</td>
<td>$300 million for NHSC</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$691 million for other programs</td>
</tr>
<tr>
<td>Greater focus on minority health</td>
<td>Yes</td>
<td>Yes</td>
<td>To be appropriated as necessary</td>
</tr>
<tr>
<td>Increasing diversity in the health professions</td>
<td>Yes</td>
<td>Yes</td>
<td>$96 million for HBMSs</td>
</tr>
<tr>
<td>The Medical Home Model</td>
<td>Yes</td>
<td>Yes</td>
<td>Up to $2 million per state for ten-state Demonstration Project for 3 years</td>
</tr>
<tr>
<td>Expanding/improving community health centers</td>
<td>Yes</td>
<td>Yes</td>
<td>$14 billion plus $230 million/5 years for community-based teaching</td>
</tr>
<tr>
<td>Patient-centered research (CER)</td>
<td>Yes</td>
<td>Yes</td>
<td>$1.1 billion (from ARRA funds)</td>
</tr>
</tbody>
</table>

(continued)
Table 10.2 (continued)

<table>
<thead>
<tr>
<th>Item</th>
<th>Included in law</th>
<th>Authorized for funding</th>
<th>Funding appropriated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cultural competency</td>
<td>Yes</td>
<td>Yes</td>
<td>Appropriations as necessary</td>
</tr>
<tr>
<td>Combating HIV/AIDS</td>
<td>Yes</td>
<td>Yes</td>
<td>$30 million for education in high-risk areas; $19.4 billion from HHS prior to PPACA; $25 million to states from HHS for treatment</td>
</tr>
<tr>
<td>Health information technology (HIT)</td>
<td>N/A</td>
<td>N/A</td>
<td>$ 29 billion (from ARRA)</td>
</tr>
<tr>
<td>Development of quality measures</td>
<td>Yes</td>
<td>Yes</td>
<td>$60 million to establish adult quality measures for Medicaid; $75 million to CMS and $20 million to HHS to establish quality measures</td>
</tr>
<tr>
<td>Wellness, health promotion, and disease prevention</td>
<td>Yes</td>
<td>Yes</td>
<td>$500 million 2010–2015; $2 billion/year thereafter</td>
</tr>
</tbody>
</table>

PPACA Patient Protection and Affordable Care Act; ARRA American Recovery and Reinvestment Act (Stimulus Act of 2009); HBCUs Historically Black Colleges and Universities; HBMSs Historically Black Medical Schools; CER Comparative Effectiveness Research

1. **Collection and Reporting of Data by Race, Ethnicity, and Language.** The complexity of the racial and ethnic mix in the United States is staggering, with approximately 100 different ethnic groups of 100,000 population living in the United States. This is more than any other country in the world. In order to determine the health status of minority individuals or to assess the health circumstances of various groups, it is necessary to collect health data by race and ethnicity for everyone in the nation. Although there is some collection of data, the methods of collection are not standardized, making meaningful comparisons between racial and ethnic groups as defined by the government (OMB-15) very difficult. Disaggregation of compiled data is also desirable rather than lumping all data together. The new law mandates racial and ethnic data collection in any activity dealing with health that receives federal funds, and it uses very strong language in establishing this mandate. The new statute requires that within 2 years of enactment, any federally conducted or supported health care or public health program, activity, or survey must collect and report data on (a) race, ethnicity, sex, primary language, and disability status for applicants, recipients, or participants; (b) geographic location; (c) information to generate statistically reliable estimates by race, ethnicity, sex, primary language, and disability status; and (d) any other demographic data as deemed appropriate by the Secretary of HHS regarding health-care disparities. Further, data analysis “shall be used to detect and monitor trends in health disparities.” It should be apparent that this type of monitoring is essential for eliminating health-care disparities. However, despite the expert advice of the Institute of Medicine (IOM) articulated in its
landmark report, *Unequal Treatment* [4] in which data collection on the “race, ethnicity, socioeconomic status, and ... primary language” of patients was recommended, and despite the fact that the IOM went further in 2009 to recommend standards for data collection [5], there are still detractors who oppose these actions, sometimes on the basis of perceived civil rights and privacy violations, such as Ward Connerly; a former regent of the University of California system, who heads a group paradoxically named the American Civil Rights Institute, is an individual who has railed against this activity for years as well as Affirmative Action (he infamously authored Proposition 209 in California, a state ballot measure which was approved by the electorate in 1996, resulting in up to a 65% decrease in minority student enrollment in University of California schools and a drop in minority medical school enrollment from 23.1 to 14.3% between 1993 and 1997), and although such opposition might be regarded as intuitively anti-intellectual and disingenuous, his position has attracted attention and has provided some distraction from the essential purpose of data collection. Fortunately, there is strong support for collecting demographic data linked with data on quality. Measures of quality that may be used by physician practices have been developed and have become part of “meaningful use” criteria under federal Health Information Technology for Economic and Clinical Health (HITECH) requirements [3]. Implementation of an electronic health record (EHR) system will facilitate the collection of data by race and ethnicity, which will have a significant impact on dispelling disparities. Without the collection of such data, there is no way that we will be able to identify disparities, comparatively examine outcomes of treatment, and locate deficiencies in care. The Secretary of HHS must report within 2 years on the implementation of approaches to data collection efforts. The only “negative” to the apparent determination to these efforts is the provision in the law regarding authorization for appropriations to collect data accordingly: the authorization for funds is to be on an “as-needed” basis, and it requires an appropriations act of Congress for funding for FY 2010–2014. This is a potential stumbling block for implementation.

2. *Expanding Health Insurance Coverage and Affordability.* Health insurance is a major gateway for accessing health care. Without it, acquiring quality treatment is virtually impossible, and many needy people essentially have no provider to turn to except the emergency room when they become ill. The statistics on lack of insurance are very stark: an estimated 47 million people in this country are uninsured or underinsured. About half of this number consists of minorities. In 2005, Latinos comprised the largest group of uninsured; two-thirds had no coverage, compared with 6 million African American adults, which is one-third of the black adult population, compared to 20% of whites who are uninsured. The new law provides coverage for 32 million currently uninsured individuals by 2019, which will make insurance available and affordable for 94% of the American public, an increase from the current 83%. Half of the additional people covered will obtain their coverage under Medicaid and the Children’s Health Insurance Program (CHIP). Some of the strong provisions include: a prohibition of exclusion based on preexisting conditions; and expansion of income eligibility
for Medicaid to 133% of the federal poverty level (FPL), which will add 25% of the most impoverished patients to Medicaid rolls, or about 16 million additional people. Low-income adults who do not have children will be eligible for the first time if their incomes do not exceed $14,404 or 133% of the FPL. Other important aspects of insurance coverage that are related either directly or indirectly to disparities are: a prohibition, effective by 2014 (2010 for children), of barring people with preexisting medical conditions from purchasing insurance; insurance companies are banned from setting lifetime caps or limits on coverage, which will prevent catastrophic financial consequences that have occurred when coverage has expired; annual limits on coverage will be banned by 2014; unmarried adults under age 26 may remain on their parents’ insurance plan; improvement of the Medicare prescription drug policy, which will eliminate the “donut hole” situation by 2020 in which seniors have to pay out of pocket for medical expenses after they reach a certain financial threshold; elimination of the Medicare co-pay for annual wellness visits; exemption of Medicare and privately covered patients from deductibles for preventive services by 2011, which will increase preventive services and emphasize wellness by making these services free for screenings such as for breast, prostate, and colon cancer; and a discount on branded prescription drugs. The cost of health-care reform has been calculated by the impartial Congressional Budget Office (CBO) to be $938 billion over the next decade. The CBO also projects a narrowing of the federal deficit by $143 billion over the same time period due to the money saved by more cost-efficiently delivered health care associated with improved health insurance coverage, and a saving of over $1 trillion in the decade after that.

3. **Improving Health Literacy.** It is estimated that 90 million people, or half of the American adult population, do not understand health information and do not know how to use it. Health illiteracy is a pathway to health-care disparities. The National Adult Literacy Survey (NALS) of 1992 [6] provided the most accurate picture of literacy skills in the United States and it led to the organization of an effort to combat the problem. A report released by the Institute of Medicine on April 8, 2004 titled *Health Literacy: A Prescription to End Confusion* [7] was the result of the deliberations of an expert panel that seriously considered this problem from cultural, sociological, communications, educational, medical, anthropological, and public health standpoints. They defined health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic information and services needed to make decisions regarding their health” and further stated that “the public’s ability to understand and make informed decisions about their health is a frequently ignored problem that can have a profound impact on individuals’ health and the health care system. Most professionals and policy-makers have little understanding of the extent and effects of this problem.” According to David A. Kindig, MD, PhD, professor emeritus of population health sciences at the University of Wisconsin-Madison and chair of the IOM committee that produced the report, “health literacy is fundamental to quality care.” The consensus is that attempts to improve the quality of care, reduce costs, and eliminate disparities cannot succeed without
improvements in health literacy. The IOM health literacy report was followed by another survey of print literacy skills, the National Assessment of Adult Literacy (NAALS), which was made available in December 2005 by the Department of Education; this showed that health literacy skills have not changed much in the last decade [8]. Based on the IOM committee’s deliberations, a number of recommendations were issued including an urgent call for increased federal and non-federal funds for health literacy research. Provisions for this have been included in the new health reform law, indicating that the recommendations are being taken seriously [9, 10]. However, funding support is weak under Patient Protection and Affordable Care Act (PPACA or ACA), which will make implementation of needed advances very difficult unless Congress amends the current law to appropriate more funds.

4. Special Provisions Relating to American Indians and Alaska Natives. The uninsured rate for nonelderly American Indians and Alaska Natives is 28%, which is the second highest rate among all racial and ethnic minorities, and one in three of them lives in poverty. They experience worse outcomes than most Americans and suffer some of the highest rates of diabetes, heart disease, and psychological stress. The Indian Health Services provides care for many in this subpopulation, but it has been chronically underfunded, leading to rationing of care [11]. There are new provisions that will help to relieve the strain on facilities that are used by this group, such as through the Indian Healthcare and Improvement Act of 2009 (IHCIA), which aims to increase the number of American Indian and Alaska Native health providers and to address other issues of access to health care. An attempt is being made under the new law to enroll more of them into Medicaid by changing the eligibility criteria. Cost sharing will be eliminated, and they will be exempted from penalties for non-enrollment in health insurance plans. These changes are among the most meritorious in health reform and will address serious deficiencies in health-care delivery to this long-suffering group. Despite these gains, however, much more is needed to help improve what has been an ugly, neglected, and shameful area in our response to a desperate need.

5. Community Empowerment. Communities of color particularly need to feel empowered to plan their own health destinies, and they must have encouragement, funding, and support in order to accomplish this goal. Patient education, concerns about health literacy, engagement of community residents who have limited English proficiency (LEP), and community-based health policy development based on evidence-based information are some of the areas that will need government assistance. Yet less than 5% of total health-care funding is allocated to population-based services such as public health. Greater employment of community health workers is a goal that also needs more support from the federal level. Under the PPACA, Sec. 447, subtitle C, there is a provision for Creating Healthier Communities, and under Sec. 4201, Community Transformation grants will be made available. The health reform law has appropriated $50 million for “prioritizing strategies to reduce racial and ethnic disparities and geographic determinants of health.” PPACA also provides for the establishment and development of prevention programs beginning with an
allocation of $1.5 billion in 2014 and continuing with $2 billion in each subsequent year, and it creates a Prevention and Public Health Fund to expand the government’s investment in wellness and prevention. These provisions would appear to be very helpful for allowing community health to improve, but in fact, they are woefully inadequate, because the federal government is not investing enough in the public health system operating at the state and local levels. For example, instead of providing direct grants to states for health education and media outreach campaigns, PPACA authorizes $500 million to be used by the Centers for Disease Control and Prevention to fund such activities. This seems to be an awkward way of trying to accomplish a very important objective of community health education, and it is a missed opportunity for assisting community empowerment at the grass-roots level. A better option which was in the House bill but did not make it into the final statute that became the PPACA would have been the enactment of the Public Health Investment Fund which would have awarded grants to state health departments to fill needs such as workforce development, laboratories, information technology, and organizational restructuring which are vitally needed at the community level to operate public health systems in an efficient manner [12]. In addition, the PPACA is not clear on what the sources of the aforementioned funds are, and it uses ambiguous language associated with the designated projects such as “such funds as may be necessary for each fiscal year” and “out of any monies in the Treasury not otherwise appropriated.” Thus, the seeming progress toward real community empowerment rests on shaky grounds, and what appears to be a serious federal commitment may have its direction changed in the reverse direction at the whim of Congress and other politicians. Hopefully, more solid amendments to the health-care reform law in the future will help to shore up the integrity of public and community health systems, which will help to increase access to health care, and in doing so, should decrease health-care disparities.

6. **Provisions for Higher Education.** It is axiomatic that the nation must improve and expand its capabilities of developing a more robust health workforce by providing more support for higher education. Accordingly, the Health Care and Reconciliation Act, based on HR 4782, establishes the following: (a) Provides $2 billion for community colleges to develop and improve educational or career training programs; (b) Invests $2.55 billion in Historically Black Colleges and Universities and Minority-Serving Institutions; (c) Includes $750 million for college access and completion support programs for students; (d) Increases Pell Grant funding for student tuition assistance by $36 billion over 10 years; and (e) Substantially increases the investment in Community Health Centers (CHC) in order to expand access to health care in communities where it is most needed. These and other provisions indicate that the federal government recognizes the significance of stimulating educational pursuits as a pathway to improving health care.

7. **Improving the Health-care Workforce.** It is estimated by the Association of American Medical Colleges (AAMC) and the American Medical Association (AMA) that in the coming decades we will have a shortfall of doctors at the very
time when we will need more to care for the large numbers of additional patients who will be enrolled in the reformed health-care system. This is particularly urgent at the community level, where currently 65 million Americans do not have easy access to a primary care provider. It is estimated that an additional 16,500 doctors are required to meet their needs. For this reason, the federal government is investing in the National Health Service Corps’ scholarship and loan repayment programs ($300 million) so that the health-care workforce will be expanded. Incentives such as bonuses are also provided to primary care practitioners and other providers to incentivize their practicing in underserved areas. In addition, the new health reform law establishes a new $230 million program of grants over a 5-year period for community-based teaching programs as well as a grant program ($47.6 million) for the development of residency training programs in primary care in community health centers. Importantly, the law also authorizes the creation of a National Health Workforce Commission Sec. (5101) to gather information on the health-care workforce and to better coordinate and implement planning and analysis, which is necessary to make an accurate determination of the nation’s health-care needs. Members are to be appointed by the Comptroller General and will be empanelled by September 2010. The Commission will determine the health-care workforce needs of special populations such as racial and ethnic minorities, and rural and medically underserved areas. The National Health Care Workforce has no budget so far but PPACA authorized such appropriations as necessary. In 2010, there will be only $8 million available for planning grants and $150 million in implementation grants. Provisions are also made for investing in programs to improve the diversity of the workforce, including scholarship and loan repayment programs ($195 million for student loans in 2010), and Centers of Excellence. In addition, Sec. 5402 establishes the Health Care Training for Diversity program, which covers loan repayments, fellowships, and scholarships for disadvantaged students. Sixty million dollars has been appropriated for 2010.

8. **A Greater Focus on Minority Health.** To strengthen its authority, increase its funding, and make its function more directly tied to documented needs, new legislation establishes the National Center for Health and Health Disparities (NCMHD) within the National Institutes of Health (NIH), and it will now become an Institute in its own right, which will give it more clout, and more funds, to deal with minority health and health disparity matters. It now has the authority to issue grants and contracts independently. The Director, Dr. John Ruffin, will coordinate all research and activities of NIH dealing with minority health and health disparities. Additionally, the Office of Minority Health (OMH), a separate agency, has been transferred from the Public Health Service and will now come under the Department of Health and Human Services (HHS). It will receive mandated annual performance reports from every minority health office within HHS such as that within the FDA, AHRQ, Health Resources and Services Administration (HRSA), CMS, etc. Its monitoring function gives it oversight of the entire minority health spectrum within HHS, where each agency now has a responsibility to operate a minority health office that reports to the head of the
Office of Minority Health. This restructuring, to be headed by the Deputy Assistant Secretary for Minority Health, Dr. Garth Graham, should result in greater efficacy, improved action, and better coordination and funding of efforts aimed at eliminating health-care disparities.

9. Increasing Diversity in the Health Professions. The term “opportunity gap” has been used to describe the situation in which racial and ethnic minority students have been deprived of the chance to gain the education and training necessary to enter the health professions because of race, ethnicity, gender, socioeconomic status, lack of social capital, or breach of civil, political, or human rights laws. Considering that Hispanics and African Americans are the fastest-growing subgroups in the US population, constituting 25% of the total, it is shocking to see that they make up only 6% of doctors in practice [12]. The numbers of doctors who are members of under-represented minority (URM) groups in this country are disproportionate to the numbers of URM citizens in the general population. This is a disparity of gigantic proportions. One of the most glaring discrepancies related to the “doctor disparity” is the relatively small numbers of URM students in medical schools. The Association of American Medical Colleges (AAMC) revealed data in 2007 showing that only 7.2% of students were Hispanic/Latino, 6.4% were African American, and 0.3% were American Indian/Alaska Native, in contrast to 59.9% who were white [13]. The connection between educational barriers and workforce disparities in the medical profession is obvious. The workforce data of 2007 show that there were 973,524 non-federal doctors in the United States and its territories; only 2% were African American, 3% were Hispanic, less than 1% were American Indian, 8% were Asian, and 44% were white. An inadequacy in the number of doctors overall in the country is expected to become critical by 2025, and according to the AAMC, we can expect a shortage of up to 125,000 physicians by that time. The Health Resources and Services Administration (HRSA) estimates that the supply of primary care doctors will be sufficient until 2020; after that time, they predict a shortfall of 65,560 physicians. And the American Academy of Family Physicians (AAFP) estimates that we will need approximately 149,000 more doctors by that time [14]. These expected shortages, if they occur, will have an especially devastating impact on the poor, on rural areas, and on racial and ethnic minorities, making the recruitment and training of more minority physicians more urgent, particularly since such doctors tend to provide service more to these areas and subpopulations. Greater financial support for Historically Black Medical Schools (HBMSs) which have produced the great majority of African American doctors, most of whom have served in the areas of greatest need, should be a priority for the federal government. Recently, a coalition of academic leaders in medical schools including Howard, Meharry, Drew, and Morehouse made 3 key recommendations for federal support to HBMSs: (a) The establishment of a core operating infrastructure fund in the amount of $16 million per year for each HBMS; (b) the donation of state-of-the-art electronic medical records systems; and (c) creation of a dedicated liaison office to coordinate a series of public-private partnerships and overcome longstanding dual standards for HBMSs [15]. To the government’s credit, HHS recently (July 2010)
doled out $96 million in grants to colleges and universities across the country, money that is especially intended to increase the diversity of the health-care workforce by keeping minority students in health classes. For instance, Howard University received $1.5 million from the Obama Administration to train student nurses and others in sciences such as occupational therapy and radiology.

10. The Medical Home Model. This is a concept that was initiated a few years ago, based on the fact that many poor minorities lacked a definite place, or “home,” to look for their medical care. It actually was introduced by the American Academy of Pediatrics (AAP) in 1967 with the objective of improving care of special needs of children, and has now evolved into an initiative which places most of its emphasis on adults with chronic diseases, with the intent of strengthening primary care practice in the United States while simultaneously decreasing the cost of health-care delivery, especially under Medicare and Medicaid. In the intervening time, the concept has been advanced in several states, and 13 of them now have pilot projects of what is now termed “patient-centered medical homes” (PCMHs) that focus on delivering primary care on a culturally sensitive and linguistically appropriate basis. These sites give promise of reducing costs by keeping patients out of the hospital and of providing high-quality care. In addition, by increasing access to care, these homes decrease health-care disparities. There is a mutually beneficial relationship in that the homes receive enhanced payments over and above what might be expected in routine practice. This may be accomplished through a monthly per-patient fee paid to the practitioner. The federal government has a vested interest in promoting the medical home concept because of the promise that it holds for managing the primary care of large numbers of patients nationwide in a cost-effective manner, and has established a Medical Home Pilot Project to address the issue of chronic diseases (see above). This 3-year demonstration project was a response to a mandate in the Tax Relief and Health Care Act of 2006, and is being administered by the Centers for Medicare and Medicaid Services (CMS); it will operate in rural, urban, and underserved areas. Congress intends to utilize the program to “redesign the health care delivery system to provide targeted, accessible, continuous and coordinated, family-centered care to high-need populations.” Core features of a patient-centered medical home include a physician-directed medical practice; a personal doctor for every patient; the capacity to deliver and coordinate high quality, accessible care; and payments from CMS that recognize a medical home’s added value for patients [16]. In addition to the federal demonstration project, there are several others including the National Demonstration Project (NDP), a 2-year, 36-practice consortium launched in June 2006 by the American Academy of Family Physicians (AAFP) as the first in the nation. The recent report of the NDP concludes that PCMH is still evolving and requires extensive health-care reform and practice revisions in order to work. In a series of articles contained in a supplement in the *Annals of Family Medicine*, the authors explained the outcomes, implications, and lessons learned from the NDP. They stated, “The articles in this supplement demonstrate that it is possible for highly motivated, independent practices to implement most of the predominantly
technological components of the PCMH” which “…results in improved indicators of chronic disease care as assessed from medical records, but at the cost of reducing the quality of key attributes of primary care as rated by patients” [17]. Although there are barriers to implementation of the PCMH, there is widespread enthusiasm about its prospects for stimulating a rejuvenation of primary care. To further implementation, several Fortune 100 companies and other organizations have joined to create the Patient-Centered Primary Care Collaborative to strategize and advocate for its adoption [18]. In addition, the Safety Net Medical Home Initiative, which is aimed at helping primary care safety net clinics qualify as high-performing patient-centered medical homes, is being rolled out in a demonstration project that has been sponsored by the Commonwealth Fund in conjunction with the Group Health Research Institute and Qualis Health [19]. The hope is that these demonstration projects will provide the template on which the PCMH may be replicated nationally.

11. **Expanding and Improving Community Health Centers (CHC).** Initiated by the Health Resources and Services Administration (HRSA) more than 40 years ago, these centers are community-based and patient-directed organizations with boards of directors that are at least 51% of patients from the area served. There are at present 8,000 CHCs in the country, providing medical care to millions of uninsured as well as insured (mostly Medicaid and Medicare) patients. They serve largely as the primary care providers for indigent people, bringing care to people in the communities where they reside. Since their inception in 1965 during President Lyndon Johnson’s War on Poverty, they have been administered by HRSA as medical homes for over 20 million Americans [20]. They are truly a safety net system; more than 50% of their patients are members of minority groups, and 70% are poor. There are certain fundamental requirements for a CHC: (a) it must be located in or must serve an area of high need; (b) it must be governed by a community board; (c) it must provide primary care as well as supportive services such as education, translation, transportation to provide access to care; (d) it must provide service to all regardless of ability to pay or insured status (any fees charged are on a sliding scale based on ability to pay); and (e) it must have appropriate administrative, financial, and clinical capabilities. It must serve people of all ages; people with and without health insurance (about 38% of the population served in 2008); all races and ethnicities (in 2008, 28% were African American and 33% were Hispanic, more than twice the proportions of these two groups in the overall US population); and it must serve migrant and seasonal farm workers (834,000 in 2008), public housing residents (157,000 in 2008), and the homeless (934,000 in 2008). The Grant-Supported Federally Qualified Health Centers (FQHCs) are a special group of public and private non-profit health-care organizations, which meet certain criteria under the Medicare and Medicaid programs, and meet the definition of “health center” under Section 330 of the Public Health Service Act, although they do not receive grant funding from that source. A CHC may be one type of FQHC. Although the CHC concept has been widely approved and accepted, there are still inadequate centers to accommodate the nation’s needs; it is estimated that 43% of medically
underserved areas do not have a CHC site. In addition, the PPACA reforms will add more patients to the CHC list, such as 20 million newly insured patients who will seek care at CHCs. Because of these circumstances, it is paramount to increase the numbers of and funding for CHCs to protect them against becoming overwhelmed. Fortunately, the ACA provides funding to augment the $2.1 billion annual support currently provided. In fact, this is a “good” part of the PPACA, because of the one-time grant of $2 billion to the system as well as $12 billion in total funds authorized under the Health Care and Education Reconciliation Act (formerly HR 4782) that was passed after the PPACA and signed into law by the President. The PPACA also authorized a new Title III grant program of $2.30 million over 5 years to support community-based teaching as well as a Title VII grant program for primary care residencies in the CHCs. With these provisions, CHCs will be prepared to deal with the huge increase in patient volume that will be triggered by the expansion of Medicaid, and they should be able to do it without compromising quality.

12. **Patient-Centered Research.** Also called Comparative Effectiveness Research (CER), this is an area that has particular relevancy to health-care disparities and to racial and ethnic minorities. CER is simply a matter of producing the best data comparing two or more approaches to treatment that will allow doctors to choose the best, safest, and most effective option for their patients. It was initially funded by the federal government (HR 2502, the Comparative Effectiveness Research Act of 2009) via the American Reinvestment and Recovery Act (ARRA), or President Obama’s “Stimulus” package (HR 1), to the extent of $1.1 billion, which created the federal CER Institute. In brief, CER is all about determining what works and what doesn’t work, with evidence-based information being produced and handled with transparency, accountability, and openness, which includes all health-care stakeholders. CER efforts are administered by a Federal Coordinating Council for Comparative Effectiveness Research, which must address a number of roadblocks and problems [21]. The Council was created by the ARRA and is funded with $400 million made available to the Secretary of HHS. In addition, allocations of $300 million each were provided to the National Institutes of Health (NIH) and to the Agency for Healthcare Research and Quality (AHRQ) for CER.

13. **Cultural Competency.** The PPACA authorizes the Secretary of HHS to establish cultural competency training and education for health-care professionals. This mandate is established under Title V (Healthcare Workforce), Section 5307 of the PPACA. It pertains specifically to the health-care workforce regarding training in cultural competency, prevention, public health, and individuals with disabilities. This is a grants program that is well conceived and well intended, but unfortunately, appropriations are to be on an as-needed basis. It is unclear why definite funding was not provided for this important area.

14. **Combating HIV/AIDS: A Moral Imperative.** The most recent epidemiological data available from the Centers for Disease Control and Prevention (CDC) as of 2007 indicate that an estimated 1,106,400 people were infected with this disease at the end of 2006 (prevalence), with an estimated 21% undiagnosed, and that
incidence of newly infected cases was 56,300, with the incidence being seven times higher in African Americans as compared to Caucasians [22]. Forty-seven percent of HIV/AIDS cases are in blacks (Fig. 10.1). HIV/AIDS qualifies as a true epidemic and presents a crisis of control, especially in the black population, where the vast majority of cases are black patients. Although there has been some control seen among white patients, this is not the case in the black community, and there is a widening gap between blacks and whites (Fig. 10.2). Blacks represent about 12% of the population but more than half of the newly diagnosed cases. From 2005 to 2008, there was a 12% increase in HIV/AIDS incidence. The black

Fig. 10.1 AIDS in Blacks/Africans Americans

![AIDS in Blacks/African Americans](image)

Fig. 10.2 Percentages of AIDS cases among adults and adolescents, by race/ethnicity and year of diagnosis 1985–2007 – United States and dependent areas

![Percentages of AIDS cases among adults and adolescents, by race/ethnicity and year of diagnosis 1985–2007 – United States and dependent areas](image)
male incidence rate is six times that for white men, three times the rate for Hispanic men, and twice as high as the rate for black women. Mortality is also higher for blacks than for whites. In 2006, HIV/AIDS was the third leading cause of death for black males and females aged 35–44, and was the fourth leading cause of death for Hispanics in the same age range [23]. These statistics reveal that HIV/AIDS strikes racial and ethnic populations disproportionately, and that, despite the development of excellent treatment regimens in the past few years, the scourge continues and is getting even worser. In fact, the prevalence rates among blacks are higher than those seen in sub-Saharan African countries, where resources are limited [24]. There has been some criticism of the Obama Administration for not doing more to abate this growing epidemic by providing more funding for programs aimed at controlling it. HHS has responded to some degree recently by announcing that $30 million will be devoted to this item under a new strategy, which is the first money to be allocated under the new health reform law. This is in addition to $25 million just allocated to the states by HHS for drug treatment programs, and $19.4 billion in 2010 for domestic programs and research. However, the Secretary indicated that there will be no “large infusion of new resources” and that the money released will be focused on programs, which she hopes within 5 years will reduce the annual rate of new cases by 25%, increase the percentage of newly diagnosed patients getting swift care by 30%, and markedly reduce racial and ethnic disparities in care by increasing knowledge about the virus. This is the basis of the government’s new strategy on combating HIV/AIDS. The $30 million will come from the prevention fund and apparently will be used primarily for education in communities at particular risk. Thus, although the government is rearranging its priorities by concentrating resources in racial and ethnic communities, there are questions about whether the amount of funds is adequate to do the job. Andy Izquierdo of the National Minority AIDS Council said, “HIV/AIDS as an epidemic has fallen off the radar screen. A lot of people don’t see it as an issue anymore, even though it’s hitting some communities of color worse than ever.” That seems to be the gist of the problem.

15. **Wellness, Health Promotion, and Disease Prevention.** Chronic disease is the hallmark of the American medical system problems, and it grows in magnitude with each passing day. Our efforts to repair the system are constantly being dragged down by the steady progression of chronic illnesses. To a large extent, we are the victims of our own technological success in creating medical advances that have allowed people to survive acute medical conditions and to live longer and older than ever before; their increased longevity has positioned them to become victims of diseases that may have led to their demise in previous times. As a result, there are now more than 100 million Americans who suffer from chronic diseases, almost one-third of the US population, and the number is projected to increase to 134 million by 2020, affecting one in six Americans over the age of 65 [25]. Four chronic diseases, cardiovascular disease, cancer, chronic obstructive pulmonary disease, and diabetes are responsible for 75% of all deaths in this country. The economic cost of chronic diseases is staggering: 70% of direct medical costs are attributable to them.
Underserved racial and ethnic minorities are particularly hard hit by the rampage of chronic diseases, and health-care disparities abound; 51% of Hispanics and 46% of blacks over age 55 are affected by chronic disease conditions, compared to 23% of whites [26]. Worse, racial and ethnic minorities are less likely than whites to receive care that might prevent the development chronic diseases; much of the lack of access to preventive care is due to the fact that Hispanics and African Americans are 2.5–3 times less likely than whites to have medical insurance that would enable them to visit a doctor on a regular basis for possible early detection of potentially serious medical conditions. Instead, they are the recipients of crisis treatment in emergency rooms and urgent care centers rather than being the beneficiaries of wellness examinations, which could anticipate and head off serious sequelae of unrecognized medical problems.

With the current scenario in mind, the US Congress passed a series of statutes in the Patient Protection and Affordable Care Act (PPACA) that focus on health promotion, wellness, and control of chronic diseases. These measures are encompassed primarily in Title IV of the law but are also present in other areas of PPACA. Some of the relevant provisions of the Act, as detailed by Assistant Secretary for Health Dr. Howard K. Koh and Secretary of Health and Human Services Kathleen G. Sebelius [27], may be summarized as follows: First, the Act provides improved access to clinical preventive services with no cost sharing by the beneficiary; therefore, cost as a barrier to access to care will be removed. Second, the Act promotes comprehensive workplace wellness programs through the provision of grants to small businesses. Third, the Act attempts to strengthen the community’s role in disease prevention through Community Transformation grants aimed at improving nutrition, increasing physical exercise, promoting smoking cessation, controlling overweight and obesity, and reducing health-care disparities overall. Fourth, the Act establishes a new National Prevention, Health Promotion, and Public Health Council and a new Prevention and Public Health Fund, which receives a yearly appropriation of $500 million beginning in 2010 and continuing at this level of funding until 2015, when it will escalate perpetually to $2 billion per year after that. This makes it clear that health promotion, wellness, and reduction of the burden of chronic diseases has been established as a national priority.

Vital Signs: Concluding Remarks

Performing a critique of this landmark legislation is a task that itself is open to speculation and questions. In the interest of providing information to the public about how the new law will affect disparities, we have conducted a “physical examination” of the Patient Protection and Accountable Care Act and can conclude that it contains several potent ingredients that should help to eliminate health-care disparities. However, although it is a very viable statute that has many admirable characteristics, it needs strengthening in several areas. For example, there are glaring deficiencies with regard to adequate funding of key areas. “Appropriations as
necessary” will not get the job done. It must also be noted that many of the PPACA provisions relating to health care for minorities are grants programs and demonstration projects, which involve funding that does not directly reach racial and ethnic minorities at the grass-roots level, for instance, in the communities where they live. Surveys and information-gathering studies do not pay for needed medication, provide dental care, or pay for groceries, and there is no certainty that their findings will be translated into programs which will benefit the needy. It must also be acknowledged that health-care reform does not deal with some of the root causes of health-care disparities such as poor education, inadequate housing, improper nutrition, and rampant poverty. In addition, there are people who still will not be covered by health insurance at this time; therefore, we do not have truly universal coverage. Perhaps some of the slack will be taken up with the deployment of insurance pools and exchanges. This should have a beneficial impact upon racial and ethnic minorities regarding their ability to achieve coverage at rates which they can afford. The question of the “public option” that was ejected from the bill before passage is still in the background and will almost certainly be reconsidered for inclusion after the fact. The Obama Administration must be credited with constructing a measure which has the potential to revolutionize the health-care system in America for the first time in history, but it is not perfect and is not to be thought of as a panacea that will cure all of the ills and evils of inequity.

The job of implementing the changes that have been made is daunting but is doable and is eminently compelling. In fact, implementation of the law is the most overarching of all of the aspects of health-care reform, and it is far from a sure thing. As stated by health policy analyst Henry J. Aaron of the Brookings Institution [28], although legislation can authorize spending, only Congress can appropriate funds actually to be used. The PPACA contains 64 specific “authorizations” for up to $105.6 billion to be spent, and 51 general authorizations to spend “such sums as are necessary” between 2010 and 2019. In order for any money to flow, Congress (in whatever bipartisan makeup and mood it finds itself) must enact specific appropriation bills, and there is no certainty that Congress will do this. In addition, the Congressional Budget Office estimates that up to $10 billion will be required between 2010 and 2019 to implement the law and funds that have not been appropriated as yet. A huge implementation problem despite its wonderful prospects is the enrollment of millions of new patients into Medicaid, which would provide health coverage for needy citizens but which will also cost the states billions of dollars which they do not have. If they do not receive some relief on this issue, this phase of the new law will be crippled.

As we move forward with resuscitating and reinvigorating the system, we must constantly measure its “pulse” to ensure that its heartbeat does not falter; we must continually assess its “blood pressure” to make certain that the initiatives which have been drafted are being accomplished with the proper intensity; we must make certain that its “respiratory” functions will provide a regular intake of new life-sustaining measures; and we must ensure that its “temperature” is maintained at a level that will allow it to remain of perpetual, vital interest to the public. This is a work that needs to be performed not only by lawmakers and health-care
professionals but also by the public and other stakeholders and gatekeepers who must monitor the system and continue to push for equity in health-care quality and delivery. One very meritorious aspect of PPACA is the inclusion of appropriations for assessing the quality of health-care delivery to the public. Title II contains an appropriation of $60 million to establish “Adult Health Quality Measures of Improving the Quality of Medicaid.” Title III appropriates $75 million to CMS and $20 million to HHS for “Quality Measure Development.”

We are all responsible for the ultimate success of health-care reform and for its improvement. Hopefully, we can unite as a nation to create a more robust health-care system for the American people and for our descendants. Our very survival is at stake.

References

27. Koh HK, Sebelius KG. Promoting prevention through the Affordable Care Act. 10.1056/New Engl J Medp1008560, published online at NEJM.org.
Chapter 11
The Diversity Benefit: How Does Diversity Among Health Professionals Address Public Needs?

Brian D. Smedley and Ilana S. Mittman

Abstract The Patient Protection and Affordable Care Act (PPACA) signed by President Obama on March 23, 2010, is a far-reaching law intended to improve access to and the quality of health care for Americans. Recognizing the importance of the health workforce to the nation’s health, the Act addresses health workforce and health professions education and training issues through provisions to strengthen the primary care workforce, provide tax relief for health professionals with state loan repayments, establish a national Health Care Workforce Commission, and expand the primary healthcare workforce by increasing and improving low-interest student loans. It is estimated that PPACA would afford access to health care for 32 million more currently uninsured new healthcare consumers, many of which ethnic and racial minorities or members of other vulnerable groups.

As the Act is enacted, the nation is experiencing unprecedented demographic change. When the 2010 Census counts are tallied, we may finally grasp the degree of demographic shifts that the nation has undergone in the past decade. Since the 2000 Census, data gleaned from the American Community Survey and demographic models such as the one carried out by the Pew Research Center (Passel and Cohn, U.S. population projections: 2005–2050. Washington, DC: Pew Research Center: Social and Demographic Trends, 2008) predict major population shifts. By 2042, one in two Americans will be an Asian American, Pacific Islander, African American, Hispanic, American Indian, and/or Alaska Native. Since 2000, Hispanics have accounted for over one-half of the population increase in the United States. The number of Asian Americans grew at a larger proportion (9.0%) than any other racial or ethnic group during this same time period. In at least four states (California, Hawaii, Texas, and New Mexico) and the District of Columbia, racial and ethnic “minorities” constitute a majority of the population (U.S. Census Bureau, An older and more diverse nation by midcentury, 2008. http://www.census.gov/Press-Release/www/releases/archives/population/012496.html, Accessed 22 Oct 2008; U.S. Bureau
of Census, Hispanic Americans by the number, 2008. http://www.infoplease.com/spot/hhmensus1.html, Accessed 9 Jan 2010). Moreover, because of reproductive and immigration patterns, minorities are disproportionately represented among the younger population. Today, minorities account for 43% of Americans under 20 years of age, and it is projected that over the next two decades minority students will account for almost 40% of the total college population (Roberts, Minorities often a majority of the population under 20, The New York Times, 2008).

Despite the rapid growth of racial and ethnic minority groups in the United States, many are dramatically underrepresented among the nation’s health professionals. The percentage of African American, Hispanic, American Indian, Alaska Native, or Pacific Islander1 in the health professions has grown only modestly at best over the past 30 years. Yet relative to the growth of the minority population in the United States, this rate of increase still leaves the proportion of minority health professionals outstripped by several fold. Hispanics, for example, comprise over 15% of the U.S. population, but only 2% of the registered nurse population, 4.6% of psychologists, and 5.0% of physicians. Similarly, one in eight individuals in the United States is African American, yet less than 1 in 20 dentists or physicians are African American. Minorities are severely underrepresented in academia. During the 2007–2008 academic year, URMs (underrepresented minorities) made up only 7.4% of U.S. medical school faculty, fewer than 7% of undergraduate faculty, less than 10% of baccalaureate and graduate nursing school faculty, 12% of clinical psychology faculty, and 8.6% of dental school faculty (Moreno et al., Using multiple lenses: an examination of the economic and racial/ethnic diversity of college students. In: Univ AoACa, editor. California: The James Irvine Foundation, Claremont Graduate University, 2006; Institute of Medicine, In the nation’s compelling interest: ensuring diversity in the health-care workforce. Washington, DC: Institute of Medicine, 2004; Hall, Clin Psychol Sci Pract 13:258–261, 2006).

**Keywords** Racial and ethnic diversity • Ethnic and racial concordance • Communication • Racial stereotypes • Underrepresented minorities • “Distributive justice” • Health workforce shortage • Educational pipeline • Health professions educational institutions (HPEIs).

In 2004, two major reports on racial and ethnic diversity among healthcare professionals – one released by the Institute of Medicine (IOM) [1] and another released by a commission chaired by the former U.S. Secretary of Health and Human Services, Dr. Louis Sullivan (The Sullivan Commission [2]) – sounded an urgent call for new strategies and greater effort to increase diversity among health professionals. This urgency, these reports argued, is driven by the dramatic change in the demographic composition of the United States, as well as by persistent concerns about the quality of health care for racial and ethnic minority populations.

---

1Groups that are considered among those underrepresented in medicine (URM).
As the Sullivan Commission report starkly noted, “[t]he fact that the nation’s health professions have not kept pace with changing demographics may be an even greater cause of disparities in health access and outcomes than the persistent lack of health insurance for tens of millions of Americans (Sullivan Commission)” [2].

Most recently, the Association of Academic Health Centers (AAHC) and the Josiah Macy Foundation (JMF) issued reports illustrating the critical state of the nation’s health workforce and its inability to meet the population’s needs in the twenty-first century [3, 4]. The reports highlight the critical shortage of health professionals, which would be much execrated by the recent passage of the Patient Protection and Affordable Care Act (PPACA). They also note the growing cultural and linguistic diversity of U.S. healthcare consumers.

How should the health professions respond to the current demographic shifts and the looming overhaul of the healthcare system? Does diversity among health professionals make a difference in addressing the healthcare needs of communities of color, many of which are disproportionately hit by high rates of death and disability due to diseases such as diabetes, HIV/AIDS, cardiovascular diseases, and other chronic and infectious illnesses? Does diversity among health professionals address the nation’s healthcare system as a whole? And if so, how can greater diversity among health professionals be achieved? This paper will briefly summarize research relevant to these questions.

**Does Diversity Make a Difference?**

This question historically has been at the forefront of a national debate starting with the civil rights movement and the resulting attempts at desegregation of public schools, the debate over race conscious admissions, and more recently the role of diversity in the mission and accreditation standards of U.S. medical schools [5].

Traditionally diversity has been framed in its role of eliminating health disparities. Researchers, policymakers, healthcare administrators, and public health officials are increasingly focused on reducing and eliminating racial and ethnic disparities in health care. Often, their discussions focus the role of diversity among health professionals in closing the healthcare gap. To what extent can greater diversity be expected to help close this gap?

A comprehensive review of the literature illustrates that there is a fairly substantive body of research examining and documenting the benefits of ethnic and racial diversity in the healthcare workforce [6–18]. LaVeist et al. illustrated in their 2003 study that this literature can be organized into five main categories: (1) utilization and outcomes of health care; (2) patient satisfaction and trust; (3) patient choice of providers; (4) physician choice of practice location; and (5) the overall training of healthcare providers [6].

We will start by asking the following question: When racial and ethnic minority patients and providers are matched on race and ethnicity, are patient outcomes better than when these dyads are not matched?
Racial Concordance in the Medical Encounter

Ethnic and racial concordance in the medical encounter has been touted as a chief argument for diversity. However, studies in the past two decades have generated equivocal conclusions and the race concordance data has been strongly scrutinized by some [12, 19].

We will start this review by presenting data supportive of ethnic and racial concordance in the medical encounter and follow it up with review of the criticism to these data.

Diversity and Minority Patient Choice and Satisfaction

That racial and ethnic minority patients prefer to be seen by a physician from a similar race has been consistently documented in the literature. A 2002 study found that African American and Hispanic patients were likely to choose same-race physicians when given a choice [14]. Similarly, a study published a decade later found that compared to patients who were assigned a physician, minority patients who chose their physician were more likely to have a same-race physician [16].

Racial and ethnic minority patients are generally more satisfied with the care that they receive from minority physicians. Saha, Komaromy, Koepsell, and Bindman [13], for example, found that African American patients who receive care from physicians of the same race were more likely than African Americans with nonminority clinicians to rate their physicians as excellent in providing health care, in treating them with respect, in explaining their medical problems, in listening to their concerns, and in being accessible. Hispanic patients in this study with an ethnically concordant provider were also more likely to be satisfied with their overall health care, although Hispanic patients in this study who received care from Hispanic physicians did not rate their doctors as significantly better than Hispanic patients with non-Hispanic healthcare clinicians.

LaVeist and Nuru-Jeter [10] examined the relationship between patient-provider racial concordance and satisfaction with care among a sample of white, African American, and Hispanic patients. Among all racial and ethnic groups, patients who reported having at least some choice in selecting a physician were more likely to choose a race- or ethnic-concordant physician. African Americans with higher incomes and Hispanic patients who did not speak English as a primary language were also more likely to have a race-concordant physician. After adjusting for patients’ age, sex, marital status, income, health insurance status, and whether the respondent reporting having a choice in physician, African American patients in race-concordant relationships were found to report higher satisfaction than those African Americans in race-discordant relationships. Furthermore, Hispanic patients in ethnic-concordant relationships reported greater satisfaction than patients from other racial and ethnic groups in similarly concordant relationships. Similarly, Cooper-Patrick and her colleagues [20] also found that minority patients’ ratings of
The quality of their health care were generally higher in racially and ethnically concordant than racially and ethnically discordant settings. Overall, African American patients rated their visits as significantly less participatory than whites, after adjusting for patient age, gender, education, marital status, health status, and length of the patient–physician relationship. Patients in race- and ethnic-concordant relationships, however, rated their visits as significantly more participatory than patients in race- and ethnic-discordant relationships.

**Ethnicity and Language Concordance**

Research indicates that healthcare processes and the quality of communication are influenced by cultural and linguistic barriers that minority clinicians are often able to address. Perez-Stable, Napoles-Springer, and Miramontes [21], for example, assessed the effects of ethnicity and language concordance between patients and their physicians on health outcomes, use of health services, and clinical outcomes among a sample of Spanish-speaking and non-Spanish-speaking Hispanic and non-Hispanic patients with hypertension or diabetes. Of the 74 Spanish-speaking Latinos, 60% were treated by clinicians who spoke Spanish, while 40% were treated by non-Spanish-speaking clinicians. After controlling for patient age, gender, education, number of medical problems, and number of prescribed medications, the authors found that having a language-concordant physician was associated with better patient self-reported physical functioning, psychological well-being, health perceptions, and lower pain. Hispanic patients also reported better satisfaction and adherence to treatment plans when their physician not only spoke Spanish, but also shared the same cultural background [21].

**Diversity and Quality of Healthcare Process and Communication for Minority Patients**

A substantial body of literature supports the notion that racial and ethnic concordance does seem to facilitate effective communication between patients and providers. Overall, white, black, Asian, and Hispanic patients in racially concordant settings are more likely to use needed services, and are less likely to postpone seeking care [11]. Moreover, patients in a concordant health encounter pose more questions, have an increased trust of providers, have a higher level of agreement about recommended life-style changes, and a higher intention to follow up with treatment regimens [15, 22, 23]. Cooper et al. showed that race concordance was associated with longer visits and were characterized by a higher level of decision sharing between provider and patient [7].

In addition, research indicates that minority physicians display better process-of-care behaviors with minority patients than nonminority clinicians. Cooper-Patrick
and colleagues [20], in a study of over 1,800 adults enrolled in managed care plans, found that patients in race-concordant relationships rated their physicians’ participatory decision-making styles – that is, their tendency to involve the patient in treatment decisions – as significantly more participatory than patients in race-discordant relationships. In a more recent study, Cooper et al. [7] audio-taped actual clinical encounters of African American and white patients in race-concordant and race-discordant relationships to assess whether communication behaviors explain differences in patient ratings of satisfaction and participatory decision-making. On average, race-concordant visits were longer, and patients reported higher levels of positive affect in these visits than did patients in non-concordant dyads. Patient in race-concordant relationships also reported higher levels of satisfaction with care, and rated their physicians as more participatory than patients in non-concordant dyads. Measures of physicians’ communication styles, however, did not explain differences in patients’ ratings of participatory decision-making or satisfaction, suggesting that other cultural factors in the race-concordant arrangements may help to engender trust and comfort between the patient and physician.

A recent study examining race and the effectiveness of pain treatment in the Emergency Department concluded that 61% of patients treated by nonwhite physicians achieved important reductions in pain intensity as compared to 47% of those treated by white physicians, with use of a similar dosage of pain medication. The study attributed these differences to better patient–physician communications in the concordant relationship [24].

These studies suggest that cross-cultural education and communications strategies may help to improve healthcare process measures and communication among racial and ethnic minority patients. Should training programs improve physicians’ participatory decision-making, communication, and thereby increase patient satisfaction, they may affect patients’ healthcare outcomes, in that patient satisfaction is associated with greater patient compliance with treatment regimens, participation in treatment decisions, and use of preventive care services [25].

It is evident that market forces recognize the importance of race concordance in the medical encounter. Brown et al. stipulated that supply and demand in the physician labor market drive earning potential. They investigated whether demand for same-race/ethnicity physicians in particular areas will result in increased premiums for minority physicians. The authors established that per-hour earnings of Hispanic and Asian physicians are sensitive to the degree of area-level racial/ethnic concordance. They noted an increase in the per-hour earning for Hispanic and Asian physicians that is proportionate to the increase of Hispanic and Asian patients in their service area [6] estimated as 1% higher earnings for a 1% increase in minority populations. Traylor et al. (2010) studied predictors of race concordance in healthcare interactions and found that meeting race concordance preference is at least partly associated with the availability of same-race physicians [16]. The authors also found that language concordance match is not dependent on the availability of same-race/ethnicity providers [16]. Lastly, Brown et al. found that black and Hispanic physicians are more likely to remain in an area as the level of representation of physicians from their group worsens – areas that tend to have a higher density of minorities [26].
The Diversity Benefit: How Does Diversity Among Health Professionals

Criticism of the Racial and Ethnic Concordance in Health

Those who criticize the race concordance argument maintain that the concept of race concordance is oversimplified and lacks consideration of the vast heterogeneity that exists within “racial” groups. They also note that the existence of multi- and bi-racial groups and foreign-born minorities illuminate the complex notion of race and therefore race “resemblance,” as race in itself is a social rather than biological construct. Shaw points out the fallacy that ethnic and racial identity automatically confer “cultural expertise,” and other studies illuminate the importance of patient-centered care approaches and culturally responsive care, which they maintain are concepts that are acquired through training and immersion experience.

Meghani et al. and Shaw et al. argue that calling for race concordance in the medical encounter is a dangerous move towards segregated medicine, and stands to perpetuate the very kind of stereotypes that most health professions educators seek to eliminate. Moreover, they maintain that the belief that solving health disparities rests simply in the hands of minority providers insinuates that the problem resides in these quarters.

The most significant criticism of the race concordance argument is that the literature fails to consistently show clear benefits in patient outcomes [12, 15]. Meghani et al. reviewed 27 U.S. studies with a clear research question related to race concordance and its impact on minority health issues. The authors concluded that benefits of race concordance were illustrated in only nine studies with eight showing no benefits and the remaining showing mixed findings. The authors concluded that there is “inconclusive data to support that race concordance is beneficial for minorities.”

One study, by Chen and colleagues [27] found no differences in rates of cardiac catheterization between black and white Medicare patients who had suffered an acute myocardial infarction. Consistent with other studies, blacks were less likely than whites to receive catheterization within 60 days of hospitalization, regardless of whether the patients’ physicians were black or white [28]. In another study, Konrad et al. (2005) did not find racial concordance to be a significant factor in the management of hypertension [29]. Street et al. (2008) note that while patient–physician race concordance was linked to a sense of shared values and personal beliefs, which in turn increased patients’ trust, higher satisfaction with care, and stronger desire to adhere to treatment regimen, concordance did not seem to be related to patient outcomes.

Meghani et al. suggest that race concordance is a heterogeneous construct embodying complex patient, provider, and system variables. They maintain that there could be a multitude of factors that together with racial concordance improve health outcomes, including the patient’s age, education, provider’s cultural sensitivity and responsiveness, and the degree of patient-centered communication. They suggest that these factors may act to either mediate or moderate the outcomes of race concordance.

In summary, racial and ethnic concordance in the healthcare encounter tends to result in better access to care, higher utilization of services, higher patient
satisfaction and trust, higher level of joint decision-making, and better compliance with treatment regimen. However, we must be careful not to over-simplify the case of ethnic and racial concordance in health care. Many nonminority health professionals are supremely skilled and sensitive clinicians who provide excellent care—and achieve excellent outcomes—for the minority patients that they serve. Similarly, many health professionals of color provide outstanding care to nonminority patients. And of course, in some cases health professionals provide less-than-optimal care to patients, even for patients who share their own background. The factors that make a patient and healthcare provider “click” as a team are varied, with some outcomes importantly based on personality, shared trust, communication styles, and the like. In many cases these factors are importantly related to race, culture, and ethnicity, while in other instances they are less so.

Given the multiplicity of forces at play, the mere presence of ethnic and racial concordance in the medical encounter is in itself insufficient to improve patient outcomes. System level factors related to healthcare institutions and the built environment, as well as individual-level factors related to patients and providers are important determinants of healthcare outcomes. Racial and ethnic concordance seems to be vital in the medical encounter especially when it is coupled with patient-centered care and cultural awareness. However, its impact on health status will not be fully realized until we overcome the inherent individual, institutional, and structural inequalities still present in our society.

Racial Stereotypes and Bias in Medical Care

While the literature is equivocal regarding the role of patient and provider race concordance in the medical encounter, patient outcomes, and the mechanisms by which it operates, the presence of biases in the healthcare delivery system is indisputable. A growing body of literature demonstrates that clinical decisions regarding patient management—in particular those related to invasive procedures—are influenced by patient race and ethnicity [24, 30–37]. The Institute of Medicine panel concluded that healthcare disparities persist even when controlling for access-related issues and found evidence that “stereotypes, biases and uncertainty on the part of healthcare providers can all contribute to unequal treatment” [28]. Dovidio et al. in their review article about bias and health disparities concluded that there is “sufficient data … to conclude that subtle racism is a significant contributor to health care disparities” [31]. The authors noted that treatment disparities seem to be highest when physicians engage in “high discretion” procedures, namely, recommending a test or making a referral for a procedure or prescribing drug therapy. Examples for significant disparities in clinical decision-making related to racial minorities are vast, beginning notably with Schulman’s 1999 study of differences in cardiac procedure by patient race [34]. In this study, physicians partaking in simulated patient encounters were less likely to refer blacks presenting with chest pain for follow-up procedures than they were whites with identical presentation and
The Diversity Benefit: How Does Diversity Among Health Professionals

Green et al. documented that implicit bias scores (IAT) predicted differential treatment patterns for black and white patients regarding thrombolysis for suspected myocardial infarction. IAT scores were negatively correlated with thrombolysis recommendations for black patients and positively correlated with recommending the procedure to white patients. Study participants disproportionately associated negative attributes to blacks on the IAT measure, while mostly not admitting explicitly to any racial biases [32]. Avenanti et al. (2010), used transcranial magnetic stimulation to measure sensorimotor emphatic brain responses. They found that group-specific lack of emphatic reactivity was higher among subjects exhibiting a stronger implicit racial bias [38]. Ferguson et al. noted that ethnic and racial minorities are less likely to engender empathy from physicians, receive sufficient information, and receive encouragement to participate in their medical decision-making [39].

Disparities in treatment recommendations are well documented with respect to implantable cardioverter-defibrillators (ICDs), an instrument that can avert untimely death. Hernandez et al. noted that rates of ICD use were lower among eligible women and black patients than among white men [33]. Other disparities in treatment recommendations negatively affecting minorities have been noted with respect to pain management and dissemination of analgesics [24], decisions to prescribe opioids for chronic low back pain, recommendations for coronary artery bypass graft (CABG) surgery [36], testing for osteoporosis, and active treatment for prostate cancer [31]. Physician stereotypes assuming drug abuse, reduced intelligence and education, lack of compliance, and “challenging” behaviors were associated with discrepant physicians’ treatment recommendations [31]. Interestingly, some of these perceptions were found even after controlling for patients’ age, gender, socioeconomic status, and disease severity. Rosenheck [40] found that, compared to black physicians, white physicians treating black veterans suffering from post-traumatic stress disorder rated their patients as having lower levels of participation in the treatment plan and showing lower levels of clinical improvement in 1 of 15 health outcomes.

Racial and Ethnic Diversity Among Health Professionals and Access to Health Care for Minority Patients

The disproportionate tendency of minority physicians to practice in underserved areas is used frequently in arguments for diversity, as a potential strategy to remedy the woeful shortage of physicians serving underserved communities. Early studies show that racial and ethnic minority healthcare professionals were significantly more likely than their white peers to serve minority and medically underserved communities, thereby helping to improve problems of limited minority access to care. This was true across a range of health professions, although the bulk of this research has focused on the practice patterns of physicians. International Medical Graduates (IMGs) who make up a quarter of physicians in the United States are also disproportionately...
represented among physicians serving in shortage areas and engaging in primary care. IMGs are mostly Asian from India and Pakistan, whites, and Hispanics, with other major groups from the Philippines, Middle Eastern, and African nations [39].

Minority neighborhoods are more likely than nonminority communities to face shortages of physicians, yet physicians of color are disproportionately more likely than their peers to serve in these communities. Moy and Bartman [41], for example, in a nationwide survey of households, found that minority patients were more than four times more likely than white patients to receive health care from nonwhite physicians. Medically indigent patients were also between 1.4 and 2.6 times more likely to receive care from minority physicians than were more affluent patients. These findings held true even after controlling for physician gender, specialization, workplace, and geographic location. Cantor et al. [42] found that minority and women physicians, as well as those from lower socioeconomic backgrounds, were disproportionately more likely to serve minority, low-income, and Medicaid populations, even after adjustment for physician specialty, practice setting, and practice location. Komaromy et al. [43] in a survey of over 1,000 physicians in California found that African American and Hispanic physicians were five and two times more likely, respectively, than their white peers to practice in communities with high proportions of African American and Hispanic residents. Over half of the patients seen by African American and Hispanic physicians, on average, were members of these clinicians’ racial or ethnic group. Hispanic and black physicians tended to practice in areas with fewer primary care physicians per capita, but even after adjustment for the proportion of minority residents in the communities studied, African American and Hispanic physicians were more likely to care for African American and Hispanic patients, respectively.

Racial and ethnic minority dentists were also shown to be more likely than their white peers to practice in racial and ethnic minority communities. Solomon, Williams, and Sinkford [44], in a study of African American and white dentists in Texas, found that a larger percentage of African American dentists practiced in communities with a high residential African American population than white dentists. African American dentists were also found to be more likely to practice in communities characterized by lower levels of education and income than white dentists. Similarly, Mertz and Grumbach [45], in an assessment of the availability of dental services in California, found that approximately one in five California communities – disproportionately minority, low-income, and rural – have a shortage of dentists, and that minority dentists were more likely to practice in minority communities.

The literature cited above was published between 1995 and 2001, therefore reflecting on practice trends from the early to mid-1990s. Different factors seem to influence residency decisions in different time periods. For example, the number of U.S. medical school graduate students matching in the various areas of primary care residency has declined by 50% between 1997 and 2009 [46]. It is therefore of interest given current economic pressures whether there have been changes in trends regarding practice location and specialty type for underrepresented minority (URM) physicians, who have been shown to have a larger amount of total debt compared to non-URMs, as discussed below [47].
Wayne et al. recently evaluated attitudes towards underserved populations among 826 medical students in the University of New Mexico School of Medicine, using logistic regression to evaluate the effect of attitudes on actual selection of a primary care residency. Importantly, the study compared two groups defined by year of entry into medical school to reflect 1992–1999 and 2000–2005 [46]. Although the study found that students’ attitudes regarding responsibility to the welfare of vulnerable communities remained high, there was a statistically significant association between positive attitudes for service and primary care residency only in the earlier cohort. The study found that in the early cohort, an indication of professional responsibility towards underserved populations was highly correlated with an entry into primary care residency. For the later cohort, though, these attitudes were no longer associated with choosing primary care. Although a higher attitude score on the Professional Responsibility subscale was significantly associated with a primary care residency match in both cohorts, such a match was not associated with ethnicity.

Jaffe et al. conducted a longitudinal study with a nationally representative sample of U.S. graduates attending LCME-accredited medical schools assessing trends in specialty choice, sampling a total of 102,673 individuals [48]. The authors found that female graduates and those who planned to practice in underserved communities espoused more altruistic beliefs, had a high sense of social responsibility, and were likely to choose a primary care specialty. Graduates with higher debt were more likely to choose obstetrics and gynecology and less likely to choose internal medicine or pediatric specialties. In this study, URM graduates were less likely than whites to choose general internal medicine, general pediatrics, or family medicine, but were more likely to choose obstetrics-gynecology. The authors conclude that “… efforts to increase levels of racial/ethnic diversity among U.S. graduates of LCME-accredited medical schools will not, alone, necessarily result in greater numbers of generalist-primary care physicians ….” The authors did not report whether race and ethnicity predicted the level of social responsibility scores.

These finding are interesting as the most recent results of the Association of American Medical College (AAMC) Graduation Questionnaire show that Black, Hispanic, and Native American graduates are far more likely to indicate plans to practice in an underserved area as compared to whites and Asians (45.3%, 31.6%, 50%, 19.1%, and 15.3%, respectively). In addition, Saha et al. in their study sampling 64% of all medical school graduating students in the years 2003–2004 concluded that URM students were “substantially more likely than white or non-white, non-URM students to plan to serve the underserved (48.7% vs. 18.8% vs. 16.2%, respectively, p<0.001) [49]. Moreover, Brown et al. conducted a study assessing whether the variation of representation of minority physicians across California affects the location decisions of minority physicians [26]. The study found that new physicians just entering the labor workforce were less likely to choose a location based on the level of minority physicians in the area. However, Hispanic and Black physicians in practice longer tended to not leave an area in which physicians from their ethnic or racial group are underrepresented. They were also likely to move to an area with similar minority physician representation.
Mullan et al. studied secondary data disposition and practice specialties of more 60,000 physicians in active care who have graduated from medical school between 1999 and 2001. The authors found that graduates from HBCUs (historically black colleges and universities) are disproportionally more likely to practice in primary care [5]. These data may suggest a recent shift in specialty choice pertaining to ethnic and racial minorities, with new graduates shying away from primary care as compared to more established minority physicians. The new trends related to primary care practice choice seem to correlate with a changing economy.

The period since 1997 is marked by escalating cost of medical education rising at more than twice the cost of inflation in recent years [50]. Moreover, median student debt burden has increased by more than 50% from 1998 to 2008 to $140,000 with a quarter of graduates owing more than $200,000 in educational loans. Adding to this crisis were substantial cuts to Title VII programs in 2006 severely impacting graduate medical education.

The financial challenges facing medical students are more pronounced for underrepresented minorities. Hispanic and black students have a higher percentage of undergraduate debt as compared to white and Asian students (43.7% and 59.1% as compared to 36.2% and 31.6%, respectively), and a higher percentage of them depend on scholarships as they are less likely to receive family support [51]. This, as discussed earlier, leads to an overall total debt of URM medical school graduates that is higher than that of other students [47].

We can surmise that the forces leading to the decline in the choice of primary care specialties since 1997 impacted minority students at least to the same degree as it had all other students. One assumption is that attitudes pervasive among minority medical school graduates showing a high commitment to serving the underserved have not changed, but that changing economic forces lead to the changing trends of entry into primary care.

Is Diversity Only Beneficial for Minorities’ Sake?

This paper will argue that the more important questions to ask regarding diversity relate to how diversity affects broader health system efforts toward achieving culturally competent care, how it impacts the capacity and quality of the entire health system, and how it contributes to the depth and breadth of research. Lee and Franks, in their comprehensive review of diversity in medical education in a 40-year period, stated that “The lack of a diverse physician workforce engaged in active patient care – both primary and specialty care – all aspects of research, and teaching bears directly on people’s access to care, quality of care, and outcomes of care as well as on the future benefits of research to the health of diverse populations, and the education and training of future generations of physicians in the nation and in California” [39]. Viewed in this context, greater diversity among health professionals confers broad benefits to all but clearly entails distinct benefits for minority and disadvantaged communities.
The diversity movement framed its arguments traditionally on the benefits that diversity confers to racial and ethnic minority communities through individual interactions, by assuming a utilitarian role in specialty and service location choices and by contributing to minority health research. With the exception of diversity increasing the cultural sensitivity and responsiveness of all health trainees and providers, the benefits of diversity to all of society are rarely illuminated.

**Distributive Justice**

Almost entirely left out of the diversity discussion is the fact that diversity is important for all. As Shaw frames it, diversity “is good for its own sake.” The author coins the term “distributive justice” and talks about inherent institutional barriers hindering minorities’ access to the health professions [19]. The author maintains that diversity efforts justifiably should be undertaken to address the exclusion of minorities from the health professions as a result of unequal opportunity and practices of discrimination. Access to health careers is a desirable commodity as health professions are rewarding, prestigious, and generally high paying in a stable occupational discipline. In 2006, URMs made up 28% of the population at large, but accounted for only 15% of medical students and 8% of practicing physicians [52]. From the perspective of distributive justice, this should be disquieting.

**Who Will Care?**

Diversity in the health professions is paramount for the capacity of the nation’s healthcare system. Simply put, if we do not attempt to remedy the barriers limiting minorities’ access to health careers, we will fail to generate enough healthcare providers to provide sufficient care for Americans. As the “Baby Boom” generation ages (the leading edge of “Baby Boomers” reaches 65 in 2010), the number of Americans 65 and older is expected to soar to 88.5 million by 2050, accelerating the increase in demand for and utilization of health services [3, 53–55]. Among this aging population are healthcare professionals who will retire or reduce their work hours, contributing to a critical health workforce shortage. The PricewaterhouseCoopers Health Research Institute predicts a shortage of 24,000 physicians by 2020 [56] leading to a call by the Association of American Medical Colleges for a 30% increase in medical school enrollment and an expansion of Graduate Medical Education positions by the year 2015 [55, 57]. A severe nursing shortage has been reported by the vast majority of U.S. hospitals and it is projected that by 2020 the shortage of nurses will be between 400,000 and one million [56]. The Association of Schools of Public Health estimates that by 2020, 250,000 more public health workers will be needed in the nation [58]. Lastly, a shortfall of more than 150,000 pharmacists is projected by 2020 [59, 60].
The current shortage of healthcare providers, compounded by longer longevity, the increase in development and use of medical procedures, the upcoming retirement of baby boomers, and the anticipated increase in the number of Americans to access health care stand to devastate the capacity of the U.S. healthcare system. Considering the current population trends among the school age population, it is clear that failure to recruit and graduate minorities from health professions schools will severely compromise our ability to provide needed health care to the American public.

**Diversity Among Health Professionals: Benefits for Research and Health Policy**

Another universal benefit for diversity is its benefits to overall intellectual output of society at large. Page articulates a model in which diversity improves overall performance of teams and institutions [61]. Page’s model shows that identity diversity leads to cognitive diversity, which improves the problem-solving capacity and creativity of teams, from corporate America to the workforce and the research environment. Differences in life experiences, perceptions, and practices shape the thinking of an individual, and it is these differences, Page argues, that “provide the seeds of innovation, progress and understanding.” Researchers come equipped with their vision, shaped by their life experiences, upbringing, cultural beliefs, and the communities they call their own. Cohen et al. make the case that investigators in medical research envision research questions based on their life experiences and therefore can find solutions to currently unsolved health problems [18]. Diversifying the healthcare system stands to yield more productive healthcare providers, hospital administrators, health policy experts, and clinical, social, and basic scientists.

Greater participation of minority scientists in health research can also improve the scientific understanding of the causes and consequences of racial and ethnic health disparities, as they bring a wide range of cultural perspectives and experiences to research teams. This increases the likelihood that sociocultural issues influencing health outcomes will be addressed in research design and study questions [62].

Minority clinical researchers may also prove valuable in efforts to increase the enrollment of minority patients in clinical trials, whose participation in clinical research as human subjects is typically lower than among nonminority populations, even though some minorities experience higher rates of chronic and infectious diseases than whites. Low participation rates among minorities may be traced to a variety of historic and cultural factors (e.g., the legacy of abuse and mistreatment of minorities at the hands of the scientific and medical establishment, as exemplified in the infamous Tuskegee syphilis experiment). Yet more minorities are needed to participate in clinical research to better understand how to improve the health of these populations and close the health gap. As a result of their generally broader cross-cultural experiences, minority investigators are often able to address minority patient mistrust and improve communication between the scientific and lay communities [62].
Give a Voice to the Voiceless

Greater racial and ethnic diversity in health professions is also needed to enhance the representation of minority groups among the leadership in the health policy and health research enterprises. Racial and ethnic minority health professionals are often able to bring diverse and underrepresented perspectives to both health policy and health systems leadership, which may lead to organizational and programmatic changes that can improve the accessibility and cultural competence of health systems. Diversity in health systems leadership should not, however, be assumed (in and of itself) to lead to more culturally competent health systems; such diversity merely increases the likelihood that broader systems change will include and be guided by diverse perspectives [1].

Diversity and Quality of Training for All Health Professionals

As noted above, racial and ethnic minority patients, when given a choice, tend to choose healthcare professionals from similar backgrounds. But because the proportion of racial and ethnic minority healthcare clinicians is small relative to the proportion of racial and ethnic minorities in the general population, it is important that all healthcare professionals must develop the skills and competencies to serve diverse patient populations. Evidence suggests that diversity in health professions training settings may assist in efforts to improve the cross-cultural training and cultural competencies of all trainees. Whitla et al. [63], for example, in a survey of medical school graduates’ attitudes regarding diversity in medical education, found that students reported experiencing greater levels of diversity in medical school than in their prior educational experiences, as the percentage of students reporting contact with other groups increased from 50% prior to college to 85% in medical school. Overwhelmingly, these students viewed diversity among their medical student peers as a positive; 86% thought that classroom diversity enhanced discussion, and was more likely to foster serious discussions of alternate viewpoints. Over three-quarters of the students surveyed found that diversity helped them to rethink their viewpoints when racial and ethnic conflicts occurred, and the same percentage felt that diversity provided them with a greater understanding of medical conditions and treatments. The pattern of responses did not differ by respondents’ racial or ethnic group [63]. Saha et al. measured students’ attitudes in association with URM proportion in the student body. White students within the cohorts with the highest classroom diversity were more likely to rate themselves as better prepared to care for minority populations than those in the lowest diversity cohorts. In addition, students in the highest URM cohort were also more likely to have strong attitudes endorsing equitable access to care [49].

Students from diverse backgrounds interacting with each other in training settings may therefore help to challenge stereotypes and broaden students’ perspectives regarding racial, ethnic, and cultural differences.
In addition, there is growing evidence – primarily from studies of college students’ undergraduate experiences – that student diversity is associated with greater gains in students’ learning and community involvement [64, 65]. Diversity among students in training settings, these studies find, may enrich classroom discussions and spur changes in curricula to address students’ cross-cultural education needs. Gurin and colleagues, for example, utilized data from longitudinal surveys of undergraduate students to assess whether students’ diversity experiences as undergraduates were related to their “learning outcomes” (defined as the use of active thinking, intellectual engagement and motivation, and academic skills) and “democracy outcomes” (i.e., citizenship engagement, belief in the compatibility of group differences and democracy, the ability to take the perspective of others, and cultural awareness and engagement). The investigators found that diversity experiences were significantly related to learning outcomes after graduation, even after adjusting for students’ academic and socioeconomic background (i.e., gender, SAT scores, high school GPA, parents’ educational level, racial composition of high school, and neighborhood growing up), institutional characteristics, and initial (pre-test) scores on learning outcome measures. Informal interactions across racial and ethnic lines were especially significant for all racial/ethnic groups in predicting intellectual engagement and academic skills. Similarly, diversity experiences were found to significantly predict students’ democracy outcomes, even after adjustment for students’ prior academic and socioeconomic background and pre-college racial exposure, as well as measures of democracy orientation upon initial assessment. For all racial groups, informal interactions across racial and ethnic lines were associated with higher levels of citizenship engagement and awareness and appreciation of racial and cultural diversity [65].

In summary, keeping the diversity argument focused on its benefits to minorities only perpetuates stereotypes, undermines the talent and potential of minority health professionals, and limits their freedom to use their passion and talent in choosing their calling. This argument of “minorities for minorities” marginalizes the role of minority health professionals in society and echoes Abraham Flexner’s own words in the 1910 report on medical education. In that report Flexner states that “the negro shall serve the negro … in the villages and plantations, and shall engage in sanitation and hygiene rather than surgery” [66, 67]. Finally, holding minorities responsible for solving health disparities absolves the rest of society from shared responsibility and accountability – which is vital in a thriving society.

Strategies to Increase Diversity in the Health Professions

Over the past 40 years, federal and state governments, many leading health philanthropies, health professionals, health professions education societies, higher education institutions, and health professions schools have developed initiatives to increase diversity among health professionals. Regretfully, the panoply of these diversity initiatives fell short of remedying the “plateaued” numbers of underrepresented
minorities entering the U.S. health professions. In 2003, two overarching national initiatives were convened to craft a roadmap for the diversification of the nation’s health workforce: the Sullivan Commission on Diversity in the Healthcare Workforce, and the IOM Committee on Institutional and Policy-Level Strategies for Increasing the Diversity of the U.S. Healthcare Workforce. These two national panels deliberated for a period of 18 months each and together engaged 31 national experts representing a host of disciplines including health, education, economy, and law. In their “fact finding” mission, these two groups combed the country and the literature, listened to public testimonies, and held town hall meetings, workshops, and field hearings. Collectively they generated 62 policy recommendations for system change in their respective reports: In the Nation’s Compelling Interest: Ensuring Diversity in the Health Workforce, and Missing Persons: Minorities in the Health Professions, both issued in 2004 [1, 68].

Recommendations of the Sullivan Commission report focus on the following areas: (1) focusing on the historical roots of disparities; (2) the pipeline of healthcare professions; (3) financing education in the health professions; and (4) accountability of all stakeholders especially leadership at the highest level. The IOM report’s recommendations include: (1) reducing financial barriers; (2) encouraging diversity efforts through accreditation; (3) improving the institutional climate for diversity; (4) applying community benefit to diversity efforts; and (5) identifying mechanisms for support for diversity efforts.

In order to insure that this expansive and laborious process would not “rest on a shelf” but would instead generate national momentum for action, the Sullivan Alliance to Transform America’s Health Professions was established in 2005 to serve as a catalyst for the implementation of the recommendations from the IOM committee and the Sullivan Commission [67]. The Alliance focuses its resources on increasing the racial and ethnic diversity of students in medicine, nursing, dentistry, psychology, public health, and the mental health professions with an understanding that gains and insights within these disciplines will positively impact all health professions’ disciplines.

The Association of American Medical Colleges’ (AAMC) Project 3,000 × 2,000, for example, sought to achieve the goal of admitting and graduating 3,000 new underrepresented minority medical students by the year 2000. AAMC was able to achieve significant gains in the early 1990s in the number of underrepresented minority students who were admitted to medical schools, and by the mid-1990s appeared to be on course to achieve the 3,000 × 2,000 goal. But by 1996 and 1997, several state referenda (i.e., Initiative 200 in Washington State and Proposition 209 in California) and federal court rulings (e.g., the Fifth Circuit Court’s decision in the Hopwood case) severely limited the ability of public universities and health professions educational institutions (HPEIs) to consider applicants’ race or ethnicity in admissions decisions, resulting in significant downturns (in some cases, temporarily) in the recruitment and admission of minority students in health professions schools [69].

Efforts to diversify the nation’s health workforce have been sporadic, and “siloed.” The lack of a national, overarching, coordinated effort to expand health
workforce diversity leads to lack of coordination, which duplicates efforts and wastes resources across disciplines, often within the same academic institutions. Diversity programs regularly come and go, depending on individual initiative and leadership for sustenance, and significant reports and recommendations all too often languish on the shelves of government and academic institutions.

Critical reviews of diversity strategies suggest the need for improvements in approaches to address the significant and chronic disparities in access to health careers. Grumbach et al. found in their 2003 review of strategies to diversify the health professions that discontinuity of interventions across regions and across stages of the educational pipeline make it difficult to sustain gains from one educational stage to the next [70]. They also noted poor coordination and articulation between programs and funders. Grumbach et al. call for “convening a national working group that meets regularly to coordinate activities among the many program sponsors and to develop a national strategic plan for promoting URM academic achievements and entry into the health professions.” The same report also calls for the formation of coalitions between organizations and institutions committed to racial and ethnic diversity in the health professions.

A more recent publication, funded by the Josiah Macy Foundation, Diversity in U.S. Medical Schools: Revitalizing Efforts to Increase Diversity in a Changing Context, 1960–2000s, reviewed four decades of diversity efforts in U.S. medical schools [39]. The paper offered eight overarching recommendations to U.S. medical schools and contained a similar emphasis on the need for a more “comprehensive and consistent over time” approach to addressing the health workforce.

To a great extent, the reasons for the failure of the health professions to achieve greater racial and ethnic diversity lie within the failure of our nation to provide more equitable educational opportunities, particularly for minority and low-income students. Structural and systemic inequities in K-12 education present these students with fewer educational resources and opportunities than their non-minority and wealthier peers. Black and Latino children, for example, are four times more likely than white children to be raised in poverty, and are far less likely to attend schools that are integrated along socioeconomic or racial and ethnic lines. The wealthiest 10% of school districts – which are often characterized by scant racial and ethnic diversity – spend nearly ten times more than the poorest 10% of schools districts, which tend to be overwhelmingly the minority. Nearly two-thirds of underrepresented minority students attend predominantly minority schools, and one-third of black students attend intensely (90% or more minority enrollment) segregated schools. These schools have poorer physical facilities, offer fewer Advanced Placement courses or other college-level curricula, and have higher dropout rates. In contrast, schools in more affluent districts provide more rigorous curricula, have better-credentialed, more experienced teachers, and the resources to address students’ learning and counseling needs. And studies demonstrate conclusively that teacher quality and preparation is correlated with student performance [71].

Not surprisingly in light of these statistics, underrepresented minorities tend to perform poorly relative to their nonminority peers on a range of standardized tests,
ranging from tests of early reading and mathematics skills to college entrance exams (e.g., the SAT) and graduate health professions education admissions tests (e.g., the MCAT, the DAT) [72]. And even when minorities who attended poor quality schools succeed despite the odds and gain admission to higher education institutions or health professions educational institutions (HPEIs), their poor prior education leaves many unprepared to handle the demanding curriculum of a pre-health professions or health professions course of study [73].

The Sullivan Commission and IOM *Compelling Interest* reports acknowledge this reality, and call for wholesale changes in our nation’s K-12 education policies, so that educational opportunities may be more equitable for students of all backgrounds. But these reports also argue that despite the conditions wrought by a tilted educational playing field, HPEIs and their stakeholders must take a range of steps to improve the opportunities and prospects of underrepresented minority students who seek to become health professionals. Many of these steps, the reports note, will also improve the overall quality of students admitted to HPEIs, and improve the quality of their training to serve a racially and ethnically diverse patient population [1, 68].

**Priming the Educational Pipeline**

The Sullivan Commission report calls for efforts to provide support to underrepresented minority students through strategies such as mentoring, counseling, and training in test taking and interview skills, and to raise awareness of health professions career options. The Commission recommends that:

- HPEIs, hospitals, and other organizations should partner with businesses, public school systems, and other stakeholders to provide academic enrichment programs in the sciences and to promote parental and family involvement in student learning.
- The U.S. Public Health Service, state health departments, HPEIs, and others should support a public awareness campaign to encourage minority students to pursue careers in health professions.
- HPEIs should develop avenues for underrepresented minorities, particularly those in allied health professions fields, to pursue a second career in the health professions.

Similar efforts to enhance the preparation and academic skills of underrepresented minority students have demonstrated success. The Minority Medical Education Program, for example, an intensive summer educational program for minority college students focused on training in the sciences and improvement of writing, verbal reasoning, studying, test taking, and presentation skills, succeeded in helping nearly half of over 450 students in the 1997 cohort to gain acceptance to at least one medical school, a significant improvement over the admission rates of minority students who did not participate in the program [74].
**Bridge Programs**

“Bridge” programs focus on ensuring a successful educational transition between steps in the path toward matriculation in and graduation from a health professions training program, and ultimately to health professions careers. Such programs can be geared to the transition of high school students to college pre-health professions programs, from 2- to 4-year colleges, from baccalaureate programs to graduate health professions training programs, or from graduate training to faculty careers. The Sullivan Commission report recommends that:

- Baccalaureate programs and HPEIs should develop “bridging” programs that help graduates of 2-year colleges – particularly graduates of 2-year community college nursing programs – to succeed in earning baccalaureate degrees.
- Colleges, universities, and HPEIs should support lower-income students with an array of services, including mentoring, test-taking strategies, counseling on HPEI application procedures, and interviewing skills.

**Financial Aid**

Because underrepresented racial and ethnic minority students often face greater financial obstacles to financing higher education and an education in a health professions field, financial barriers to attaining a health professions degree must be removed. In recent years, tuition and other educational costs have climbed steadily, while at the same time sources of grant aid have decreased (Advisory Committee on Student Financial Assistance, 2002). The trends toward increased tuition costs and deceased need-based aid have resulted in higher levels of unmet need for lower-income students. At the federal level, Congress should provide greater resources to the National Health Service Corps and Title VII and VIII of the Public Health Service Act. These titles authorize funding, through a variety of programs for students and institutions, in order to increase the quality of the education and training of the primary care provider workforce, with special attention to the geographic, racial, and ethnic diversity of the U.S. healthcare workforce. These programs have provided support for many minority health professions students, yet Congressional appropriations for these programs have fluctuated as a result of budget pressures.

Federal financial aid is unlikely to be sufficient, however, to meet the financial needs of minority and low-income students who wish to attain a health professions degree. Public and private partnerships are therefore needed to establish scholarships, loan forgiveness programs, tuition reimbursement, and other creative strategies to reduce loan debt, particularly for individuals who seek to work in underserved communities.
Changing Institutional Policies and Practices

Health professions education institutions, through the institutional policies and practices that they adopt, exert a strong influence on the success or failure of diversity efforts. To ensure that this influence is a positive one, HPEIs must begin by assessing the role that diversity plays in helping the institution to achieve its goals and mission (e.g., development of health professionals to serve the institution’s region or community). HPEI leadership must then outline the specific steps necessary to achieve diversity goals, and reward faculty and administrators who demonstrate progress toward these goals. HPEI leadership must clearly communicate the value and importance of institutional diversity efforts to all members of the campus community, and provide training regarding diversity’s benefits and means to maximize these benefits. HPEIs must also assess and develop plans to improve, where necessary, the campus climate for diversity, and redouble efforts to recruit and retain underrepresented minority faculty.

Just as importantly, HPEIs must carefully examine their admissions policies and practices, to assess whether the institution is admitting a diverse and highly qualified student body that fulfills the institutional mission. Some HPEIs have begun to reconceptualize their admissions policies and practices to place greater weight on applicants’ qualitative attributes, such as leadership, commitment to service, community orientation, experience with diverse groups, and other factors. This shift of emphasis to professional and “humanistic” factors is also consistent with a growing recognition in health professions fields that these attributes must receive greater attention in the admissions process to maintain professional quality, to ensure that future health professionals are prepared to address societal needs, and to maintain the public’s trust in the integrity and skill of health professionals [75]. The IOM and Sullivan Commission reports encourage HPEIs to:

- Encourage admissions procedures to closely follow the institutions’ stated mission with regard to teaching, research, and service – particularly if the needs of medically underserved communities are a part of the institutional mission
- Encourage a comprehensive review of applicants’ files, to understand how students’ personal, community, and professional backgrounds may influence students’ prior academic performance and contribute to the learning environment
- Require admissions committee members to receive training aimed at improving their ability to assess underrepresented applicants, and sharpening interviewing skills
- De-emphasize standardized test data in the admissions equation, after a diverse group of academically qualified candidates are identified
- Include representatives from groups affected by the institution’s admissions decisions on admissions committees, and increase incentives for faculty participation on admissions committees
Accountability

The HPEI accreditation process – the voluntary, self-regulatory function of establishing and enforcing standards for training program quality – is perhaps the key to improving HPEIs’ responses to diversity needs. By setting standards for educational programs and methods for institutional peer review, accrediting bodies advance academic quality, encourage institutional progress and improvement, provide a mechanism for continual assessment of educational goals, and ensure accountability to the public. The accreditation process is therefore an important vehicle for institutional change, and a powerful lever to encourage diversity efforts.

The IOM report recommends that health professions education accreditation bodies should develop explicit policies articulating the value and importance of providing culturally competent health care, and the role it sees for racial and ethnic diversity among health professionals in achieving this goal. Health professions education accreditation bodies should develop standards and criteria that more effectively encourage health professions schools to recruit URM students and faculty, to develop cultural competence curricula, and to develop an institutional climate that encourages and sustains the development of a critical mass of diversity. If implemented in the spirit of collaboration between accrediting bodies and their member institutions, these standards will tend to encourage and stimulate institutional progress and innovation.

Leadership

These recommendations require strong leadership for their successful implementation. Both the Sullivan Commission and IOM reports strongly emphasize this point, noting that “[i]nstitutional leaders must establish expectations regarding diversity goals, ‘set the tone’ for how diversity objectives will be met, and hold all members of the campus community accountable for achievement of these goals [76].” The importance of institutional leadership is readily apparent, given that diversity efforts require strong, sustained institutional commitment and support from many sectors of the university community. Institutional leaders can help to galvanize and sustain such support, and thereby improve the institutional culture and responsiveness to diversity.

Conclusion

Achieving greater racial and ethnic diversity among the nation’s health professionals is an increasingly urgent goal. Yet little progress has been made toward this goal, as a result of many complex factors – including inequitable educational
opportunities for many low-income and minority students, institutional resistance
to diversity, reductions in need-based financial aid, judicial and policy decisions
that have hampered efforts to consider the importance of diversity in the admissions
process, the fragmented nature of interventions, and the lack of a national impetus.
Many of these barriers can be reduced, if not eliminated, if the individuals and
organizations that stand to benefit from greater diversity among health profession-
als – including health professionals, the HPEI community, health policymakers,
grassroots and community leaders, educators, corporate and business leaders, orga-
nized labor, and the general public – can commit to work in coalitions to create the
necessary “push” to support strategies to increase diversity among health profes-
sionals. As a start, health professions organizations should assess and disseminate
information about HPEI applicants, matriculants, and graduates from underrepre-
sented racial and ethnic groups, as well as data on the participation of these groups
among HPEI faculty, staff, and professionals in the workforce. This data dissemina-
tion should be coupled with educational efforts to raise awareness of the imperative
to enhance diversity among health professionals, and to build consensus among a
range of stakeholders regarding action steps to achieve this goal. Broad coalitions
of stakeholder organizations can also help to create a political impetus for federal,
state, and local strategies to increase diversity. The groups should encourage
HPEIs, their accreditation bodies, and federal and state sources of student financial
aid, to adopt policies to enhance diversity among health professionals.

Creation of statewide alliances such as those established within the Sullivan
Alliance offer a viable way to get institutions within and between states to develop
statewide and regional consortiums of minority undergraduate colleges and aca-
demic health centers. Institutional state partners can act as “pathfinders” to identify
and test best practices to diversify the health workforce. The alliances’ findings can
then be profiled in order to encourage federal action. These collaboratives can
enhance the efficiency of diversity initiatives encouraging resource sharing and pro-
ductive partnerships, while ameliorating achieved gains and building momentum.

Finally, Congress and federal and state government health agencies should
increase support for policies that increase diversity among health professionals, and
should explore new initiatives to create incentives for HPEIs to adopt diversity
efforts.

As we illustrated, diversity is important for all of society and in the healthcare
context is crucial for the capacity and quality of the U.S. health system as a whole.
Keeping the argument for diversity focused on its benefits to minorities only mar-
ginalizes ethnic and racial minorities in the health professions, and absolves society
from assuming collective responsibility for the care of all our citizens. In terms of
health policy, framing the policy argument for diversity in terms of its benefits to
vulnerable communities – rather than our legislators’ ability to get needed health
care in 10 years, for example – has obvious disadvantages. Diversity initiatives
must focus not only on matriculation and education but also upon the career trajec-
tory of underrepresented health professionals, academic faculty of all ranks, univer-
sity governing boards, university and medical school administrators, and other
health leaders in the nation.
History has demonstrated that absence of such a multi-faceted, collective approach, diversity efforts will fail to fully achieve their potential. More significantly, the ability of the American healthcare workforce to meet the needs of our nation will continue to erode.

References


71. Lee PR, Frank PE. Diversity in U.S. medical schools revitalizing efforts to increase diversity in a changing context, 1960–2000s. San Francisco: Institute for Health Policy Studies, School of Medicine University of California; 2009.


Chapter 12
The Role of Communities in Eliminating Health Disparities: Getting Down to the Grass Roots

JudyAnn Bigby

Abstract  Racial disparities in health status and health care have been documented for decades, yet the exact causes of these disparities are unknown. It is known that an array of factors including personal risk, interaction with the physical and social environment in communities, and interaction with the health-care system influence health status. Efforts to eliminate health disparities will not succeed unless they include multipronged approaches focused on the multiple levels of causation. Much attention has been focused on causes of health-care disparities that operate primarily at the level of the individual and emphasize personal behaviors and individuals’ access to and experience in the health-care system. In addition, the role of individual health-care providers’ biased attitudes, stereotyping, and discrimination toward people of color is often offered as an explanation of health-care disparities. Barriers to accessing care and poorer quality of health care for minority populations have also received significant attention.

Addressing individual patient or provider behavior can help to reduce but will not be sufficient to eliminate disparities. Individual characteristics and biology (e.g., race, sex, genes) contribute to health, but health status is largely determined by other factors including those that exist outside the health-care system. The health of individuals is determined by multiple factors including the extent and quality of health care, individual characteristics, family factors, exposure in communities, and by social and political factors. These factors influence access to health care and risk and personal health behaviors. The decision to engage in specific personal health behaviors (smoking or regular exercise, for example) is not made in isolation but is influenced by community characteristics, environmental conditions, and social and economic factors (McGinniss and Foege, JAMA 270:2207–2212, 1993; Flournoy and Yen, The influence of community factors on health: an annotated bibliography. Oakland: PolicyLink and The California Endowment, 2004). Access to affordable food, tobacco products, and illicit drugs vary significantly in communities across the USA and have been demonstrated to influence personal health behaviors. Asthma,

J. Bigby (*)
Secretary, Executive Office of Health and Human Services, Commonwealth of Massachusetts, Boston, Massachusetts, USA
e-mail: judyannbigby@state.ma.us
heart disease, diabetes, HIV and AIDS, and poor birth outcomes such as low birth weight are some of the conditions that are highly prevalent in communities of color. Communities that suffer disproportionately from disparities in health also bear a higher burden of physical and mental illness, disability, and mortality. This burden has an immense influence on economic and educational opportunities, leading to a vicious cycle of socioeconomic inequality and poor health. This chapter provides an overview of the relationship between health and community conditions, specifically related to understanding disparities in health. The chapter will also describe community-based and community-driven efforts that can help to make substantial progress toward improving the health of populations that experience the greatest health disparities.

**Keywords** Community • Health status • Fast-food restaurants • Supermarkets • Violence • Crime • Pollution • Nutritious food • Alcohol • Toxic waste disposal • Green space • Stress • Mental health • Income and poverty • Safety net facilities • Premature mortality • Low birth weight • Faith-based initiatives • Community transformation

**What Is “The Community?”**

Definitions of community vary depending on the context of interest. In this chapter, community is defined as a geographic entity that includes neighborhoods where people live and have a collective sense of sharing certain characteristics. Communities are comprised of many members, including, but not limited to families...
and individuals who live or work in the community, civic organizations including ethnic and cultural groups, businesses, nonprofits, and voluntary or social institutions. Distinct neighborhoods may be as small as just a few city blocks. Changes in neighborhoods often track with changes in health status. Neighborhoods also make up larger communities where people work, go to school, conduct business, participate in spiritual activities, and/or socialize. Communities can be parts of larger cities or municipalities in both urban and rural areas.

Often communities are dynamic entities due to fluctuation in economic factors and other influences such as those that contribute to gentrification in urban communities.

The Role of Communities in Determining Health Status

There is increasing recognition of the role that communities play in promoting the health of the people who live there. Neighborhood factors influence health in several ways. For example, violence and pollution have a direct effect on mental and physical health. The presence of fast-food restaurants and the absence of supermarkets have indirect effects on health behaviors. The availability and quality of neighborhood health-care services affect access to care. Having access to resources related to employment and recreation also affect health [1, 2] (Table 12.1). In urban areas, especially those with large populations of persons

<table>
<thead>
<tr>
<th>Table 12.1</th>
<th>Factors contributing to the health of communities (Adapted from PolicyLink)</th>
</tr>
</thead>
</table>
| Socioeconomic factors | • Income  
|  | • Job opportunities  
|  | • Segregation resulting in concentrated poverty  
|  | • Cultural norms and behaviors  
|  | • Civic engagement (community mobilization, political power, community leaders)  
|  | • Violence  
| Natural and built environment | • Air and water quality  
|  | • Exposure to toxins and toxic waste  
|  | • Safety of work environment  
|  | • Quality of housing stock  
|  | • Parks and recreational space  
|  | • Condition of streets and sidewalks  
|  | • Cleanliness and sanitation of public areas  
|  | • Transportation systems  
| Access to and quality of services | • Quality and affordability of comprehensive health-care services including mental and oral health care  
|  | • Quality and capacity of public schools  
|  | • Quality and capacity of police and fire services  
|  | • Presence of full service community services (churches, mosques and other faith-based institutions, child care centers, grocery stores, banks and lending institutions, pharmacies) |
from racial and ethnic minority groups, serious health problems are concentrated in distressed neighborhoods. In rural areas, health problems may not always be clearly geographically defined but the health of the poor and persons from racial and ethnic minority groups is disproportionately affected by lack of geographic access to health-care services, jobs, quality education, decent housing, and nutritious food.

Epidemiologic evidence has demonstrated that after controlling for individual socioeconomic risk, social structures at the neighborhood level that limit individual educational attainment, employment, and social relationships can influence individual health. Ross et al. analyzed neighborhood-level factors in Montréal and found that there was significant variation in health status between neighborhoods and that neighborhood-level factors accounted for about 3% of the variance in health after controlling for individual level factors [3].

The natural and built environment influences the health of communities. Communities of color are often more likely to be sites for toxic waste disposal and to have poor air quality. Green space and parks are less likely to be placed or maintained in communities of color. People are less likely to exercise or engage in physical activity in communities with poorly maintained houses and with crime. There is a relationship between stress and high levels of noise, crime, and violence in communities [1]. The housing in communities of color is often substandard, lead contaminated, or dangerous due to multiple housing code violations. Houses that are poorly maintained often lead to hazardous conditions such as improper heating and ventilation, water leaks leading to mold and other allergens, pests, inadequate safety precautions such as window guards, and exposure to toxins such as lead.

There are fewer services such as health care, quality schools, and public transportation available in communities of color. Communities of color often rely on safety net facilities such as community health centers or public hospitals for health care. These facilities are severely underfunded and in many communities they have been closed or been converted to private institutions over the last decade. One study reports that the best predictor of which hospitals closed in Philadelphia during the movement to decrease beds and downsize was the percent of black patients a hospital served [4].

Access to nutritious and reasonably priced food often depends on having easily accessible supermarkets. Even in geographically close neighborhoods, race predicts the availability of healthy foods [5]. Communities with higher home values and that are racially homogeneous have more supermarkets. Communities of color have higher concentrations of liquor stores, bars, fast-food restaurants, and advertisements for tobacco and alcohol [2].

It is misleading to paint communities of color as devoid of assets. There are assets that create support and enable resiliency among community members to promote health. These assets include strong social networks through faith-based organizations, culturally distinct social service organizations, and the tradition of relying on extended family often inclusive of individuals who have no blood relationship. These and other assets can be marshaled in the effort to eliminate health disparities.
Socioeconomic Factors

Income and Poverty

A person’s income has long been known to influence individual health. Community level economic factors have increasingly been recognized as important in influencing the health of the population residing in a defined community. In 2004, 12.6% of blacks and 8.6% of Latinos were poor compared to 4.3% of whites (US Census Bureau, 2004 American Community Survey). Blacks and Latinos were also more likely than whites were to live in poor neighborhoods. According to the Census, low-income blacks are more likely than any other racial or ethnic group to live in neighborhoods with high concentrations of poverty. Blacks who are not poor are also more likely to live in communities that are poor due to racial segregation in housing.

Independent of their individual income level, people who live in poor communities have higher rates of premature mortality, cardiovascular disease, cancer, and other chronic medical problems [6]. The birth weight of African American babies is lower in communities with concentrated poverty. Smoking, alcohol use, and seat belt use have also been found to vary depending on the poverty level of a community [7]. Communities with pockets of concentrated poverty have higher rates of unemployed males, high rates of single female-headed households, and violence. In one study of West Oakland, California researchers found that living in a largely African American neighborhood was an independent risk factor for poor health [8].

Poor neighborhoods receive fewer resources for infrastructure such as trash collection and maintenance of public spaces and are more likely to have polluting industries in their neighborhoods. Segregation by race and income also limits communities’ access to full service grocery stores and other assets such as parks and walkable sidewalks.

Educational status and employment status predict health and health status in communities. Rates of morbidity and mortality increase as socioeconomic indicators decrease in communities [2]. Children living in neighborhoods of low socioeconomic status are twice as likely as children living in neighborhoods of high socioeconomic status to have mental illness [9].

Access to Health-Care Services

People of color are more likely than whites to live in health profession shortage areas. Latinos and blacks are more likely than whites to report they have little or no choice in where they seek care [10]. In the last decade many hospitals have closed in poor and minority communities creating access problems unrelated to insurance status. In 2001, D.C. General Hospital closed leaving residents in the neighborhood without access to emergency services. In California, 23 hospitals closed between 1995 and 2000, mostly in urban areas with populations that were predominantly people of color. In New York City, pharmacies in neighborhoods of color are less likely to carry narcotic analgesics [11]. Persons of color have less access to specialists and are more likely to see physicians who are not board certified [12].
Social Relationships

Higher levels of social connectedness are associated with lower levels of mortality. A neighborhood with low levels of social connectedness has mortality rates ten times higher than neighborhoods of similar socioeconomic status and high levels of social connectedness as measured by resident’s willingness to intervene when children participate in delinquent behavior or when community resources are threatened [13]. Social connectedness is influenced by concentration of disadvantage, immigration concentration, and residential stability.

Community Initiatives to Eliminate Health Disparities

To address health disparities in communities of color requires interventions at multiple levels because of the multiple contributors to poor health. Efforts that address access to health care and individual health behaviors will not alone achieve health status equity. Yet eliminating poverty and racism as the mechanism for eliminating health disparities is an overwhelming task that is unlikely to gain the support of policy makers, health-care leaders, and others. It is therefore important for individuals, health-care leaders, communities, governments, and others to develop a framework for eliminating health-care disparities that recognizes the specific intersecting contributing factors and identifies specific interventions (Fig. 12.1). Health-care interventions should be connected to efforts to address resources and conditions in neighborhoods.

Historically, health-care providers and organizations have not partnered with communities to address health issues. Even public health departments approached improving the health of populations by delivering programs to individuals in communities, conducting research without community participation except as subjects, and making policy decisions that were sometimes doomed to fail because they were incongruous with the values in the community. Fortunately, community leadership, collaboration, and participation are recognized as important strategies to achieve improved health in communities. There are many resources available to define successful strategies for achieving true community-driven and community-based interventions to improve health [14–17].

Working in communities with a goal to achieve community-driven grassroots efforts to eliminate health disparities has many advantages and challenges. Addressing key principles for developing community-driven and community-based initiatives helps to identify and capitalize on the advantages and to avoid the pitfalls that can often lead to increased distrust of health-care institutions and providers, duplication of efforts, and squandering of resources. The challenges include:

1. Different governance structures of health-care systems and community organizations
2. Different leadership styles including an emphasis on hierarchy in health-care institutions
The Role of Communities in Eliminating Health Disparities

3. Disproportionately more resources in health care
4. Racial, ethnic, socioeconomic, and educational differences between leaders and other involved parties representing communities and health care
5. Different and often conflicting priorities

Working in partnership with communities has many advantages that, in genuine partnerships, outweigh the challenges. These include:

1. Possibility of sustained, permanent, and institutionalized health improvement strategies
2. Activated communities that empower others to more actively participate in their health
3. Interventions that influence outcomes across disease entities
4. Increased social capital
5. Improved relations between health-care systems and communities resulting in improved community accountability

Working in partnership means sharing power, shared decision-making, and a willingness to examine new ways of doing things. Developing partnerships takes time, sometimes years before substantial work can be done. Resources are required for supporting efforts to establish true partnerships. The need for more long-term commitments is often not recognized by funders who support community-based interventions.

Strategies for True Community Engagement

There are many strategies for working with communities to address health issues. They include (ranging from high to low community involvement) identifying and working with coalitions, developing partnerships with a few individuals or organizations, developing a community advisory or oversight board, and providing information to communities about efforts that are relevant to the community. Some groups have found that a true partnership may require a new not-for-profit organization that represents the true collaborative function of the partnership and allows all partners to share power in ways that is not possible if participants represent the interest of their respective institutions.

Successful Collaborations

Successful collaborations with community partners share common themes. Successful groups are able to articulate a shared vision for the health of the community. This can only be accomplished if community groups are brought into the process from the beginning, before any decisions have been made. Getting to a shared vision often requires frank discussions, re-airing of past grievances, and acknowledging differences in motivation, values, and other important issues. Collaborations must provide an opportunity for regular communication between
and among partners and an organized method to share information. Successful institutions identify key stakeholders and include them in the assessment and planning phase for community-based interventions. Strong community engagement and an awareness of the social dynamics should be viewed as an asset, not a barrier. It is essential to have clear programmatic interventions, clear achievable goals, measurable indicators for successful partnerships, and to identify both short-term and long-term desired outcomes. Having facilitated discussions about how race, class, and gender affect the partnership and giving people skills to address these issues is a difficult and sometimes expensive intervention. However mediated, such discussions can help to advance partnerships that have failed in the past. Gaining trust is an important goal for partnerships. Trust building strategies include having an open process, identifying opportunities to gain a better understanding of the partners, focusing on synergies among parties, paying attention to process, and constant vigilance toward achieving the desired goal.

**Strategies for Engaging Communities**

**Organizing Community Residents**

Organizing and empowering community residents to identify and respond to health needs in their community can lead to benefits for the community that extend beyond health. The lack of knowledge about the existence of health disparities is a barrier to organizing communities to focus on disparities. A national survey conducted by the Kaiser Family Foundation found that whites, blacks, and Hispanics were unaware of the extent of racial disparities. Competing priorities such as violence, employment, and schools may make it difficult to engage communities about health outcomes. Helping communities understand the link between these issues and health is an effective way to motivate residents to advocate for policies and programs that can improve health status.

**Convening Stakeholders**

Coalitions and partnerships should include representations from community residents and involve public, non-profit, and the business community. In Boston, Massachusetts, the mayor convened hospital CEOs, community health center leaders, public health official, nonprofits, and others to learn about disparities, identify the root causes, and to develop a blueprint to address disparities. Community coalitions focusing on disparities in breast and cervical cancer mortality between black women and others, and heart disease and diabetes between black elders and others participated in the development of the recommendations (see [www.bphc.org/disparites](http://www.bphc.org/disparites)). The recommendations focus on health care, economic opportunity,
education, housing, tobacco control, violence prevention, and workforce diversity. The health department has allocated resources through an open process to implement the recommendations.

**Community Action Model**

Working with communities to achieve measurable outcomes requires a structured process to engage all the partners to identify a specific issue for action, to assess the problem from the community’s perspective, to develop an action plan, and to agree upon an evaluation of the outcomes of the efforts. There are several models for guiding such a process including the Planned Approach to Community Health and the Community Health Improvement Process [18, 19]. The Community Action Model (Fig. 12.2) is a five-step community-driven model that recognizes the need to facilitate equal skills and understanding of public health principles and strategies among all community partners and focuses on community action as a method to change policies and develop new programs [20].

![Community Action Model Diagram]

**Fig. 12.2** Strategy for collaborative public health action by communities (Adapted from Lavery [20])
Community Health Workers

Community health workers (CHWs) are widely used to educate communities about health, facilitate access to screening and care, connect individuals to community-based resources, promote risk reduction behaviors, and other health promoting activities. CHWs are described as or have overlapping responsibilities with lay case managers, health educators, patient navigators, promotoras, doulas, and others. CHWs generally reflect the demographics of the community they serve and often act as a bridge between the health-care system and the community. They are strong advocates for individuals and for high quality and culturally competent services. They may be particularly important for promoting improved access and quality of care for populations for whom English is not the first language. A systematic review of the effects of CHW intervention suggests they have significant value for addressing specific health disparities such as immunizations in children and adults, improving care for HIV/AIDS, and promoting breast feeding. Several studies demonstrate CHW effectiveness in improving screenings for cancer [21].

Faith-Based Initiatives

Faith-based health promotion has been prominent in many communities, especially African American communities. Recent federal government efforts to bring faith-based organizations into the fold to address many of the health and social conditions that contribute to disparities have increased health-care organizations’ willingness to work with faith-based communities, to the extent that some complain of being “coalitioned” to death. Several elements are necessary for successful faith-based health promotion programs including true partnerships, availability of services to refer individuals with identified needs, access to appropriate facilities in communities, community-focused interventions, supportive social relationships, and willingness to promote health behavior change [22]. Cancer screening, cardiovascular risk reduction, and teen pregnancy prevention are several areas of intervention among faith-based initiatives.

Community Initiatives to Eliminate Health Disparities

Many of the most common health disparities are amenable to community interventions. Interventions to address diet and physical activity have the potential to influence rates of overweight and obesity, heart disease, and some cancers. Other interventions to address low birth weight and infant mortality have the potential of influencing health outcomes for several generations because of the increasing evidence that low birth weight infants are at higher risk for obesity and heart disease in later life [23, 24] and for having low birth weight infants themselves [25]. Thus, though many community-based interventions are disease-specific, they have the potential of influencing a
diversity of health disparities. Table 12.2 summarizes a selected group of community interventions that are described in more detail below.

**Diabetes**

Community interventions may be particularly effective in preventing diabetes or complications from diabetes because of the relationship to overweight and obesity, the role that social support plays in engaging individuals and groups in healthy eating and physical activity behaviors, and the role that education and social support can play in diabetes self-management. Community conditions such as the availability of affordable healthy foods, safe spaces to engage in physical activity, and the presence of fast-food restaurants strongly influence the potential for successful initiatives for primary and secondary prevention of diabetes. A community coalition in East Harlem where 50% of Latinos and 40% of African Americans have diabetes has addressed a wide array of community environmental issues to reverse the trend in diabetes morbidity and mortality. They have investigated the availability of healthy foods in their neighborhood, worked with area restaurants to prepare traditional foods in a healthier manner, and used a neighborhood artist to develop health education materials including highly visible street art [5].

**Tobacco Control**

Tobacco control is an important area of community intervention because of disproportionate targeting of communities of color for tobacco advertising and promotion, the addictive nature and therefore long-term consequences of tobacco use, and the connection to heart disease and cancer, the leading causes of death in communities of color. Communities were dismayed by the revelation that tobacco

---

**Table 12.2** Sample community interventions addressing health-care disparities

<table>
<thead>
<tr>
<th>Health issue</th>
<th>Method</th>
<th>Level of intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>Community coalition, community-based participatory research, advocacy [5]</td>
<td>Neighborhood bodegas, restaurants; community education</td>
</tr>
<tr>
<td>Smoking</td>
<td>Community mobilization related to tobacco control [20]</td>
<td>School board, regulation of smoking products by city and public universities, housing complexes</td>
</tr>
<tr>
<td>Asthma</td>
<td>Community health workers [26]</td>
<td>Homes of asthmatic children</td>
</tr>
<tr>
<td>Breast and cervical cancer</td>
<td>Community activation, coalition [27]</td>
<td>Health-care system policies and procedures, community awareness of disparities, neighborhood resources</td>
</tr>
</tbody>
</table>
companies were targeting minority communities. Several communities have formed coalitions locally as well as nationally to address this issue. Several successful efforts in San Francisco used the Community Action Model to mobilize and educate communities and to design appropriate actions to address the availability of tobacco products, to boycott nontobacco products made by tobacco subsidiaries, to develop smoke-free policies in public spaces, and prevent access to tobacco by adolescents [20].

Asthma

Asthma has increased in prevalence among urban, minority children for more than two decades. In some urban school systems more than 25% of children have asthma. Neighborhood, home, and school environmental conditions are associated with asthma rates and morbidity. Communities show high levels of interest and frustration with the lack of attention to environmental issues that impact asthma. One program used CHWs to provide environmental assessments, education, and advocacy for resources to facilitate remediation of environmental problems. Children in homes with the CHW intervention experienced fewer days with symptoms of asthma and less frequently utilized urgent health-care services [26].

Breast and Cervical Cancer

Cancer disparities are particularly amenable to community-based interventions because of the multiple determinants of cancer risk, effective prevention strategies, and the importance of public knowledge about the benefits of early diagnosis [28]. The Centers for Disease Control and Prevention funds several community-based initiatives to address breast and cervical cancer disparities in the Racial and Ethnic Approaches to Community Health (REACH) program (http://www.cdc.gov/reach2010/). REACH supports community coalitions in designing, implementing, and evaluating community-driven strategies to eliminate health disparities. The Boston-based REACH 2010 Breast and Cervical Cancer Coalition completed an assessment of the factors contributing to higher rates of breast and cervical cancer mortality among women of African descent in Boston and developed several interventions to address these factors in a coordinated effort. The initiative includes educating the community about disparities and the impact of race on health and promotes health-care system changes to decrease barriers to care [27]. CHWs provide education in homes, reminiscent of Tupperware parties. Community residents concerned about the link between obesity and breast cancer investigated the affordability and quality of nutritious foods in their neighborhoods. They also advocated for training and education of health-care providers to address cultural competence.
Summary

Communities are an important place to focus health disparities interventions. Neighborhood conditions are key determinants of health and health disparities. Community members are in a unique position to formulate priorities for addressing neighborhood-level factors that influence health outcomes, to mobilize and advocate for improved health care and other services, are effective agents of change and information, and enhance the effectiveness of initiatives to address health problems. Emerging models for community participation and collaboration acknowledge the important roles communities play and highlight the challenges to community-based interventions. Resources are required to support effective community-based strategies and to sustain programs that demonstrate effectiveness.

The recently passed Patient Protection and Affordable Care Act (PPACA) contains some elements that may provide more community empowerment and funding appropriations of at least $1.5 billion beginning in 2014. For example, under Section 4201, community transformation grants will be made available through the Centers for Disease Control and Prevention for preventive health services to reduce chronic diseases, to address health disparities, and to develop a stronger evidence base of effective evidence programming. Grants will also be provided to promote the Community Health Workforce including the recruitment and training of community health workers. In addition, grants will be made to "promote positive health behaviors and outcomes" (Section 399V). Another promising area in the new law is the authorization of a community-based Collaborative Care Network Program, with funding to be provided on an as-needed basis. There are other newly authorized resources that should help to serve community health needs, such as the increase in funding for Community Health Clinics (at least $14 billion), and the Nurse-Managed Health Clinics (NMHC, Section 5208, $50 million).

Finally, it is important to bear in mind the following statement and its relevance to the community health situation:

> Inequities in health and health inequalities arise because of the circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness. The conditions in which people live and die are, in turn, shaped by social, political, and economic forces.


Extent and quality of health care – includes the types of services that are available to individuals (e.g., primary care, specialty care, mental health, oral health), the structure of the health-care system (e.g., location and hours of operation), the competence and technical ability of staff and professionals, availability of support services (e.g., transportation, interpreters, outreach workers, health educators), and quality of care (e.g., patient-centeredness, efficiency, equity, safety, appropriateness).

Individual and family factors – includes genetic predispositions, gender roles, social consequences of race, and family attitudes toward wellness and health care.

Community – includes quality of services, built and natural environment, location of health-care facilities, and violence.
Social and political context – includes policies that determine health-care coverage and cost, employment, housing and educational opportunities, and the level of support for services.

Risk and personal health behaviors are influenced by community level factors (e.g., safe green space for exercise), individual and family factors (e.g., risk perception, coping mechanisms to deal with stress, and cultural norms for dietary choices), and interaction with health care (e.g., time spent with providers and language and literacy appropriate health education).

Access to health care is determined by all the factors in the model including the structure of the health-care system (e.g., hours of operation, diversity of health-care providers), individual and family factors (e.g., support for biomedical models of care), community factors (e.g., availability of comprehensive services), and the social and political context (e.g., budget for Medicaid).

References


Chapter 13
The Potential Impact of Performance Incentive Programs on Racial Disparities in Health Care

Alyna T. Chien

Abstract Performance incentive programs – also known as pay-for-performance, public reporting, and value-based purchasing programs – continue to receive national attention. Although these programs have become even more diverse, their basic features have not changed and the potential mechanisms by which these programs may impact racial and ethnic disparities in health care in a neutral, narrowing, or widening manner remain the same. We repeated the systematic search of the literature for the 4 intervening years since the last edition of this book. We found that although hundreds of articles continue to be written on this subject each year, there were no additions to the empirical evidence regarding the impact of performance incentive program on disparities. While the 2009 Patient Protection and Affordable Care Act will significantly alter the American healthcare landscape, recommendations regarding particular aspects of program design should be approached with disparity-reducing goals in mind that also remain unchanged and may be somewhat more achievable. Given the changing landscape, it is even more important that incentive programs are evaluated for their intended effect, as well as for their unintended effect on racial/ethnic disparities in health care.

Keywords Quality • Equity • Racial disparities • Performance incentives • Pay-for-performance • Public reporting

Equity Is a Part of Healthcare Quality

Since the first Institute of Medicine report on the quality of American health care, equity has evolved into a cross-cutting dimension of all the components of quality (effectiveness, safety, timeliness, patient/family-centeredness, access, and efficiency) [1, 2]. This is in recognition of the need to raise awareness of the pervasiveness of...
healthcare disparities – the fact that minorities have less access to health care, are less likely to have good experiences with healthcare providers when they do gain access, receive recommended processes of care less often, and have poorer outcomes for their health [3–17]. A greater awareness of disparities may lead to better efforts for reducing them [18, 19].

Performance incentive programs continue to play an important role in the effort to align incentives with quality. While the common parlance for these programs has evolved slightly, over 100 “pay-for-performance” programs continue to be underway in the private sector, the Centers for Medicare and Medicaid Services have invested $21 million in several large-scale demonstration programs involving both hospitals and outpatient settings, and more than half of State Medicaid programs are now using performance incentive strategies in their health plan contracts [20–27]. Practical experience with performance incentive strategies is increasing, but our updated systematic review of the literature shows that the empirical evidence regarding positive or negative consequences for disparities remains limited.

Additionally, the 2009 Patient Protection and Affordable Care Act will alter the landscape upon which our current understanding of the relationship between performance incentives and disparities is based. For example, through its individual health insurance mandate, health reform is likely to reduce overall uninsurance rates. If the Massachusetts experience bears true for the nation, health reform is likely to reduce disparities in insurance coverage but may exacerbate disparities in the accessibility and timeliness of care [28, 29]. Other aspects of this legislation – requirements to enhance data collection on race/ethnicity – are likely to impact disparities in their own right. Simultaneously, expansions to Medicaid and the Children’s Health Insurance Program (CHIP) are also likely to have direct effects both on the use of performance incentives and racial/ethnic groups. Health reform also appropriately places a strong emphasis on stemming healthcare costs, and attention paid to promoting efficiencies may overshadow efforts to reduce disparities [30]. The changes that are about to unfold present new opportunities for better understanding the effectiveness of performance incentives in health care and its net impact on racial/ethnic disparities in that care.

Performance Incentive Programs

Definition

Performance incentive programs explicitly tie rewards and sanctions – cash payments or penalties – to healthcare processes (e.g., prescribing aspirin in heart disease) and/or outcomes (e.g., having low cardiac surgery mortality rates) [31–36]. Although some programs emphasize the monetary component of their incentives (i.e., pay-for-performance or value-based purchasing), others highlight reputation-based pressures through intra- or extra-organizational physician profiling (i.e., public reporting). We refer to both types of programs as “performance incentive programs.” This is because the distinction between these two types of programs is conceptual. In reality, pure
financial or reputation-based programs infrequently exist, and most programs use a combination of direct financial and reputation-based incentives. Second, programs that stress putting reputations at stake are thought to exert financial pressure by facilitating consumer choice and competition for health care “business” [37–39]. Last, the ways in which these programs may impact disparities are likely to be very similar. Further details regarding the theoretical and practical elements of performance incentive programs can be obtained from other sources [40–46].

**Basic Features**

**Flow of Incentives**

The flow of incentives from payers to payees to individual physicians and/or hospitals is diagrammed in Fig. 13.1. Payers of four main types are implementing performance incentive programs: (a) our Federal government through the Centers for Medicare and Medicaid Services, (b) our State governments through Medicaid, (c) commercial health plans, and (d) private stakeholders (e.g., individuals or coalitions like employers who purchase health care on behalf of their employees). These payer types will not change with health reform although there may be an expansion of

---

**Fig. 13.1** Flow of incentives
member-run health insurance companies (a.k.a. CO-OPs) [47]. Note that at Step ①, payers can provide incentives to one another. A prime example of this is between State Medicaid programs and commercial health plans. Medicaid programs negotiate contracts with commercial health plans to provide care for its beneficiaries; these health plans may or may not go on to provide further downstream incentives to provider organizations.

Payers apply pressure to a wide variety of payees. Steps ② through ④ illustrate that incentives can flow directly to physicians and hospitals, or through an umbrella provider organization, such as medical groups, Independent Practice Associations, Physician-Hospital Organizations, multihospital systems, and integrated delivery systems [20, 23–25, 31–36, 48].

Payees can go on to provide incentives to entities within their organization – individual physicians and/or hospitals. Steps ⑤ and ⑥ show these incentives. In public descriptions of these programs, how and whether an organization decides to distribute earned bonuses or rewards is often left to the discretion of the umbrella organization. Sometimes provider organizations pay bonuses to the individual provider or hospital that scores the highest within the organization, other times a group effort is made around targeted measures, and bonuses are shared equally among all within the organization [20, 23–25, 31–36, 48].

**Incentive Types, Triggers, and Measures**

Incentives are usually monetary ones or reputation-based one, although the distinction between these is mainly conceptual. Generally, monetary rewards are year-end bonus payments or higher reimbursement rates that are often presented as “carrots,” and reputation-based incentives involve looking good on “performance” or “quality” reports that are distributed or posted within an organization (usually on a web site) are considered either “sticks” or “carrots.”

Rewards and sanctions are usually triggered by the achievement of a goal or target. Targets can be an absolute measure – that is, healthcare organizations have to obtain a certain “score” (e.g., 75th percentile, 90th percentile, or a standard deviation above the mean) in order to earn a reward. Absolute measures can be set at a low, achievable level or at high, difficult-to-attain levels. A smaller proportion of programs also give rewards for improving on targeted measures from one period to the next; few, if any, programs reward improvement alone. Some programs have minimum standards that providers or healthcare organizations have to satisfy before becoming eligible for the performance incentive program (i.e., enough patients with a target condition). A proportion of programs also risk-adjust their measures for disease severity. Many programs give rewards noncompetitively; if an organization meets or exceeds the targeted standard, then it receives the bonus or higher reimbursement rate. A small fraction distribute rewards in a tournament fashion; only those reaching the top few ranks of performance receive rewards [20, 23–25, 31–36, 48].

By definition, programs incentivize clinical processes and/or outcomes. The majority of publicly listed programs provides incentives for processes of care rather
than desired patient outcomes. Presumably, this is because they believe that it is more valid to hold healthcare providers responsible for what they have control over in the clinical setting and not what happens as a result of giving those services. Additionally, some believe that incentivizing healthcare outcomes should be avoided because it holds providers accountable for events beyond their influence and may unduly cause providers to “game” the system by preferentially caring for patients whom they believe will do well [46, 49–51].

Many programs also target aspects of health care beyond clinical care processes and/or outcomes. These include but are not limited to: clinical access (e.g., availability of appointments, openness to plan members), patient satisfaction (most often assessed by CAHPS®, the Consumer Assessment of Healthcare Providers and Systems), patient safety (most often computerized physician order entry), physician prescribing behavior (e.g., use of generic and/or formulary medications), and/or administrative efficiency (usually the use of electronic claims submission or ability to have an appointment quickly scheduled). Most programs use measures developed by HEDIS®, the National Committee for Quality Assurance, the Joint Commission on Accreditation of Healthcare Organizations, and/or the Consumer Assessment of Healthcare Providers and Systems [20, 22–25].

With increased experience with these programs, more attention is being paid to how to create composite measures [52–58], and whether process measures require risk-adjustment [59].

Potential Impact on Disparities

Proponents of performance incentive program movement often hypothesize that promoting quality generally will benefit everyone equally. While this appears hypothetically true at the surface – if all eligible women are offered a mammogram, then how could an African American woman fare differently than a White one? – it may not bear true in reality. Breast cancer mortality has declined by 4.4% between 1990 and 2002, but disparities in mortality grew because declines were greater among the majority than among the minority [13, 14]. This next section highlights how performance incentives may narrow, widen, or maintain disparities in health care.

Neutral Impact

Disparities in health care are pervasive – its roots are found to be poor patient–physician communication, cultural and linguistic indifference and/or incompetence, differential care, and decades of institutional and/or overt racism [3, 46]. Performance incentive programs will have no effect on disparities if they simply help organizations look good on the surface. This could happen if they merely induce better documentation without substantively changing the underlying quality of that care. Of the three randomized controlled trials that demonstrate that financial
incentives have a significant impact on desired measures, two attribute the significance to better documentation and not underlying quality [60–62].

Even if performance incentive programs promote improving the underlying quality of care, it may encourage organizations to rely upon a one-size-fits-all approach to their patients which may not be enough to reduce disparities. There is some empirical evidence for this argument. A general approach to improving hemodialysis dosing for patients with end-stage renal disease did not change the disparity between black and white patients even though it led to an overall 40% improvement across the 8-year study period [63].

Narrowing

Health care increasingly measures the things it wants to improve. If health care is going to remove the inequities within its system, it must measure race and ethnicity, compare what minority populations receive relative to the majority, and investigate the sources of the disparity between groups, if any. The health reform bill requires enhanced collection of racial/ethnic information along with other information important for vulnerable populations such as primary language, disability status, and rural locations. Centers for Medicare and Medicaid Services (CMS) has also improved its methods for improving the race/ethnicity coding for Medicare beneficiaries [64]. This should improve our general ability to assess disparities despite it being a potentially socially and politically charged topic in the past [65].

The “‘minority’ maxim” is the shorthand term that this chapter will use to refer to a concept and strategy that arises from the quality improvement literature – that improvement efforts that aim to meet the cultural, linguistic, and educational needs of minorities are likely to improve care of both minorities and the general population, whereas the converse may not necessarily be true [66, 67]. Again, there is some empirical evidence to support this position. In contrast to the end-stage renal failure effort described above, a “collaborative” approach to improving depression care – one that recognized that disease-burden and treatment choices were different across race and ethnicity – was equally effective at improving anti-depressant and psychotherapy use in both minority and nonminority elderly patients even when minority patients started out with more severe disease [68]. Performance incentive programs may need to adopt strategies that support the “‘minority’ maxim” approach to quality improvement if incentive programs are to help reduce disparities while raising overall quality.

Widening

A performance incentive program that promotes a one-size-fits-all approach to quality improvement could also widen disparities. This situation could occur if the changes that are implemented are more useful for mainstream patients (e.g., those
who can read and speak English well or have mainstream cultural beliefs) than it is for minority subgroups. In this situation, disparities may widen because minority groups get left behind [13, 14]. While there are many ways to address disparities, performance incentive programs that promote disparity reduction or help identify minority subgroups in need of more tailored programs may be better positioned to reduce disparities than those that do not.

Performance incentive programs can also widen disparities by altering how willing a physician or healthcare organization is to care for minority patients. Performance incentive programs are based on scoring systems that are sensitive to small changes – eliminating a small number of “difficult” patients with greater comorbidities, more disability, or lower health literacy may improve a provider’s score dramatically [69]. Programs may cause physicians and organizations to “cherry-pick” patients – either by preferentially selecting those who may help them score well or by avoiding or “referring on” those that may cause them to score poorly. To the extent that minority patients are viewed as higher risk, performance incentive programs may disincentivize their care [70].

Performance incentive programs may widen the resource gap that exists between organizations that serve large numbers of minority patients and those that do not. Organizations that traditionally serve large numbers of minorities generally work in environments with fewer resources than those that don’t – they are small or solo practices in nonaffluent neighborhoods, municipal clinics and hospitals, emergency departments, and federally qualified community health centers. Each of these providers works with rising numbers of the uninsured and underinsured and has significant difficulty recruiting and retaining board-certified physicians [71–75]. Organizations that serve minorities, however, may be judged by the same performance standards as better-resourced ones [76]. Performance incentive programs that inadequately level the playing field may reward majority-serving organizations for meeting standards that are much more attainable with more resources and/or a majority patient population and inadvertently penalize less well-resourced and minority-serving organizations – in either scenario, resource disparities widen [77].

Evidence/Literature Review

Several have systematically reviewed the literature on performance incentive programs [78, 79], and we have focused on their potential impact on racial/ethnic disparities in health care [80]. We repeated our prior search of the literature from 1966 to 2006, limiting our review to literature that may have emerged in the period from 2007 through 2009. We expanded our search terms slightly to account for contemporary parlance (e.g., included free-text terms for value-based purchasing) and excluded articles that did not meet our definitional criteria as a performance incentive program, those that were nonempirical, those not written in English, and those not conducted in the United States.

In the 3 years between 2007 and 2009, we identified 507 articles related to performance incentive programs and race/ethnicity, nearly the same number of articles
that were identified from the search of articles from 1966 to 2006. However, while the number of articles is greater, only 16 articles met our inclusion criteria, and none met the goal of scoring 26 of the 27 scoring items in the validated Downs and Black tool (we did not use the final item regarding power calculations because the data needed for these calculations are routinely absent in published studies) [81]. Thus, the literature supporting the effectiveness of incentive programs has not changed significantly and is best characterized as mixed. Six of these studies demonstrate a significant effect on the intended process [60–62, 82–84], four studies demonstrate a partial effect [36, 85–87], and three demonstrate no effect [88–90]. In terms of setting, four of these studies were done in healthcare settings serving vulnerable populations; two of these four demonstrated a significant effect, while the remaining two were split equally between having a mixed or null effect [60, 82, 86, 88]. All programs were directed at care for conditions that disproportionately afflict racial and ethnic minorities (chronic conditions like diabetes, substance abuse, and screening and immunizations for adults and children).

A performance incentive program’s intended impact can be significant, but so can its unintended effect [62, 91]. One study found that a performance incentive program aimed at improving the quality of substance abuse care lowered the likelihood of whether substance abuse patients with more severe disease were treated [91]. Only one of the studies in this small body of literature examined the effect of performance incentives on racial and ethnic disparities in care. Again, the performance incentive program that was evaluated was viewed as successful; it achieved its intended effect [84]. This program was then examined for its impact on racial and ethnic disparities in CABG rates and was found to widen disparities [70]. Changes could not be accounted for by secular trends in CABG rates, greater uptake of related procedures (i.e., cardiac catheterization and percutaneous transluminal coronary angioplasty), surgeon movement, or patient transfers. Of note, this program did risk-adjust its measures prior to reporting, suggesting that risk-adjustment alone may not adequately mitigate cherry-picking behaviors.

Table 13.1 provides a summary of this literature, how effective the incentive program appeared to be, the type of healthcare settings in which these programs were implemented and the conditions that they targeted.

There were, however, important insights from cross-sectional or uncontrolled studies during this period. Interviews with those designing performance incentive programs illustrated that program leaders were not designing these programs with disparities in mind, lacked racial/ethnic data to assess the impact of their programs, and thought that elements of their programs could promote the worsening of disparities [80]. One year after physician-level performance incentives were introduced at a federally qualified health center, HbA1c testing rates improved although HbA1c levels did not change significantly [92]. A study of hospital-based care showed that risk-adjustment changed hospital performance rankings and eligibility for bonuses in a performance incentive program [59]. Further, another study also found that hospitals with large minority populations showed that these hospitals may be less able to earn rewards in performance incentive programs [93].
Table 13.1 Summary of empirically tested performance incentive programs

<table>
<thead>
<tr>
<th>Author/year</th>
<th>Effect of program on intended measure</th>
<th>Setting</th>
<th>General primary care</th>
<th>Condition targeted</th>
<th>Screening/immunization (adult)</th>
<th>Screening/immunization (pediatric)</th>
<th>Other</th>
<th>Unintended consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beaulieu 2005</td>
<td>Significant</td>
<td>●</td>
<td>Partial</td>
<td>●</td>
<td>Vulnerable</td>
<td>●</td>
<td>General primary care</td>
<td>Other</td>
</tr>
<tr>
<td>Commons 1997/Shen 2003</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fairbrother 1999a</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fairbrother 2001a</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grady 1997</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hillman 1998a</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hillman 1999a</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kouides 1998a</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Norton 1992b</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pourat 2005</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rosenthal 2005</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Roski 2003a</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NY State/Werner 2005</td>
<td>●</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTALS 6 4 3 4 7 2 2 4 5 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*aRandomized study design
How Program Features Can Be Modified to Reduce Disparities

Where minorities tend to receive care is well known – minorities disproportionately receive care from solo and small group practices, municipally run clinics and hospitals, emergency departments, federally qualified health centers, and the Veterans Administration [71–75]. In contrast, whether and how these potential payees are included in or excluded from existing programs is not well described. Anecdotally, it appears that some performance incentive programs exclude solo and small group practices simply because they may not have enough patients with targeted conditions [20]. On the one hand, healthcare providers caring for minority patients in a resource-constrained environment will not have to compete against providers with more resources. On the other hand, those providers lose the opportunity to earn additional bonuses if they indeed do good work or learn about methods of measuring and improving quality. If we are to narrow disparities, programs will need to include those that traditionally provide care for minorities and to level the playing field.

It is unclear whether the type of incentive bears on whether performance incentive programs lead to widened or narrowed disparities, if at all. It would be incorrect to assume that reputation-based incentives are “dangerous” and monetary-based ones are “safe” because the only study evaluating this issue found a widening effect as a result of a program with a strong reputation-based incentive. There is also one study that supports the contention that monetary-based incentives lead providers to avoid severely ill patients. Given that minorities disproportionately suffer from all major conditions, adverse patient selection even based on severity is likely to disparately affect racial and ethnic minorities.

Two main tactics can be used to reduce the incentive to cherry-pick patients: (a) rewarding improvement and (b) risk-adjustment. Both tactics can be double-edged swords. Programs that reward improvement or “risk-adjust” may reduce the incentives for healthcare organizations to cherry-pick patients, but they may “excuse” physicians or healthcare organizations from reaching equitable standards of care for minority populations (e.g., getting “credit” for achieving an average HgA1c of 9 in a minority population when the standard is less than 8 in the majority population).

Based on existing evidence, it is unlikely that performance incentive programs will lead to dramatic improvements in quality in and of themselves. It is more likely that these programs will spur quality measurement, which may lead to organizational self-examination, and to the development of meaningful changes in improvement philosophies and processes. To the extent that performance incentive programs serve as useful adjuncts to quality improvement, programs should reward the development of quality improvement skills and progress towards goals as opposed to achievement of absolute measures. It is also important to note that risk-adjustment did not prevent physicians from exhibiting differential behavior towards minorities. Further studies need to be undertaken to better understand if, and why risk-adjustment offers insufficient protection against cherry-picking behavior.

Currently, none of these programs are targeting measures related specifically to the needs of minority patients and/or disparity reduction, although it is possible that disparity-reduction efforts exist but are not described. More likely, performance
incentive programs are in an early phase of development, and the issue of disparity reduction has not been viewed as being on par with other dimensions of quality: safety, effectiveness, patient-centeredness, timeliness, and efficiency. Many programs do target conditions that disproportionately afflict racial and ethnic minorities both in terms of disease morbidity and mortality (in particular, diabetes, cardiovascular disease, depression, and cancers of the breast and colon), so the potential exists for these programs to improve the quality of health care delivered to minorities and/or narrow disparities. Other disparity-reducing strategies – cultural competency training, “disparity” measures (e.g., how the races compare on a particular measure or set of measures), and identifying subgroups in need of more tailored programs – are also absent from these descriptions.

Data to really tackle the issue of disparities may not yet be available but appears to be in the pipelines. For example, the Centers for Medicare and Medicaid Services (CMS) programs are actively verifying the accuracy and completeness of their individual-level race and ethnicity data obtained through the Social Security Administration, although they have not publicly disclosed that this will be incorporated into its existing pay-for-performance demonstration programs [56]. Proxy measures based on zip codes and census tracks may provide meaningful, more immediate information until individual-level race and/or ethnicity data become available.

Summary Recommendations

Proceed with Caution

In summary, performance incentive programs offer a new strategy for improving the quality of American health care (see Table 13.2). Unfortunately, we do not have much experience with these programs, and it is unclear as to whether these

Table 13.2 Recommendations for designing and implementing performance incentive programs that reduce disparities

<table>
<thead>
<tr>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Proceed with caution</td>
</tr>
<tr>
<td>2. Measure race and ethnicity</td>
</tr>
<tr>
<td>3. Make stratified comparisons within a program – i.e., compare how minorities compare to the majority on targeted quality measures</td>
</tr>
<tr>
<td>4. Make stratified comparisons across programs – i.e., compare how programs cause minorities to shift from one provider organization to another</td>
</tr>
<tr>
<td>5. Critically evaluate programs for their intended effects</td>
</tr>
<tr>
<td>6. Critically evaluate programs for their unintended effects, particularly for disparities</td>
</tr>
<tr>
<td>7. Include providers that traditionally serve racial and ethnic minorities</td>
</tr>
<tr>
<td>8. Promote the “‘minority’ maxim,” particularly for providers that serve the majority</td>
</tr>
<tr>
<td>9. Reward improvement along with achievement</td>
</tr>
<tr>
<td>10. Develop risk-adjustment strategies that give providers credit obvious for caring for medically and/or socially complicated patients</td>
</tr>
</tbody>
</table>
A.T. Chien

programs work. There are theoretical and empirical reasons to be concerned that they may not work or may even worsen existing disparities. The only study that has been done on this subject suggests that performance incentive programs can widen disparities between the majority and minority populations.

Measure Race and Ethnicity

The only way to assess how performance incentive programs impact minority groups and disparities is to measure and study it with the same passion and fervor that is being directed at all five other dimensions of quality. Some may argue that dealing with disparities – by collecting and using information on patient race and ethnicity up front – would complicate and probably delay implementation of these programs. Program leaders may believe – explicitly or implicitly – that it does not make sense to delay programs to include features that may or may not be important, and that incentives may benefit minorities by providing absolute gains as opposed to relative ones.

These arguments underestimate the importance of the opportunity at hand. Performance incentive programs represent a unique opportunity to make sure that our payment system supports and incentivizes equitable health care. Our health-care system has been inequitable for a long time, and this situation must be rectified. We have reason to be concerned about evidence that these programs can widen disparities and/or harm minorities; such an outcome would be morally unacceptable and appropriate protective measures should be taken to avoid this potentiality. Lastly, if incentive programs really can improve quality, it would not take much additional effort to ensure that they reduce disparities while raising overall quality.

Make Stratified Comparisons Within a Program: That is, Compare How Minorities Compare to the Majority on Targeted Quality Measures

One relatively quick and less onerous way of assessing the effect of performance incentive programs on disparities is to make stratified comparisons of targeted quality measures based on race. For example, the colon cancer screening rate of patients with majority backgrounds can be compared side-by-side with the rate for those with minority backgrounds. If individual level data is not available for this, then neighborhood or practice-level information can be used as a more crude comparison. If differences are noted, then more should be done to understand the source of the disparity and to correct it.
Make Stratified Comparisons Across Programs: That is, Compare How Programs Cause Minorities to Shift from One Provider Organization to Another

Unfortunately, stratified comparisons within a performance incentive program will not illuminate whether differences, or lack thereof, are due to shifts in patient populations. More sophisticated methods will need to be employed to determine whether adverse patient selection is occurring. Significant changes in patient populations either by race, ethnicity, or disease severity can serve as a warning sign that cherry-picking is occurring so that it can be stopped.

Critically Evaluate Programs for Their Intended Effects

The literature on the effectiveness of performance incentive programs is simply inadequate given the pace at which these programs are being introduced. Efforts should be made to answer basic questions about whether these programs work and the factors that contribute to success and/or failure.

Critically Evaluate Programs for Their Unintended Effect

Given the theoretical and empirical evidence that these programs can have unintended effects that can be particularly harmful to minorities and the medically complex, research on the effects of performance incentive programs on disparities in healthcare delivery is urgently needed. Evaluation of these potential effects should be built into the design and implementation of performance incentive programs. Although their task is difficult, given the lack of data, leaders of these programs may want to try to strike a balance between rapid implementation of the programs and the inclusion of features that may help them monitor, and hopefully reduce, disparities. These programs should be called upon to live up to one of the basic tenets of medicine, “do no harm.”

Include Providers That Traditionally Serve Racial and Ethnic Minorities

If performance incentive programs are going to impact the quality of care provided minorities, then they must include provider organizations who potentially serve them. Well-performing organizations should be encouraged to particularly tend to
the needs of their minority subgroups. In addition, special attention should be paid to how programs judge and reward providers that traditionally serve racial and ethnic minorities. These providers often work in under-resourced environments which may need different performance incentive programs, adjunctive supports, and/or judgment criteria than wealthier organizations. Research should help clarify these differential needs.

**Promote the “‘Minority’ Maxim,” Particularly for Providers That Serve the Majority**

Evidence from the quality improvement literature may help us better understand how to narrow disparities at the same time we improve quality. Programs and researchers should investigate ways to design performance incentive programs that promote the “‘minority’ maxim” approach over the one-size-fits-all strategy, which could yield neutral or widening consequences.

**Reward Improvement Along with Achievement**

Based on the current literature, it is safer to assume that performance incentive programs will play a more adjunctive role in improving quality than a direct one. It should encourage ongoing improvements in quality structures, processes, and outcomes rather than the mere achievement of a certain quality measure. The former may prove to be the better long-term investment because it allows for continual improvement and adaptation; these abilities are essential for a field that must constantly update and integrate evolving technologies.

**Develop Risk-Adjustment Strategies That Give Providers Obvious Credit for Caring for Medically and/or Socially Complicated Patients**

While sophisticated risk-adjustment techniques are being developed and applied, more work may need to be done to ensure that providers understand these techniques to the point that they believe they are getting appropriate credit for caring for medically and/or socially complicated patients. Otherwise, they may avoid these patients for fear of poor performance ratings. Since minorities are disproportionately represented among the medically and/or socially complex, they are at highest risk for being avoided. Vigorous efforts should be directed towards mitigating this very real threat to minority health and health care.
Performance incentive programs have the potential to narrow, widen, or maintain disparities in health care. The former is the most preferable effect, but based on the literature to date, we should not assume that it will happen automatically. The second scenario – the one in which performance incentives widen disparities – is morally unacceptable and appropriate measures should be taken to ensure that these programs do no harm. The latter situation may be acceptable to some, but given that there are six presumably equivalent dimensions to quality, many may question why we are capable of being so ambitious when it comes to safety, effectiveness, efficiency, patient-centeredness, and timeliness, but of being laggards with respect to equity. We should question why, with all the promise in the air, it is sufficient to simply ask all “boats” to float higher when it is feasible to get them to float at the same height no matter what level they started from. Equity is a key dimension of quality; performance incentive programs should be designed to promote it.

References

67. Nerenz DR, Hunt KA, Escarce JJ. Health care organizations’ use of data on race/ethnicity to address disparities in health care. Health Serv Res. 2006;41:1444–50.
Chapter 14
Eliminating Disparities in Health Care Through Quality Improvement

Kevin Fiscella

Abstract This chapter discusses the role of quality improvement (QI) as a vehicle for eliminating racial and ethnic disparities in health care. Disparities in health and disparities health care are not synonymous. The latter represents only one of many contributors to disparities in health. Furthermore, healthcare disparities result from a complex constellation of patient, provider, organizational, and community/societal factors. Tackling inequities in health care requires addressing the predominant cause for a particular healthcare disparity. This can be done through well-designed quality improvement interventions. Such interventions can potentially reduce healthcare disparities through either targeted or universally applied strategies. The former specifically targets minority patients within a healthcare organization or targets organizations that serve largely minority patients. The latter applies quality improvement activities to all patients in the expectation that the intervention disproportionately benefits minorities. A range of quality improvement tools exist to improve care to minorities. Review of available evidence shows that it is possible to reduce, if not eliminate, disparities in health care using these tools. However, doing so requires a concerted commitment on the part of health plans and insurance payers to adequately fund such efforts. Health reform legislation and better tracking of healthcare disparities may spur progress towards the elimination of healthcare disparities.

Keywords Minority groups • Delivery of health care • Quality of health care • Health care accessibility • Quality improvement • Patient factors • Provider factors • Organizational factors • Community and societal factors • Cultural competency • Screening • Cancer • Depression • Immunization
The release of “Healthy People 2010 Goals for the Nation” and the Institute of Medicine (IOM) report, “Unequal Treatment” [1], shifted focus from merely documenting disparities in health care to implementing interventions designed to address them. In another report, the IOM acknowledges equity as a core dimension of quality [2]. This acknowledgement effectively institutionalizes the elimination of disparities in health care as an essential function of quality improvement (QI). The National Healthcare Disparities Report, which tracks annual progress, has shown limited progress to date in achieving this goal [3].

An overarching theme of this chapter is the critical role that adequately funded and targeted QI can play in the elimination of racial/ethnic disparities in health care. The chapter reviews the potential causes of these disparities and discusses QI tools potentially relevant to addressing disparities in health care. The chapter concludes with a discussion of current QI efforts specifically designed to address disparities in health care.

### Health Disparities vs. Healthcare Disparities

Race is defined as a social construct based on a combination of selected arbitrary physical characteristics, continental ancestry, and ethnic identity. Ethnicity refers to group identity based on shared culture, language, and/or beliefs. Given the overlap between these two definitions, the term race/ethnicity will be used, which combines these closely related terms. Notably, by the year 2050, half the US population is estimated to be minority [4].

Racial/ethnic disparities in health refer to instances where members of minority populations experience inferior health to those of the majority population. Healthcare disparities contribute to health disparities as both share some common underlying contributing causes, but they are not synonymous.

Racial/ethnic disparities in health often result from the effects of life-long, intergenerational social exclusion (e.g., racism and socioeconomic disadvantage). These factors also contribute to disparities in health care. Moreover, because disparities in health care represent inequities in the process of health care, they are potentially addressable through interventions designed to impact health delivery. Eliminating healthcare disparities will facilitate progress towards the eliminating disparities in health. However, achievement of the national goal of eliminating racial and ethnic disparities in health will likely require fundamental society reform that address underlying social disadvantage.

### Disparities in Health

Racial and ethnic minorities, particularly African Americans, have historically experienced inferior health outcomes as compared to whites [5]. African Americans have higher adult and infant mortality than whites and other minority groups [6–8].
They also have considerably higher mortality rates than whites from cardiovascular disease, cerebrovascular disease, cancer (lung, colorectal, breast, prostate, cervical), pneumonia/influenza, diabetes, HIV, unintentional injuries, pregnancy, sudden infant death syndrome, and homicide [9].

Other minority groups also experience disparities in health. Hispanic Americans have higher death rates than non-Hispanic whites from liver disease, diabetes, HIV, and homicide, yet lower rates from cardiovascular and cerebrovascular disease and cancer [10]. However, rates of stomach, liver, and cervical cancer among Asian Americans and Pacific Islanders also exceed those of whites [11]. Additionally, rates of disease and death for American Indians/Alaska Natives are higher than whites for pneumonia/influenza, liver disease, obesity, pediatric tuberculosis, bronchitis, diabetes, sudden infant death syndrome, and diabetic kidney disease [12, 13]. Given this information, it can be seen that disparities are larger among selected subpopulations within these broad racial/ethnic categories.

The proximal causes of disparities in health are not well understood. However, disparities in health, particularly the black–white gap, likely represent a nexus between historic socioeconomic disadvantage, racism, and residential segregation. Socioeconomic status (SES), whether measured by household income, educational level, or occupation, is powerfully linked to health [14, 15]. In fact, most of the five and half year gap in adult life expectancy between black and white males is explained by racial disparity in SES [16]. Moreover, contrary to popular portrayal, there is currently little evidence that genetics make substantive contribution to disparities in health [17, 18].

Racism also strongly affects the health of Africa Americans (and other minorities to varying extent) at three distinct levels: institutionalized policies and practices, individual discrimination and biased treatment, and internalization of racial stereotypes [19]. Each of these levels reinforces the other. Institutionalized racism, manifested by historic inequities in employment opportunities, income, wealth, education, health care, and criminal justice [20], represents a driving force behind health disparities. Individual racism is also a major contributor to disparities through bias and unconscious racial stereotypes manifested through lower educational expectations for minority students, racial profiling by police, harsher sentencing for minority defendants, and discrimination in housing, banking, and employment [21]. Racial stereotypes play a role in voting patterns and public policies that reinforce institutionalized racism. Last, internalized racism refers to introjections of racial stereotypes by the members of the targeted minority group. It may contribute to self doubt in the individual, lower school performance, school drop-out, and/or emulation of gangster subculture portrayed through popular media [22].

Minorities, particularly African Americans and American Indians are often subject to social exclusion. This can be manifested geographically through residential racial segregation or socially through networks of families and friends. This social exclusion often undermines minority health [23]. African Americans experience the greatest residential segregation of any minority group [24], resulting in a veritable American Apartheid [25]. Additionally, this social marginalization reinforces continued African American impoverishment, lack of access to employment
opportunities, substandard housing and schooling, and exposure to crime and environmental toxins. It also fosters mistrust of majority institutions, including health care [20, 21, 26]. Contrary to popular perception, lifestyle factors contribute only moderately to disparities in health [7, 27]. Thus, current federal initiatives to eliminate racial and ethnic disparities by 2010 seem somewhat misguided because they do not address the root causes – the nexus of racism, poverty, and residential segregation – but instead focus nearly exclusively on altering individual behavior and ignore contextual determinants of behavior.

Disparities in Health Care

Although racial/ethnic disparities have been highlighted in recent years, they can be traced back to the enslavement of African Americans [5]. The National Healthcare Disparities report, produced annually by the Agency for Healthcare Research and Quality (AHRQ), documents persistent disparities in healthcare quality by race, ethnicity, and socioeconomic status [3]. Nonetheless, disparities are at times subtle and by no means ubiquitous. For example, no racial disparities were observed in directly observed Prim Care encounters [28]. In their study, Escarce and Kapur found no racial or ethnic disparities in expenditures among Medicare beneficiaries [29]. Additionally, Asch et al. observed no racial disparities in the quality of health care in a national sample [30]. Even in the cardiovascular realm, disparities are not inevitable as shown by the absence of disparities in hospital management of congestive heart failure using national Medicare data [31]. Moreover, disparities vary widely by region of the country [32]. Racial disparities in the treatment of patients hospitalized with myocardial infarction are small to nonexistent within the Northeast and largest in the South [32]. Each of these studies is subject to key limitations. None disprove the existence of healthcare disparities. Rather, these studies underscore that healthcare disparities are not universal. In this sense, they lend optimism that focused quality improvement efforts might yield success in eliminating healthcare disparities when they are identified.

Racial disparities in health care have been noted across most of the key dimensions in the healthcare process (effectiveness, safety, timeliness, and patient centeredness) and also for most of the four consumer perspectives (staying healthy, getting better, living with chronic illness, and coping with end of life) [1]. African Americans have been reported to receive less appropriate treatment for breast, lung, colorectal, and prostate cancer [33, 34] as well as HIV infection [35, 36]. Blacks also receive fewer antidepressants for depression; [37] less appropriate management of congestive heart failure and pneumonia [38], poorer quality of hospital care [39]; fewer pediatric prescriptions [40], and fewer admissions for chest pain [41]. They also experience lower quality prenatal care; [42] fewer root canals compared to tooth extractions [43], and less adequate treatment for cancer pain [44].

Healthcare disparities among other racial and ethnic minorities have been less extensively studied. Nonetheless, Hispanics, Asians/Pacific Islanders, and American Indians/Alaska Natives have also been reported to receive suboptimal care in
selected instances. Hispanics have been reported to receive fewer cardiovascular procedures [45] including reperfusion therapy [46, 47], fewer appropriate medications following a myocardial infarction [48], and less analgesia for metastatic cancer [44, 49] and trauma [50]. Asians/Pacific Islanders have been reported to receive fewer Pap smears, mammograms [51], influenza vaccinations [52], and invasive cardiovascular procedures [53]. American Indians/Alaska Natives have been reported to receive lower rates of mammography and have poorer blood pressure control than whites [54]. In fact, they receive the least prenatal care of any group [55]. Among Medicare HMO enrollees, however, African Americans show the largest disparities in quality followed by Hispanics and American Indians/Alaska Natives, while Asians/Pacific Islanders receive higher quality care than whites for some measures [54].

Notably, the variation in disparities in health care across region, type of health care, and minority group strongly militates against a single “smoking gun” explanation, but rather suggests considerable heterogeneity in causes. That being understood, causes of disparities can be viewed as arising from complex interactions at the level of the patient, provider, healthcare organization, and community. Each of these factors is discussed.

**Patient Factors**

Patient-level factors clearly contribute to disparities in health care. Examples include patient knowledge [56, 57], mistrust [58], affordability [59–61], limited English proficiency (LEP) [62], healthcare literacy [63], aversion to invasive procedures [64, 65], preferences [66, 67], and self-efficacy. Of course, the salience of these factors likely varies depending on the procedure. For example, patient factors probably make substantial contributions to disparities in influenza vaccination [68, 69], but probably contribute relatively little to disparities in chemotherapy for breast cancer [70].

Carefully designed studies have shown that patient preferences do not fully account for disparities in health care [43, 67, 71], suggesting that factors beyond patients’ control likely contribute. Although some have argued that disparities represent nothing more than patient preferences [72], patient-level factors are undoubtedly affected by presence and type of healthcare insurance [73], availability of a regular source of care [74], comprehensible healthcare plan policies, location of health facilities, copayments and deductibles [59], prescription coverage [75, 76], availability of medications in community pharmacies [77], waiting times, presence of culturally competent staff, and availability of translation services [78]. Patients’ knowledge, beliefs, attitudes, and behavior are influenced by culture, education, SES, mass media, pharmaceutical marketing [79], social networks [80], racism [81], prior experience among friends and family [82], and most importantly, trusted information provided by physicians [83]. For example, familiarity with coronary artery bypass surgery, rather than race, is the stronger predictor of the willingness of the patient to undergo the procedure [64].
Provider Factors

Provider-level factors that contribute to disparities in health care include patient stereotyping [84], expectation of benefits [43], clinical uncertainty stemming from lack of cultural/linguistic competency [85–87], physician participatory decision making style [88], and competing demands during visits and cognitive overload [89, 90].

That being said, provider factors strongly affect patient factors [86] as patient “preferences” are shaped not only by prior experience but also by provider–patient trust, clear communication, and the ability to provide culturally competent care. African Americans use hospice less than whites [91], but it is unclear to what extent this represents a cultural preference or lack of communication and trust. It is interesting to note that a survey of nephrologists showed most nephrologists discounted provider factors as contributors to disparities in access to transplantation [92]. Nevertheless, black patients were less likely than whites to report being informed about transplantation options, particularly when their physicians did not view patient–physician communication and trust as an important reason for racial differences in care [92].

Provider-level factors become increasingly relevant for healthcare processes that require active physician participation such as initiating a referral or performing a diagnostic or therapeutic procedure [93]. Provider-level factors are likely to be paramount when guidelines for performing a particular procedure are unclear and medical uncertainty is high [94]. Examples include hospital admission for chest pain [41], as well as the performance of certain diagnostic or therapeutic procedures such as angiography [95], coronary artery bypass surgery [96], total hip replacement [97], and renal transplantation [98]. Physicians may be more susceptible to unconscious stereotyping and/or patient demand when confronted by medical or surgical uncertainty [90], particularly when under stress [99]. The result is often a combination of under utilization of the service by minorities and excessive use by whites [98, 100].

Organizational Factors

Organizational factors can also contribute to disparities in health care. Healthcare systems and healthcare plans influence the location of physician offices, the diversity of the work-force [101], provider continuity, availability of interpreters [78], reading level and culturally appropriateness of written materials [101], size of copayments and deductibles [102], location of facilities [103], implementation of practice guidelines, and culturally appropriate health promotions [1].

Health delivery and payment in addition to under payment by Medicaid represent hidden contributors to disparities [104, 105]. Medical students and residents commonly acquire skills from care for poor and minority patients, but in the process may also acquire biased attitudes from training within separate and unequal systems [106, 107].

Last, organizations are responsible for implementing effective quality improvement that, in turn, can affect both provider and patient behavior. For example, physician
qualifications and presence of hospital catheterization facilities accounted for 35% of racial disparity in coronary angiography in one study [108], suggesting that organizational factors represent an important lever for action.

**Community and Societal Factors**

Community and societal factors are often overlooked as key determinants for disparities in health care. These factors include community rates of insurance [109], availability of safety net providers [110], proximity and availability of providers [111], community trust in healthcare providers [112], availability of regular sources of care [74, 113], continuity of care [114, 115], community medical knowledge [116], and variation in community practice [117].

Most of the disparity in knee arthroplasty for elderly Hispanics is explained by geographic differences, while only one-third of the disparity for elderly black women and little for elderly black men is explained by geography and practice variation [117]. Inequality in other procedures also varies considerably by region of the country [118].

In some instances, minorities receive care from lower quality providers. African Americans are more likely to be seen by Prim Care physicians who report they lack the necessary resources to provide high quality care [119]. At least in New York State, African Americans are more likely to undergo cardiac surgery by surgeons with higher mortality rates [82] and are more likely to be readmitted for complications following coronary artery bypass surgery [120]. In Maryland, blacks have been reported to undergo carotid endarterectomy more often than whites by less experienced surgeons [121]. African American very low birth weight infants are more likely to be treated in hospitals with higher neonatal intensive care mortality rates [122]. Elderly African Americans are more likely to be enrolled in HMOs with lower quality ratings [123] and admitted to nursing homes of lower quality [124]. Potentially, improved consumer education in minority communities regarding quality of different providers might help to mitigate disparities. Similarly, employers and unions that represent large numbers of minorities might demand quality reports to insure appropriate care for their members. Such efforts will be significantly enhanced with mandatory reporting of quality.

Finally, lack of insurance makes a major contribution to disparities in health care. Lack of insurance has been linked to suboptimal health care (and higher mortality) [125]. Among the 46 million uninsured Americans, there are striking racial/ethnic disparities. Rates of uninsurance for whites, blacks, Hispanics, Asians, and American Indians are 8%, 15%, 23%, 13%, and 20%, respectively [126]. Among those with insurance, minorities are more likely to lack supplemental or prescription coverage [127]. African Americans are more likely to be insured through Medicaid [128], and many providers do not participate in this program [111, 128]. Racial disparities in disease control diminish once patients become eligible for Medicare [129]. Because insurance is so strongly linked to access to care [125], lack of universal health insurance and difference in quality of insurance imposes a
critical limit on reductions in racial/ethnic disparities in healthcare quality. Health care reform should diminish the contribution of insurance coverage and parity to disparities.

No One Factor Explains Healthcare Disparities

Clearly, healthcare disparities are driven by complex combinations of differing factors. The relative significance of different factors probably depends on the type of healthcare service. On one hand, patient-level factors seem to predominate for services that are largely dependent on patient adherence. These include keeping medical appointments, medication adherence, and adhering to recommendations for preventive health services [130–133]. Provider factors play a smaller role in disparities for commonly recommended preventive services, such as Pap smears, mammography, and immunizations [28, 134], but become increasingly relevant for healthcare processes that require active physician participation and complex decision making such as initiating a referral or performing a diagnostic or therapeutic procedure [93]. In addition, providers are likely to be most susceptible to bias when indications for a particular procedure are unclear and medical uncertainty is high [94]. Organizational and community factors impact healthcare disparities primarily by affecting patient and provider behavior. Often, healthcare disparities are driven by the interaction between a health care that is ill-equipped to address the needs of poor and minority patients. Mainstream health often lacks the requisite cultural competency or sensitivity, language services, attention to health literacy, and sensitivity to out-of-pocket costs necessary to address the needs of diverse populations resulting in a mismatch between care needs and resources to address those needs.

Role of QI

Despite the complexity of disparities, available evidence suggests that disparities in health care are not intractable. The finding that disparities differ between organizations and regions suggests they are not inevitable. Moreover, use of existing QI to tackle healthcare disparities helps to mainstream the disparities problem and leverage existing resources and expertise. In an era of shrinking resources for health care, it is prudent for new initiatives to use existing resources. The creation of an entirely new apparatus for addressing disparities risks marginalizing disparity initiatives and subjects them to the vagaries of shifting organizational and funding priorities. Moreover, QI has a track record and evidence base. Given the limited data on interventions explicitly designed to address disparities, it makes sense to institute interventions that have a proven track record for improving health care in the general population, and then assess their benefits for minorities. In some instances relatively simple interventions may be sufficient to overcome patient or physician barriers to improved care.
QI Strategies

QI by itself may not necessarily reduce disparities in care. QI might improve care for all groups without affecting disparities [135, 136]. Targeted approaches may be needed. This can be done in several basic ways. First, QI can target specific groups of patients, thus improving their care relative to other patients. Examples of patient targeting include sending out reminders based on zip codes, use of Spanish media in Latino communities, and use of culturally crafted messages delivered in minority communities by minority community health workers.

Second, QI can target practices that serve large numbers of minorities. African American patients often receive care from providers with fewer resources [119]. QI, particularly when accompanied by the infusion of sufficient resources, can be used to boost the overall quality of care of practices or hospitals that serve large numbers of minorities [137]. This is the approach adopted by the HHS Bureau of Prim Care’s Health Disparities Collaboratives that aimed to improve the overall quality of care among Federally Qualified Community Health Centers [138].

Third, QI efforts can target patient–provider behavior and communication skills. Conceivably, improved training in cultural competence [85] could improve providers’ ability to effectively communicate with minority patients and possibly reduce unconscious bias although no studies to date have examined these important questions. Similarly, training patients to communicate more effectively and assertively may help to counteract unconscious provider bias [139].

Fourth, QI efforts might promote use of risk-assessments that better target resources. For example, low SES is associated with higher coronary heart disease risk independent of Framingham risk factors. Taking into account SES, along with traditional risk factors, in decisions regarding lipid management will result in more appropriate allocation of resources to those at highest risk while also potentially reducing disparities in CHD [140, 141].

Last, efforts targeting reductions in inappropriate utilization such as overuse of tympanostomy tubes or cardiovascular procedures among whites will tend to reduce disparities because whites tend to overutilize these procedures more [100, 142, 143]. This approach, while not directly benefiting disparity populations, helps conserve scarce resources that might be directed toward disparity reduction.

In some instances, certain types of universally applied QI sometimes benefit minorities more than nonminorities. For example, a nursing home intervention designed to prevent pressure ulcers also eliminated racial disparities in them [144]. Similarly, interventions designed to boost rates of preventive care often concentrate efforts on patients who have not received the service. Mailing out reminders to patients who have not yet received their influenza vaccination will by default target a greater proportion of African Americans because their rates are lower than whites [68]. However, it should be noted that universally applied QI does not inevitably reduce disparities [136, 145] and, in some cases may paradoxically increase disparities if nonminorities prove more responsive to the intervention [146]. In these instances, more targeted approaches may be needed [147].
At any rate, the content and delivery of interventions should be specifically tailored to the culture of the community and use a multipronged approach [148]. If the group of interest has high rates of television viewing, then this media might be used instead of print media. Use of influential leaders in the community or peer educators such as community health workers can also promote diffusion of information throughout a community [148, 149].

QI Tools

The taxonomy of causes of disparities presented earlier is consistent with a conceptual framework for QI tools for preventive care [150]. These tools include reminders, feedback, education, financial incentives, regulatory intervention, organizational change, and media campaigns. The tools can be primarily focused on the patient, provider, or organization. There are at least ten types of interventions that offer potential for improving healthcare quality and reducing disparities. Some have been rigorously evaluated. Table 14.1 provides a summary of interventions that specifically target a cause of disparities. Each is briefly discussed below.

Reminders

Available data suggest that provider prompts improve delivery of preventive care [151]. Definitive data are limited, but provider prompts may also help reduce disparities in care [136, 152]. Providers often fail to initiate appropriate preventive care due to competing demands [89]. Due to greater healthcare needs, minority and low-income patients are more likely to present providers with competing demands for their time resulting in cognitive overload for providers [153]. Prompts at the point of service that remind the provider that a particular service is needed may minimize provider cognitive overload and unconscious bias. Reminders have also been used for patients to improve rates of preventive care [154]. However, use of letter reminders as a sole intervention may be less effective in low-income populations due to lower literacy rates and more frequent change of address [155].

Provider Feedback

Many health plans provide participating physicians with individualized feedback regarding their performance. When used alone, it has weak effects on quality measures [150, 156]. However, coupling feedback with financial incentives or achievable benchmarks may improve performance [157]. Conceivably, providing detailed but meaningful feedback to providers regarding disparities in their own
practice may reduce inequalities in health care. Such feedback may motivate providers to be more attentive to the needs of their minority or low-income patients and help reduce bias. However, empirical data regarding this approach are currently lacking.

<table>
<thead>
<tr>
<th>Table 14.1</th>
<th>Examples of interventions targeting specific causes of disparities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor targeted</td>
<td>Group targeted</td>
</tr>
<tr>
<td>Patient knowledge</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
<tr>
<td>Patient attitudes and beliefs</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
<tr>
<td>Self care skills</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
<tr>
<td>Patient self efficacy</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
<tr>
<td>Patient adherence</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Low literacy</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
<tr>
<td>Limited english proficiency</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
<tr>
<td>Affordability</td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community</td>
</tr>
<tr>
<td>Provider stereotyping</td>
<td>Provider</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Provider adherence</td>
<td>Provider</td>
</tr>
<tr>
<td>Patient–provider communication</td>
<td>Provider</td>
</tr>
<tr>
<td></td>
<td>Patient</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Provision of care based on need</td>
<td>Delivery system</td>
</tr>
</tbody>
</table>
**Provider Education**

Clinical uncertainty promotes practice variation and probably increases disparities through unconscious bias [1, 86]. Disparities are most apparent for new technologies and where indications for a procedure are marginal [158]. The development and effective implementation of guidelines may help to offset underutilization for minorities and low-income groups while minimizing over utilization for majority groups. Although guidelines alone have limited effectiveness [156], they improve performance when coupled with specific feedback or incentives. The success of effective guidelines might be further enhanced by requiring that providers document when explicit criteria have been met before undertaking particular procedures or documenting why a course of action was not undertaken when such criteria are satisfied.

**Increasingly Intensive Outreach**

A graduated approach to influencing and educating patients means that increasingly intensive outreach is employed to reach patients that have not responded to initial attempts. For example, outreach might begin with general mailings, followed by individualized mailings and telephone calls and conclude with home visits by community health workers [159]. In selected instances, assistance with transportation, child care, or language might be provided [160–162].

**Practice Guidelines**

With a few notable exceptions such as disparities in influenza vaccination (which are probably driven in part by differences in patient attitudes), the largest disparities are seen for procedures where guidelines are unclear and practice variation is high. Examples include invasive cardiovascular interventions [53], organ transplantation [98], and joint replacement surgery [117]. Clear consistent guidelines, backed by provider feedback and incentives, offer great promise for reducing disparities in care by increasing rates of appropriate care for minorities while decreasing rates of inappropriate care for others. Studies are needed to determine what effect guidelines have on disparities, under what circumstances, and whether they represent an effective means of attenuating bias.

**Patient Education**

Effective patient education is a core tool for the elimination of disparities. Patient education is needed to inform patients of the benefits and risks particular procedures might provide and to address any misconceptions the patient might have. It is also
the primary means for fostering patient self-management that typically involves behavioral changes in diet, exercise, alcohol and drug use, as well as sexual behavior or appropriate use of medication and medical equipment such as home blood pressure or glucose devices [163]. Furthermore, confirmation of patient understanding by providers improves diabetic control among low-literacy patients [164]. Brief, feasible procedures are needed to quickly assess and address gaps in patient understanding and self-efficacy. Nonphysician providers and staff represent an invaluable adjunct to primary provider-based education [165]. Patient education will be most effective in reducing disparities when both the media and content have been specifically tailored to the needs of the disparity population.

Patient Activation/Empowerment

There is evidence that patients can be trained to assume greater involvement in their care and become more assertive when these changes are associated with improved outcomes [166–173]. Furthermore, patient assertiveness may attenuate disparities in breast cancer evaluation [174] and cancer pain [172]. Studies are urgently needed to determine whether interventions designed to increase assertiveness among minority patients can reduce disparities in use of expensive technology or other areas.

Cultural Competency Training

This intervention focuses on changing provider knowledge, attitudes, and behavior. While there is evidence that physicians can be trained to communicate more effectively with patients [175–182], only a few studies show that such training affects patient outcomes [181], much less reduces disparities. In one randomized trial, cultural competency training improved clinician knowledge but not patient outcomes [183]. Research is needed to identify the key areas of knowledge, attitude, and behavior that affect disparities in order to develop effective interventions that alter these behaviors and ultimately prove that these changes affect disparities and improve minority health care.

Organizational Change/Practice Redesign

Organizational change presents a potent but relatively unstudied lever for addressing disparities. As discussed below, practice-based QI models have been shown to reduce disparities in depression management and outcomes. In theory, any organizational change that focuses on improving healthcare delivery to patients most at
risk for suboptimal care or outcomes should have the secondary benefit of reducing disparities though there are limited empirical data.

The chronic care model includes components likely to impact disparities [184]. These include self-management support, clinical information systems, delivery system redesign, decision support, healthcare reorganization, and community partnerships. These and other elements of practice redesign such as same day scheduling of appointments offer tremendous potential for reducing disparities in care. However, other innovations such as electronic patient–provider communication may actually worsen disparities due to the continuing digital divide [185].

One way to substantially improve care to minority patients is to provide safety net practices that care for large numbers of minorities with the resources they need to improve the quality of care. These providers report that they often lack the necessary resources necessary to provide optimal care [119]. The federal government currently supports care to underserved patients through partial funding to federally qualified community health centers. It has begun supporting these sites in acquiring critical health information technology necessary to support ongoing quality improvement efforts [186].

**Community-Based Interventions**

Last, community-based interventions that promote changes in community norms, knowledge, attitudes, and behavior related to health care represent a potential, but greatly understudied, intervention. Such interventions may be particularly fruitful for addressing pivotal beliefs and attitudes [56, 57] such as those related to influenza vaccination or breast feeding. Such interventions can involve social marketing campaigns or partnerships with community-based organizations using community-based participatory research approaches [187].

**Successful Models**

Although a comprehensive review of the literature conducted by the General Accounting Office found no model intervention specifically designed to address disparities [188], a number of interventions, mostly designed for other purposes, have been shown to reduce disparities. In most cases, the effectiveness of the intervention has been shown through randomized controlled trials although several are based on observational data. These are summarized in Table 14.2 and discussed in detail below.
Childhood Immunizations

Hispanic, American Indian/Alaskan Native, and in some instances, Asian/Pacific Islander children aged 19–35 months have lower immunization rates than white children [189]. Szilagyi and colleagues assessed the impact of a community-wide reminder, recall, and outreach (RRO) system for childhood immunizations on known disparities in immunization rates between inner-city vs. suburban populations and between white minority children within an entire county [190]. The RRO relied on lay community-based outreach workers assigned to city practices to track immunization rates of all 0–2-year-olds who provided a staged intervention with increasing intensity depending on the degree to which children were behind in immunizations. The components included tracking for all children, mail, or telephone reminders for most children, assistance with transportation or scheduling for some children, and home visits for 5% of children who were most behind in immunizations and who faced complex barriers. A pre vs. post comparison of immunization rates showed that the RRO intervention dramatically reduced racial and inner city–suburban disparities in child immunizations. This study demonstrates that standard RRO systems can be implemented on community or population level to effectively address disparities in childhood immunizations.

Screening for Chlamydia

Chlamydia is the most common sexually transmitted bacterial infection in the United States. In fact, statistics show that as many as 15% of young women have the disease. Treatment consists of a single dose of antibiotics. Untreated Chlamydia infection can lead to pelvic inflammatory disease, infertility, and other serious
health problems, including increased risk of HIV infection. Rates of chlamydia [191–193] and complications of Chlamydia including PID, ectopic pregnancy, and infertility are several times higher among black women [194].

A team-oriented approach to testing for Chlamydia increased the screening rate of sexually active 14–18-year-old female patients from 5 to 65% in a large California HMO. The approach consisted of organizing teams of nurses, doctors, medical assistants, and administrative staff at the HMO’s pediatric clinics and educating them about chlamydia and its silent symptoms. Team members presented data to HMO leadership showing the gap between recommended screening practice and the plan’s past performance. They held monthly meetings to discuss problem-solving strategies, used urine-based testing instead of pelvic exams, and monitored progress with clinic-specific screening rates. This is an example of QI at its best. Although rates of Chlamydia by race were not reported, given the marked variation in Chlamydia prevalence by race, it is likely that this project will reduce disparities in Chlamydia complications.

Cancer Screening

The incidence of breast cancer is lower among black women compared to white, yet death rates from breast cancer are higher among black women [11]. Medicare claims and Medicare HMO HEDIS data show that black women continue to have significantly lower mammography rates than whites [123, 195].

The Health Insurance Plan of Greater New York conducted randomized trial of the effect of mammography screening on mortality [196]. Roughly 62,000 women aged 40–64 years from the Health Insurance Plan of Greater New York were randomized to control or study groups of equal size. Study group subjects were offered an initial screening mammogram and breast examination at their medical group center and three annual follow-up examinations. Study group participants who failed to respond to the initial letter asking them to schedule received prompts including letters or a telephone call. Over the course of the study, 73% required only the initial letter, 11% a follow-up reminder, and 16% repeated follow-up efforts. Compared to white women (27%), black women (26%) were more likely to require follow-up efforts. The net result of follow-up efforts was elimination in disparity in mammography between black women (61%) and white women (60%). In contrast to contemporaneous national data, there was racial difference in breast cancer survival between black and white women. These findings suggest that relatively simple recall and reminder systems offer potential for eliminating disparities in breast cancer mortality within HMOs.

The effectiveness of more intensive follow-up in a low-income, African American urban community is supported by findings from a randomized, controlled trial conducted by Weber and Reilly that compared a simple physician reminder letter (routine care) with case management by CHWs [197]. The case management involved use increasing outreach intensity (mailed cards, telephone
calls, home visits). The CHWs also facilitated appointment scheduling, transportation, and dependent care. Rates of mammography screening were nearly three times higher among women randomized to the case-management group. Similar findings for improvements in mammography screening (in addition to improvements in colorectal cancer and cervical cancer screening) have been reported by Dietrich et al. using telephone case management and Paskett et al. using CHWs for low-income, largely minority patients [198, 199]. These findings highlight the benefits of more intensive follow-up for harder-to-reach populations and Jandorf et al. using community health workers to promote colorectal cancer screening [200].

**Cancer Diagnosis and Treatment**

African Americans, and in some instances other minorities, experience higher rates of death from most major cancers [11]. Lower rates of cancer screening, delays in follow-up on abnormal screening results, and differences in treatment may contribute to these disparities [33, 201].

In response to these disparities, the Harlem Cancer Education and Demonstration Project implemented a patient navigation program. Patient navigators were para-professional community members who were trained to assist patients in overcoming access barriers. Patients with abnormal mammograms, Pap smears, Fecal occult blood testing, or rectal examinations in addition to those hospitalized with breast or cervical cancer were assigned to a navigator. After the study was completed, it was found that navigated patients were significantly more likely to complete breast biopsies than control patients who did not receive navigation [202]. These findings have been recently confirmed through a randomized controlled trial [203]. Based on pre-post design, a combination of patient navigation and a patient tracking registry eliminated disparities in treatment for breast cancer [204].

**Depression Management**

Depression affects all ages, races, and ethnic groups, although rates are higher among women [205]. Rates of depression do not appear to differ significantly between whites and blacks, but are higher among persons with low income [205]. Yet, Whites are more likely to receive antidepressants than minority patients [37, 206]. Additionally, among patients receiving antidepressants, whites are more likely than minorities to receive selective serotonin reuptake inhibitors [206] and to receive guideline concordant treatment for depression [207].

The Quality Enhancement by Strategic Teaming (QuEST) [208] eliminated disparities in depression management between insured and uninsured patients. Twelve community Prim Care practices from three practice-based research networks participated in the study. Prior to the intervention, none of the practices had
on-site mental health specialists to provide counseling. First off, practices were matched into six pairs based on participating physicians’ baseline depression treatment patterns, and one practice in each pair was randomized to the “enhanced care” group while the other continued to provide usual care. Two physicians from each practice and one nurse from each practice participated in the enhanced care. The nurse served as a “care manager” in administering the intervention. When an eligible participant was enrolled in an enhanced care practice, the physician was cued to evaluate the patient for depression and was then asked to return to the office within 1 week to meet with the nurse care manager. At that visit, the nurse reassessed depression symptoms, counseled the patient for treatment options, and assisted in overcoming barriers to initiate/comply with treatment. At the conclusion of this initial visit with the nurse, a brief checklist was completed for the physician’s review before seeing the patient and scheduling another telephone or in-person visit for the following week. Following a similar protocol, nurses completed weekly 15-min sessions with patients for the next 5–7 weeks. Nurse care managers were then specifically trained to help depressed patients overcome insurance-related barriers. In the usual care group, insured patients compared to uninsured patients as compared to the uninsured group were significantly more likely to receive adequate treatment for depression. However, these disparities in the treatment process were eliminated in the enhanced care group. Similar effects were noted in outcomes. In the usual care group, insured persons showed a fivefold greater improvement in Mental Health Quality of Life score than uninsured persons at 6 months. In contrast, in the enhanced care group there was no difference in improvement scores between the group. These effects were sustained at 24 months [209].

A similar project reduced racial and ethnic disparities in depression [210]. Matched Prim Care practices were randomized to usual care or one of two depression QI teams in which clinicians and nurses were trained to educate, assess, and follow-up patients for depression. One of the QI groups focused on medication adherence and the other on use of psychotherapists specifically trained in cognitive behavioral therapy. Copayments for psychotherapy were also reduced for both treatment groups. At 6 months, racial and ethnic disparities in reported depression cases were reduced in both treatment groups as compared to usual care. These results suggest that a variety of approaches including use of multidisciplinary teams, case management, clinician and nurse training, use of guidelines, and improved access to cognitive behavioral therapy may reduce disparities in depression.

Control of Hypertension

The age-adjusted prevalence of hypertension is significantly higher among African Americans than in the white population [211]. Hypertension sequela,
including premature death from cardiovascular, cerebrovascular, and renal disease, have enormous impact on the health of minorities, particularly African Americans, and represent a major source of disparities in mortality [212]. Only 30% of all whites and 26% of all blacks with hypertension have their blood pressure adequately controlled [211]. Additionally, among persons being treated for hypertension, less than half have their blood pressure adequately controlled and rates are lower for blacks than whites and poor vs. nonpoor persons [54, 211, 213].

The Rand Health Insurance Experiment was a randomized, controlled trial of cost-sharing in the general US population that was conducted at six sites across the nation. More than 2,000 families were randomly assigned to 1 of 14 experimental insurance plans [214]. All plans covered ambulatory and hospital care, preventive services, most dental services, psychiatric/psychological services, and prescriptions drugs. However, the extent of cost-sharing varied—from none to catastrophic coverage (where the family paid 95% of its health bills up to a maximum of $1,000 per family with reduced amounts for those with a lower income). Not surprisingly, quality of care was significantly better for hypertensive subjects assigned to the no cost-sharing group largely because of the greater frequency of visits. Compared to hypertensives within the cost-sharing groups, the fully insured were more likely to have been prescribed a diuretic, more likely to have three or more physician visits to during the year, more likely to have potassium checked in the presence of a diuretic, and more likely to have their blood pressure controlled [214]. The largest differences in blood pressure reduction between the no cost and other groups were seen among those with low-income. These findings suggest the possibility that prescription copayments may accentuate socioeconomic disparities in hypertension management.

The Hypertension Detection and Follow-up Program randomized was a community-based randomized trial. Nearly 11,000 participants were randomized to usual care for follow-up on their hypertension (referred care) or a systematic, anti-hypertensive treatment program (stepped care) [215]. The stepped care program was designed to maximize adherence and reduce barriers to initial attendance and long-term participation. Furthermore, participants received a free standardized program of anti-hypertensive therapy. Also, emphasis was placed on clinical attendance and adherence to therapy. Drugs, visits, lab tests, and transportation, if necessary, were provided without charge. Waiting times were minimized, and appointments were made at times convenient to subjects. In addition, medications were increased in a step-wise fashion according to protocol. Differences in degree of control between the stepped care and usual care were greater for blacks than for whites [216]. Blacks showed greater reductions in mortality than whites. Given this information, it can be seen that these results are consistent with the notion that a program designed to maximize adherence and protocol driven management of hypertension reduces disparities in both intermediate and long-term outcomes. Similarly, few racial disparities in cardiovascular risk reductions were noted among subjects enrolled in the special intervention program in the Multiple Risk Factor Intervention Trial [217].
**Diabetes Management**

The prevalence of diabetes is higher among blacks, Hispanics, and American Indians and persons living in poverty [218, 219]. Age-adjusted mortality rates from diabetes for blacks and American Indians are twice those of whites [220]. Blacks are at higher risk for complications from diabetes including amputation and renal failure [221]. Data from the 1993 Medicare Current Beneficiary Survey showed that elderly African Americans received lower quality care including less frequent glycated hemoglobin testing, eye examinations, influenza immunizations, lipid testing, and physician visits, but more emergency department visits [222].

Another study, the Diabetes Control and Complications Trial (DCCT), was a randomized control trial designed to assess the impact of intensive control of diabetes type I on the development of diabetic complications [223]. Subjects randomized to conventional therapy were seen every 3 months. They received one or two daily injections of insulin (including mixed intermediate and rapid-acting insulin), daily self-monitoring of urine or blood glucose, and education about diet and exercise. Subjects in the intensive-therapy group were seen monthly at the study center and were contacted even more frequently by telephone to review and adjust their regimens. Also, they administered insulin three or more times daily by injection or an external pump. The dosage was adjusted according to the results of self-monitoring of blood glucose performed at least four times per day, dietary intake, and anticipated exercise. In the conventional group, there were significant disparities in diabetic control by education, but none in the intensive management group [224].

**Adult Immunization**

National data show that fewer blacks (39%) than whites (60%) receive the influenza vaccine [225]. Hispanics and lower income persons also have significantly lower rates of influenza vaccination than whites [226]. Additionally, age-adjusted rates of death from pneumonia/influenza are higher among African Americans than whites and among persons with low vs. high income [10]. Disparities in influenza immunizations contribute appreciably to racial disparities among the elderly [227].

The Veterans Administration Health System implemented a QI program to boost rates of influenza vaccination that included patient reminders, standing orders, free standing vaccination clinics, and most importantly assessment of vaccination rates with feedback to providers [228, 229]. Disparities in adult immunization in the VA system are much smaller than nationally [230]. Several VA hospitals have not only exceeded 2010 goals for an influenza immunization standard of 90% but also have eliminated racial disparities in receipt of influenza immunization [231]. These findings suggest that system wide QI using established interventions can eliminate disparities by achieving very high levels of performance for all groups.


**Dialysis**

African Americans have been shown to receive less adequate hemodialysis as measured by urea reduction ratios [232]. A Centers for Medicare and Medicaid Services (CMS) sponsored QI project markedly reduced both racial and gender disparities in adequacy hemodialysis dose [233]. Regional quality oversight organizations monitored hemodialysis indicators every October, November, and December for the national random patient sample. CMS distributed region-specific performance data to all clinicians after the data had been distributed. The regional quality oversight organizations sent educational material to clinicians, conducted workshops, and supervised poorly performing facilities. Following this QI project, the racial gap in the adequacy of the hemodialysis dose was reduced from 10 to 3% and the gender gap from 23 to 9% [233]. However, despite the success of the dosage adjustment, racial and gender disparities in anemia and nutritional management did not improve. These findings show that QI efforts that do not specifically target a group may reduce disparities in some areas, but unfortunately this may not translate to others.

**Liver Transplantation**

In 2002, the allocation system for liver transplantation began using the Model for End-Stage Liver Disease (MELD) score [234]. This QI innovation uses objective criteria to predict 3 month mortality. Implementation of this score eliminated national black–white disparities in liver transplantation and in mortality among those on waiting lists [234]. This finding underscores the effectiveness of combining policy to implement well-designed QI innovations to address disparities.

**Other Approaches**

As indicated earlier, provider bias seems to be implicated in racial and ethnic disparities in access to expensive technology [1]. However, there are few established interventions for reducing such bias. One such approach is to blind decision makers to the race or ethnicity of the patient. This approach was effectively implemented by the Cleveland Veterans Administration Hospital to eliminate racial disparities in coronary revascularization [235]. The primary limitation of this approach is that it removes the referring or treating clinician from the decision-making role and replaces him or her with an individual who has not had direct contact with the patient. None the less, this approach warrants rigorous study particularly for interventions that involve either use of expensive technology or where resources are particularly scarce such as organ transplantation. A similar approach using protocols
eliminated disparities in invasive care among myocardial infarction patients within a University Hospital [236].

Another approach to reducing disparities is use of interpreters for patients who are not fluent in the language of the provider. Patients are less satisfied when they lack fluency in the language of their provider [237] and receive less optimal care [62]. Use of interpreters appears to improve outcomes [238] and there may be little difference in visit satisfaction between onsite professional interpreters and telephone interpreters [162].

**Pay-for-Performance: No Easy Answer**

Data from the United Kingdom suggest that their national pay-for-performance program has narrowed ethnic disparities in health care for some process measures [239], but not for intermediate outcomes [240, 241]. Pay for performance in the United States, particularly if not linked to disparity reduction [242], may have the unintended consequence of worsening disparities by penalizing under-resourced hospitals and practices with large minority populations [243, 244]. Instead, new systems of payment should take into account the needs of the population served [104]. Private practices in the United Kingdom receive capitation payments based on the socioeconomic status of the patients they serve [245]. Adapting this policy is much more likely to generate the needed resources for practices caring for poor and minority patients than pay-for-performance.

**Will and Resources Are Critical**

There are ample examples of innovations and policies that have reduced and even eliminated long-standing disparities. These lessons need to be translated into practice. Healthcare disparities often result from failure on the part of the healthcare system to allocate sufficient resources to addressing the needs of disadvantaged groups. That is, it is naïve to assume that life-long histories of disadvantage can be addressed by the healthcare system in the absence of will and allocation of sufficient resources.

Qualitative data garnered from leaders engaged in healthcare disparities initiatives underscore the role of resources and commitment to addressing disparities. Key elements cited include external accountability and alignment of incentives to reduce disparities, organizational commitment, population health focus, use of data to inform solutions, and a comprehensive approach to quality [246]. In other words, external factors that direct resources to healthcare disparities combined with internal factors, such as leadership and use of the appropriate tools, are likely to be critical to use of QI to address disparities.
Current QI Disparity Initiatives

There are a number of ongoing initiatives that explicitly link disparities in health care to QI. The Commonwealth Fund and the Health Resources and Services Administration (HRSA) are supporting the development of a report card to assess quality at the health plan level for members of various racial/ethnic minority groups. The goal is to “determine whether health plans can obtain data on the race/ethnicity of their members through one or more possible methods and whether those data can be used to generate reports on quality of care stratified by race/ethnicity.” The project is a collaborative effort by Michigan State University, the Henry Ford Health System, the Lovelace Clinic Foundation, the University of Texas School of Public Health, and 13 health plans [247]. Results appear promising [248].

The National Committee for Quality Assurance (NCQA) assembled an expert panel on Culturally and Linguistically Appropriate Services (CLAS) to address healthcare disparities in managed care. This represents a significant first step on the part of NCQA towards the goal of incorporating race and ethnicity into HEDIS reporting and recognizing that provider cultural competence and language can affect health care for minority plan members. The National Quality Forum also assembled an expert panel in 2006 to advise them on design of quality measures to assess disparities in health care.

JCAHO has recently proposed standards that would require health organizations to collect and include, in medical and clinical records, the patient’s race, ethnicity, and primary spoken language. The inclusion would apply to standards in the Comprehensive Accreditation Manuals for Ambulatory Care, Behavioral Health Care, Home Care, Hospitals, Long-Term Care, and Assisted Living.

Aetna initiated ground-breaking work in this area with the assistance of a national advisory committee. They began collecting race and ethnicity data and used these data to implement disparity initiatives. Aetna has made a business case for this work [249]. The Aetna disparity project has demonstrated that it is feasible (and profitable) for health plans to collect race/ethnicity data, assess disparities in health care, and implement interventions when the corporate leadership is adequately committed.

Several promising national collaborative initiatives use QI to address disparities. These include the Health Disparity Collaboratives conducted with Federally qualified community health centers by the Bureau of Primary Health Care [250], the Quality Improvement Organizations funded by CMS [251], the Health Plan Collaborative funded by the Agency for Healthcare Quality and Research [252], and the Robert Wood Johnson Foundation (RWJF). Case studies of successful strategies along with toolkits are posted on the RWJF website [253]. The RWJF has also supported “Expecting Success” which has reduced disparities in cardiovascular care between participating hospitals nationally [252] and “Finding Answers” designed to stimulate innovative solutions to healthcare disparities [254]. Other promising programs include Get-with-the-Guidelines Program that improved cardiac care for all patients regardless of race [255], AHRQ’s EXCEED program [256],
Getting Started

Obtaining Race and Ethnicity Data

Addressing disparities requires that the health plan, hospital, or practice obtain race and ethnicity data on patients. Ideally, these data should be collected at the point of enrollment, initiation of care, or most recent point of care and be based on the patient’s report of their own race or ethnicity. However, in most instances these data are not immediately available and collecting them on existing patients can be challenging. Fortunately, there are indirect means for estimating the patients’ race or ethnicity. Examples include use of geocoding and surname analysis. When combined, they provide a reasonable approximation of a person’s race and ethnicity [260]. Some community physicians may be reluctant to collect race ethnicity data, but these concerns are potentially addressable [261].

Identifying Disparities in Care

Once the healthcare organization has obtained race and ethnicity data, these can be linked to current quality indicators to determine where disparities exist. Alternatively, administrative claims data can be screened to determine where disparities are likely to be found. These can be followed by more focused quality audits. Similarly, the existing literature on healthcare disparities can serve as a guide. Most organizations will observe racial and ethnic disparities for invasive cardiac procedures, organ transplantation, diagnosis and management of depression, cancer care screening, influenza vaccinations, and control of hypertension and diabetes among their members. These data can be used to guide focused analyses within the organization to determine whether disparities exist in these areas.

Implementing an Intervention

Successful interventions should be lead by quality improvement teams that include different disciplines and are racially and ethnically diverse. The previously cited successful programs can serve as a guide to the design and implementation of interventions to address disparities. It is wise to begin with small pilots and obtain feedback from patient and providers using focus groups about these pilots. These
findings can be used to inform the design of large-scale interventions. Standard quality improvement strategies, such as plan-do-study-act [262], or rapid cycle change [263], and others can be used. Whatever approach is used, it is critical that the success of the initiative be evaluated so that adaptations can be made.

**Conclusion**

Racial and ethnic disparities in healthcare quality have been extensively documented. Interventions are needed to ameliorate these disparities. Given that equity is a core dimension of quality, it is most appropriate to leverage the resources of QI to address these disparities. This chapter has outlined strategies and tools for doing so. However, no single intervention or strategy will be successful in eliminating disparities, just as no single QI intervention will transform healthcare quality. Rather, the elimination of healthcare disparities will require the development and implementation of tailored interventions directed at multiple levels. Success will depend on the vision, leadership, commitment, and allocation of adequate resources by government, health plans, hospitals, communities, practices, and most importantly, on the full and active participation of minority patients.

Passage of the Patient Protection and Affordable Health Care Act may help jumpstart progress in addressing healthcare disparities by reducing access barriers, providing additional funding and incentives for QI, expanding collection of race and ethnicity data and promoting measurement and reporting of healthcare disparities, promoting workforce diversity, facilitating health information technology, and increasing funding for community health centers. Implementation of IOM recommendations for improvements in the National Healthcare Disparities reports may facilitate better tracking of national progress and accountability for achieving this national goal [264].

**References**


69. Hebet PL, Frick KD, Kane RL, McBean AM. The causes of racial and ethnic differences in influenza vaccination among elderly Medicare beneficiaries. HSR 2005;40:(in press).
74. Lambrew JM, DeFries GH, Carey TS, Ricketts TC, Biddle AK. The effects of having a regular doctor on access to Prim Care. Med Care. 1996;34:138–51.
99. Burgess DJ. Are providers more likely to contribute to healthcare disparities under high levels of cognitive load? How features of the healthcare setting may lead to biases in medical decision making. Med Decis Making. 2010;30:246–57.
110. Cunningham PJ. Pressures on safety net access: the level of managed care penetration and uninsurance rate in a community. Health Serv Res. 1999;34:255–70.


215. Hypertension Detection and Follow-up Program Cooperative Group. Five-year findings of the hypertension detection and follow-up program. I. Reduction in mortality of persons with


259. CPHHD. NIH Centers for Population Health and Health Disparities.


Abstract  Adding insult to injury – This well-worn phrase redounds with new significance when considering healthcare disparities in the context of social inequalities in health. The very same social groups at greatest risk of being subjected to inadequate access to and unequal treatment in healthcare also endure the greatest risk of poor health status and premature mortality, reflecting the daily toll of discrimination, economic deprivation, political marginalization, and prioritization of economic gain over human needs (Smedley et al., Unequal treatment: confronting racial and ethnic disparities in health care. Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Board on Health Sciences Policy, Institute of Medicine. Washington, DC: National Academy Press, 2003; Levy and Sidel (eds), Social injustice and public health. New York: Oxford University Press, 2006; Navarro and Muntaner (eds), Political and economic determinants of population health and well-being: controversies and developments. Amityville: Baywood, 2004). Greater need and lesser care nefariously combine to create even more onerous burdens of preventable suffering, for it is within the very same bodies that these injuries and insults are integrated and embodied (Krieger (ed), Embodying inequality: epidemiologic perspectives. Amityville, NY: Baywood Publishing Co., 2004).

To right these health wrongs, and to hold accountable the institutions, policies, and priorities that routinely permit or actively benefit from the everyday health inequities so evident within and across countries, data are essential. Information is needed on the magnitude of the problem, on who is most burdened by poor health and healthcare, and whether the disparities are shrinking or expanding. Not that these data can by themselves change anything. Rather, in the hands of those working for health equity, evidence of disparities in health status and healthcare is required to identify who is most harmed, who gains, and what actions need to be taken, by which groups, to make a change for the better.


In this chapter, our focus on the lack of socioeconomic data in most US medical records and public health surveillance systems (Krieger et al., Public Health Rep 112:481–91, 1997; Friedman et al. (eds), Shaping a vision of health statistics for
Monitoring Socioeconomic Determinants for Healthcare Disparities

Public Health Disparities Geocoding Project: Purpose, Perspective, and Context

We undertook our project because of an important problem: the lack of socioeconomic data in most US public health surveillance systems [1]. This is why 72% of the 74 tables on “Health status and determinants” in the major federal report, *Health United States, 2005* include no socioeconomic data, even as they are stratified by race/ethnicity and gender [2]. It is also why 70% of the 467 *Healthy People 2010* objectives lack socioeconomic targets [3]. Clearly, without data on social class, one cannot monitor progress – or setbacks – in eliminating socioeconomic inequalities in health, let alone ascertain their contribution to racial/ethnic disparities in health (Table 15.1).

<table>
<thead>
<tr>
<th>Table 15.1</th>
<th>Synopsis of The Public Health Disparities Geocoding Project [4–15]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td>Despite longstanding evidence on intimate links between neighborhood poverty and neighborhood health, most US public health surveillance system lack socioeconomic data, thus precluding routine monitoring of socioeconomic disparities in health and their contribution to US urban health inequities</td>
</tr>
<tr>
<td>Methods</td>
<td>To address this problem, <em>The Public Health Disparities Geocoding Project</em> geocoded and linked public health surveillance data from Massachusetts and Rhode Island to 1990 census-derived ABSMs to determine which ABSMs, at which geographic level (census BG, CT, and ZC), could validly be used to monitor socioeconomic inequalities in health. Outcomes included: birth, childhood lead poisoning, sexually transmitted infections, tuberculosis, nonfatal weapons-related injuries, cancer incidence, and mortality</td>
</tr>
<tr>
<td>Results</td>
<td>In both the total population and diverse racial/ethnic-gender groups, measures of economic deprivation proved most sensitive to expected socioeconomic gradients in health, with CT ABSMs yielding the most consistent results and maximal geocoding across outcomes, and the CT poverty measure performing as well as more complex composite measures</td>
</tr>
<tr>
<td>Implications</td>
<td>Geocoding and use of the CT poverty measure permits routine monitoring and mapping of US socioeconomic inequalities in health, using a common and accessible metric</td>
</tr>
</tbody>
</table>

ABSMs area-based socioeconomic measures; BG block group; CT census tract; ZC zip code
Our study accordingly systematically investigated a possible solution, drawing on an approach used eclectically in US health research for over 75 years: that of using geocoding and area-based socioeconomic measures (ABSMs) [5, 16, 17]. The basic method is to characterize both cases and the population from which they arise by the socioeconomic characteristics of their residential areas, using US census data. This in turn permits calculating rates stratified by the ABSMs – which, because they are census-derived, can be used in any region in the United States.

However, one major problem is that, before our Project, there existed no consensus about which ABSMs should be used, and at which geographic level. Owing to the absence of a common methodology, monitoring is impossible, because results cannot be compared across regions or over time. Accordingly, the key question we sought to answer was: does choice of ABSM and geographic level matter? The answer, in brief, is “yes,” as the rest of this chapter explains.

Informing our Project was the theoretical perspective of ecosocial theory, a theory of disease distribution guided by the question “Who and what drives current and changing patterns of social inequalities in health?” (Fig. 15.1) [18–21]. Its four-core-constructs, described in detail elsewhere [18–21], pertain to: [22] “embodiment,” referring to how we literally embody, biologically, our lived experience thereby creating population patterns of health and disease; [23] “pathways of embodiment,” referring to how there are often multiple pathways to a given outcome, through diverse physical, chemical, biological, and social exposures, and involving gene expression, not just gene frequency; [24] “cumulative interplay of exposure, susceptibility, and resistance across the lifecourse,” because all three matter; and [21] “accountability and agency,” both for social inequalities

![Fig. 15.1 Ecosocial theory [18–20]](image)
in health and for ways they are – or are not – analyzed and addressed. In the case of our Project, the intent was to increase accountability for and understanding of pathways of embodiment leading to socioeconomic health inequities by doing the kind of research that lies squarely within the domain of responsibilities of health researchers: developing a methodology to overcome the absence of socioeconomic data in most US public health surveillance systems [1]. The express intent was to rectify a gap that removes class inequities in health from public view and hence from the policy and action agenda to eliminate health disparities.

**Historical Context of the Project**

However, before jumping in the methodological details it is important to put our Project in conceptual and historical context. The first point, perhaps obvious, is that awareness of what is now referred to as social inequalities in health, or health inequities, is not exactly new. In fact, it is a bit hard to miss the injurious effects of destitution, degradation, and hard work on health, and descriptions can be found in documents dating back to the earliest known medical texts. One, from around 2000 BCE in Egypt, during the time of the prosperous Middle Kingdom, recounted [25]:

… I have seen the metal worker at this task at the mouth of his furnace. His fingers were like the hide of crocodiles …. The barber shaves till late in the evening … He strains his arms to fill his belly and works as indefatigably as a bee …. The weaver in the workshop is worse off than the women (who must always sit in the house) …. He bribes the doorkeeper with bread that he may see the light …

The Hippocratic treatise, *On Diet*, likely written in the fourth century BCE, likewise observed that only a small minority of the Greek population – its vaunted citizens – had the wherewithal to lead a healthy life. The vast majority – upward of 75% of the population – could not be, described as “the mass of people” who “are obliged to work,” “who drink and eat what they happen to get,” and so “who cannot, neglecting all, take care of their health” [26].

These kinds of comments, however, were comments that were chiefly asides. What these early texts mainly provided was advice on how to live well, directed to those who could afford to live leisured lives precisely because others did the hard labor allowing them this leisure. Indeed, it would not be for another 2,000 years, in the sixteenth century CE, that the question of how work affects health would first attain sustained treatment in European medical texts [27, 28]. It was not until the early nineteenth century that studies systematically began to explore links between poverty and health and between slavery and health, and not until the later nineteenth century that research began seriously to investigate the impact of women’s work – whether at home or in the paid labor force – on women’s health [27–31]. Interest in the twentieth century in social inequalities in health, moreover, has waxed and waned [28, 30, 31], though of late it has been on the increase, such that in the United States, the elimination of social disparities in health is now one of the two overarching goals of Healthy People 2010 [3].
The neglect of what may seem obvious leads to a second point: that social inequality can shape the very picture people draw of social inequalities in health [21, 32, 33]. At issue are both description and explanation. In other words, social inequality can influence: what is seen – or ignored – by whom; how these patterns are – or are not – explained; and what sorts of remedies are – or are not – proposed. One implication is social inequalities in health – however real – can be ignored and rendered invisible if the data to document them are not collected, whether by conscious design or unconscious neglect. A second implication is that even if the data are collected, and no one disputes the reality of the disparate health status between the groups at issue, there can still be major controversies over why these disparities exist and who should do what about them.

Consider only centuries of debate in the United States over the poor health of black Americans. In the 1830s and 1840s, contrary schools of thought asked: was it because blacks are intrinsically inferior to whites? – the majority view, or because they were enslaved and economically impoverished? – as argued by, among others, James McCune Smith (1811–1865) and James S. Rock (1825–1866), two of the country’s first credentialed African American physicians [34]. The fundamental tension, then and now, is between individualistic versus contextualized theories, in other words, theories that seek causes of social inequalities in health in innate versus imposed, and individual versus societal, characteristics. Highly relevant to these debates is whether even data are available on the extent and contours of health inequities.

Also worth emphasizing is that during the early nineteenth century research indicated the utility of using neighborhood socioeconomic data to understand population health. For example, in the mid-1820s, research conducted by Louis René Villermé (1782–1863) in France broke new ground by showing that mortality rates in Parisian districts could be meaningfully ordered by a measure of neighborhood assets, whereby mortality rates were highest among areas whose residents paid the least in “untaxed rents,” a type of tax paid only by the wealthy [35, 36]. Whereas such data are not surprising now, in the early 1800s they were astounding. This is because the dominant mode of thought, until this time, had followed Hippocratic doctrine in assuming that the “natural environment” – that is, “air, water, places” – was what drove population patterns of health. Thus, before producing this table, Villermé had valiantly tried, without success, to find correlations between Parisian neighborhood mortality rates and various environmental features predicted by Hippocratic reasoning, including exposure to sunlight (or lack thereof), proximity to the Seine, wind patterns, and presence of trees and parks [35, 36]. It was only by linking data on mortality and socioeconomic resources, derived from the newly amassed and unprecedented Parisian census that Villermé could make sense of Parisian mortality data. In doing so, he empirically demonstrated – for the first time anywhere – that variations in mortality rates across neighborhoods were neither a result of solely chance nor the natural environment, but instead were profoundly patterned by poverty and wealth [31, 32, 35, 36]. The net effect was to introduce a whole new realm – societal conditions – into the lexicon of determinants of health, as well as to make socioeconomic inequalities in health a visible topic of research, monitoring, and action. Regarding the cause of these health inequalities and relevant remedies: well,
the debate was fierce, with some arguing moral sloth was the underlying cause of both poverty and poor health, and others pointing to destitution resulting from low wages and high rents.

Taking these arguments a step further, in 1844 Friedrich Engels (1820–1895) published the now classic text *The Condition of the Working Class in England* [37]. To Engels and other radical investigators, the evidence at hand led them to argue that the poor health and immiseration of the urban working class and poor was routinely and inherently produced by the heightened imperative and capacity to accumulate capital, producing great wealth for the few and poverty for the many [23, 24, 27, 28, 31, 37]. Fabulous fortunes and novel consumer goods were but the other side of a coin minted by an economic system whose deadly “dark satanic mills,” in Blake’s famous phrase [38] destroyed health through both horrendous working conditions and starvation wages.

Importantly attuned to how class matters for not only workplace conditions but also standard of living at the individual, household, and neighborhood level, Engels highlighted evidence of higher mortality among poor households in poor compared with improved streets [37]. Notably, it has only been in the past decade that this type of contextual effect has again begun to receive serious attention in contemporary research [39–41].

The basic point, then, is that issues of social inequalities in health and use of area-based socioeconomic data are not new. Conceptual frameworks and the ability to generate empirical evidence to address these issues have existed for over 150 years.

**Public Health Disparities Geocoding Project: Study Design and Key Results**

Given this background, the methodological purpose of this empirical investigation was to determine which ABSMs, at which geographic level, would be most appropriate for public health monitoring [4–15], while at the same time availing ourselves of recent advances in computer technology and software, geographic information systems, statistical methods, and ease of accessing public health surveillance data and US census data [42, 43]. Our goal was to come up with valid, robust, easy to construct, and easy to interpret ABSMs that could readily be used by any US state health department or health researcher, for any health outcome – from birth to death, for women and men, young and old alike, among any racial/ethnic group. Guided by ecosocial theory, we anticipated that different ABSMs might function differently for diverse outcomes. Thus, our outcomes spanned the gamut and included: low birthweight, childhood lead poisoning, sexually transmitted infections, tuberculosis, nonfatal weapons-related injuries, cancer incidence (all-sites and site-specific), and mortality (all-cause and cause-specific).

The study design of the *Public Health Disparities Geocoding Project* is provided in Fig. 15.2. Briefly stated, each public health surveillance data set was first geocoded to three different geographic levels: the census block group (BG), the census tract (CT), and the ZIP code® (ZC). Geocoding entails assigning a record,
based on its geographic location (in this case, the residential address), the relevant geographic codes used for this location by the US census (for the census BG and CT) and also the US post office (for the ZC). To carry out the geocoding, we used a geocoding firm whose accuracy we verified to be high (96%) [11]. Additionally, for each of the three chosen geographic levels, we created diverse ABSMs as described below. We then linked the health records and the ABSMs thereby allowing us to compute rates stratified by these ABSMs. Numerators consisted of the cases and denominators of the population (ascertained in the 1990 census) living in areas at the specified socioeconomic level. The methodological details of how we carried out each of these steps is provided, at no cost, at the Project’s website [4] (http://www.hsph.harvard.edu/thegéoencodingproject), as downloadable pdf files of our Project’s published scientific articles [4–13].

For the analyses, we computed, for each health outcome, rates stratified by the ABSMs at each level of geography and did so first for the total population of each state and then also stratified by race/ethnicity and gender. We then compared estimates of socioeconomic gradients for each outcome, within each level of ABSM, and also, for each ABSM, across levels. Before conducting these comparisons, we delineated four a priori criteria for evaluating the ABSMs [4–8]:

1. External validity: Did we detect the expected socioeconomic gradient, in magnitude and direction, based on what has been reported in the literature?
2. Robustness: Did the ABSM perform well across diverse outcomes, among both women and men, overall and by race/ethnicity?
3. Completeness: Was the ABSM affected by relatively little missing data?
4. User-friendliness: Could the ABSM be easily understood by health department staff and the general public, as opposed to by only health professionals or other researchers?
Here we emphasize that our goal was to choose an ABSM that would be appropriate for routine monitoring of socioeconomic inequities in health across many health outcomes, which is distinct from the objective of choosing, for any given health outcome, the ABSM that might be most etiologically relevant.

**Study Base and ABSMs**

Regarding the units of geography, Fig. 15.3 illustrates the relationship of the census-defined units [12, 44]. The basic census-building block is literally the census block, with an average population of approximately 85 persons. It is nested within the next unit, the census BG, which on average contains 1,000 persons and is the smallest census unit for which estimates of socioeconomic characteristics are released. Census BGs in turn are nested within Census Tracts (CTs), which typically include 4,000 people and are defined by the US census to be a “small, relatively permanent statistical subdivision of a county … designed to be relatively homogeneous with respect to population characteristics, economic status, and living conditions” [44]. Underscoring the real-life relevance of CTs for their residents, CT data are used to determine eligibility of areas for diverse programs, including “Urban Empowerment Zones,” “Medically Underserved Areas,” and “Qualified Census Tracts” for the low-income housing credit [5, 45, 46]. ZCs are not shown because they are not defined by the US census; instead, they are virtual overlapping geographic areas designed to facilitate the delivery of mail and typically contain at least 10,000 people [10, 47].

Table 15.2 presents data on the study population, defined in terms of people. In 1990, the population of Massachusetts was approximately six million persons and that of Rhode Island, about one million. The number of records obtained from each surveillance system varied by outcome, with the total equaling nearly one million. Table 15.3 in turn provides data on the study base as defined by geographic units.

![Fig. 15.3 US census-building blocks [44]](image-url)
Table 15.2  Public Health Disparities Geocoding Project: study population in terms of population – Massachusetts and Rhode Island, ca. 1990 US census [5–9]

<table>
<thead>
<tr>
<th></th>
<th>MA</th>
<th>RI</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990 Population</td>
<td>6,016,425</td>
<td>1,003,464</td>
</tr>
<tr>
<td>Mortality dataa</td>
<td>155,764</td>
<td>27,287</td>
</tr>
<tr>
<td>Cancer datab</td>
<td>140,610</td>
<td>19,798</td>
</tr>
<tr>
<td>Birth data</td>
<td>267,311</td>
<td>96,138</td>
</tr>
<tr>
<td>Childhood lead screening (RI only: 1994–1995)</td>
<td>–</td>
<td>62,514</td>
</tr>
<tr>
<td>Nonfatal weapons-related injury</td>
<td>5,517</td>
<td>–</td>
</tr>
</tbody>
</table>

MA Massachusetts; RI Rhode Island; STIs sexually transmitted infection; TB tuberculosis

Table 15.3  Public Health Disparities Geocoding Project: study population in terms of areas – Massachusetts and Rhode Island, 1990 US census [5–9]

<table>
<thead>
<tr>
<th>State</th>
<th>Geographic level</th>
<th>N</th>
<th>N</th>
<th>Standard deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>MA</td>
<td>BG</td>
<td>5603</td>
<td>1085.40</td>
<td>665.20</td>
<td>5–10,096</td>
</tr>
<tr>
<td></td>
<td>CT</td>
<td>1331</td>
<td>4571.80</td>
<td>2080.00</td>
<td>15–15,411</td>
</tr>
<tr>
<td></td>
<td>ZC</td>
<td>424</td>
<td>12,719.70</td>
<td>12,244.10</td>
<td>14–65,001</td>
</tr>
<tr>
<td></td>
<td>BG</td>
<td>897</td>
<td>1,137.70</td>
<td>670.80</td>
<td>7–5,652</td>
</tr>
<tr>
<td>RI</td>
<td>CT</td>
<td>235</td>
<td>4,325.30</td>
<td>1,810.90</td>
<td>26–9,822</td>
</tr>
<tr>
<td></td>
<td>ZC</td>
<td>70</td>
<td>14,335.20</td>
<td>13,234.80</td>
<td>63–53,763</td>
</tr>
</tbody>
</table>

MA Massachusetts; RI Rhode Island; BG block group; CT census tract; ZC ZIP code

As expected, BGs and CTs on average contained approximately 1,000 and 4,500 people, respectively, and the ZCs, about 13,000–14,000 people. Population size was most variable at the ZC level and least at the BG level.

Next, to generate the ABSMs, we drew on our conceptual understanding of social class and socioeconomic position (SEP) [30, 48]. Stated simply, “social class” refers to social groups arising from interdependent economic relationships among people. One cannot, for example, be an employee if one does not have an employer and this distinction – between employee and employer – fundamentally concerns people’s relationship to work and to others through a society’s economic structure [48]. One manifest expression of the social relationship of class is thus socioeconomic position, an aggregate concept that includes both resource-based
assets, such as income, wealth, and educational credentials, and also prestige-based measures. Given distinctions between actual assets and prestige, we use the term “socioeconomic position,” and not “socioeconomic status,” because the latter arbitrarily (if not intentionally) privileges “status” over material resources as central to the construct and lived experience of class [48].

From this vantage, we generated 19 census-derived ABSMs, 11 single variables and eight composites, intended to capture diverse domains of socioeconomic position relevant to health [4–9, 12]. Listed in Table 15.4, these included: occupational class, income and income inequality, poverty, wealth, education, crowding, and combinations of these variables, including preestablished indices, such as the Townsend deprivation index, widely used in the United Kingdom, and also the Centers for Disease Control and Prevention index of local economic resources.

Last, regarding geocoding, overall we were able to geocode 92% of the nearly one million records to the BG level, 98% to the CT level, and 98.2% to the ZC level. Importantly, we found little difference in the percent geocoded by outcome, age, gender, or race/ethnicity, or for the birth and death records, by educational level. However, nearly 6% of the records with ZC could not be linked to 1990 census, either because they were for nonresidential sites or else were in ZCs created or changed after the 1990 census. This ZC discrepancy resulted in analyses by ZCs introducing a selection bias for some outcomes sufficiently severe to reverse, and the direction of the socioeconomic gradient wrongly detected with the CT and census BG measure – with the latter importantly in the same direction as reported in the literature when using individual-level measures of socioeconomic position [10].

Table 15.4 Public Health Disparities Geocoding Project: ABSMs [4–9, 12]

<table>
<thead>
<tr>
<th>Domains:</th>
<th>11 single variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational class</td>
<td></td>
</tr>
<tr>
<td>Income + social wage</td>
<td></td>
</tr>
<tr>
<td>Wealth + debt</td>
<td>Working class (%)</td>
</tr>
<tr>
<td>Educational credentials</td>
<td>Unempolyed (%)</td>
</tr>
<tr>
<td></td>
<td>Median annual HH income</td>
</tr>
<tr>
<td></td>
<td>Low income: HH (%) &lt; 50% median income</td>
</tr>
<tr>
<td></td>
<td>High income: HH (%) ≥ 150,000 USD/yr</td>
</tr>
<tr>
<td></td>
<td>Gini coefficient (income inequality [%])</td>
</tr>
<tr>
<td></td>
<td>&lt; poverty</td>
</tr>
<tr>
<td></td>
<td>Crowded HH (%) (&gt; 1 person/room)</td>
</tr>
<tr>
<td></td>
<td>Owner-occupied homes (%) ≥ 300,000 USD</td>
</tr>
<tr>
<td></td>
<td>Low: adults (%) &lt; high school</td>
</tr>
<tr>
<td></td>
<td>High: adults (%) ≥ 4 yr college</td>
</tr>
<tr>
<td></td>
<td>Eight composite</td>
</tr>
<tr>
<td></td>
<td>UK deprivation indices: Townsend, Carstairs</td>
</tr>
<tr>
<td></td>
<td>CDC index of local economic resources</td>
</tr>
<tr>
<td></td>
<td>SEP1, SEP2, factor 1, factor 2, and SEP index</td>
</tr>
</tbody>
</table>

HH household; CDC socioeconomic position
Key Methodological Results, Caveats, and Recommendations: For Routine Monitoring, Use the CT Poverty Measure

As discussed in the Project’s publications [4–15], our key findings (Fig. 15.4), based on analyses for each outcome by each state for the overall population and by racial/ethnic-gender group, were that:

1. Measures of economic deprivation were most sensitive to expected socioeconomic gradients in health.
2. CT level analyses yielded the most consistent results with maximal geocoding (compared with the BG and ZC data).
3. These findings held for separate analyses conducted for white, black, and Hispanic women and men, and also for those outcomes that could be meaningfully analyzed among the smaller Asian and Pacific Islander and American Indian populations.
4. The single-variable measure “percent of persons below poverty” performed as well as more complex, composite measures of economic deprivation, such as the Townsend index.

Based on these results, we propose that US socioeconomic inequalities in health can be monitored with the common metric of the CT poverty measure. We further note that one advantage of this approach is that, unlike individual-level education and occupation, this measure can be applied to all persons, regardless of age and gender, whether in or out of school, and in or out of the paid labor force [5, 48–52]. Additionally, CT data can provide important information on social context that may

---

**Fig. 15.4** Public Health Disparities Geocoding Project: summary of key findings [5–15]
affect population health [5, 39–41, 48–52], even as we recognize that this etiological hypothesis can only be tested in data sets that contain both individual- and area-level socioeconomic data.

Despite these appealing features, four caveats pertain to the use of CT data for monitoring socioeconomic health inequities. The first concerns “ecological fallacy,” which occurs when both the dependent and independent variables are group-level data and confounding is introduced through the grouping process [5–9, 40, 41, 43, 53]. The second is the “modifiable areal unit problem,” [53, 54] in this case referring to whether CTs are meaningful entities relevant to shaping population health or can provide relevant data on socioeconomic heterogeneity within neighborhoods [5, 49, 55, 56]. The third pertains to etiological period, because without the study the CT data were measured only at the time of the decennial census and in a time period corresponding to that of the health outcomes of interest [5–9]. The fourth concerns omitted variables and selection bias, whereby both can yield biased estimates of exposure-outcome associations and jeopardize valid causal inference [53, 57–60].

First, regarding “ecological fallacy,” although this theoretically may be a problem, empirically research from the Public Health Disparities Geocoding Project suggests this potential fallacy is unlikely to introduce serious bias [5–9, 14, 15]. Thus, for analyses for the two outcomes for which we had individual as well as CT socioeconomic data, that is, birth and death records, the findings unambiguously demonstrated that the direction of the socioeconomic gradient was the same, and also was of similar magnitude, for both the individual-level and CT socioeconomic measures [14, 15]. The only exception occurred for mortality rates for deaths above age 65, whereby using the CT socioeconomic measures we found a linear association (more economic deprivation associated with higher mortality) but using the individual-level education data, we found evidence of a nonlinear association, with rates highest among persons reported to have at least a high school diploma but less than 4 years of college [15]. This discrepancy was likely due to selective misclassification of the individual-level educational data [15], an inference supported by other mortality studies that have compared results based on verified educational data versus educational data from the death certificate [61, 62]. These earlier studies found the same “J-shaped” curve for mortality rates by educational level among older populations, which occurred because of the tendency of decedents with less than a high school education to be reported as having had at least a high school education [61, 62].

Second, regarding the CT as an appropriate geographic unit, as noted previously, CT boundaries are drawn to be socially meaningful and to delimit administrative areas that are relevant to resource allocation ([5, 44], p. A-5). Thus, in addition to the various federal programs that use CT data to target resources for medical care, housing, and employment [45, 46], cities use CT boundaries to define neighborhoods for public health department programs, school districts, and other municipal programs [5, 43].

Third, for the purposes of monitoring, a measurement of socioeconomic position at the time the health outcome is diagnosed or reported is appropriate, insofar as the aim is to determine the population distribution of the burden of disease or death at the time that it occurs [5]. While etiological research on the causal links between socioeconomic
position and risk of poor health may want to use socioeconomic data from earlier time periods, at the individual as well as contextual level [48–52, 63], along with data on other relevant covariates, such analyses address issues quite distinct from those of routine monitoring of socioeconomic inequities in health. Additionally, concerns about being restricted to solely decennial census data will soon no longer be warranted, given the anticipated availability of yearly CT data (based on 5-year rolling averages) from the American Community Survey, starting in 2010 [64].

The fourth and final set of caveats, regarding the separate problems of omitted variables and selection bias [53, 57–60], again pertain more to etiological investigations than monitoring health inequities. In the case of omitted variables, the concern is that an unmeasured common cause of risk of living in a certain type of CT and of having a certain health outcome could produce biased estimates of the associations between CT characteristics and the health outcome, and hence the observed socioeconomic gradient. However, the same concern would hold for any socioeconomic measure, including at the individual level. Moreover, from a monitoring perspective, the observed social distribution of health is the empirical entity at issue – and which constitutes precisely the sort of needed spark for causal investigation of why the observed social patterning of morbidity and mortality exists. Health selection, in turn, could induce associations if poor health during childhood led to: [22] a reduced earning potential, hence increased risk of living in an economically disadvantaged CT (or, if data were available at other levels, having a low individual or family income) and [23] the specified health outcome [48, 51, 52, 65]. The growing body of life-course research nevertheless indicates that cumulative disadvantage, not just early life or adult conditions, is a powerful determinant of many health outcomes [21, 23, 24, 63, 66–69]. Thus, to the extent current CT characteristics can be viewed as a summary of the economic trajectories leading to its population composition, this lessens, but again does not absolve, health selection as being a previous common cause leading to an association between CT characteristics and risk of a given health outcome. In summary, although it is essential to be aware of the limitations for causal inference for analyses that use geocoding and ABSMs or other types of socioeconomic measures, these limitations in no way undercut the utility of the methodology that has been described for the routine monitoring of socioeconomic inequalities in population health. Estimating the magnitude of the problem is a necessary first step, a prelude to analyzing cause and generating remedies – and we emphasize that only routine monitoring can show whether the absolute rates of disease and health inequities are getting better or worse over time.

**Key Substantive Results: Socioeconomic Inequalities in Health, Overall and by Race/Ethnicity and Gender**

Figure 15.5 accordingly illustrates what US public health data could look like, from birth to death, using our approach, using one common metric for socioeconomic position: the CT poverty level [5–9]. For each outcome, we show the
Fig. 15.5 Public Health Disparities Geocoding Project: socioeconomic inequalities in health, from birth until death, for total population and by race/ethnicity and gender, Massachusetts and Rhode Island, ca. the 1990 US census [5]
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
socioeconomic gradient for the total population and also by racial/ethnic-gender group. The point is not that the socioeconomic gradients depicted are novel, per se, but rather that the method presented newly allows these health inequities to be routinely documented and monitored, using existing public health surveillance systems, to guide efforts to address socioeconomic inequalities in health, at the national, state, or local level. Outcomes presented are as follows:

1. Childhood: low birthweight and blood lead levels.
2. Sexually transmitted infections: gonorrhea, chlamydia, and syphilis.
3. Other infectious disease: tuberculosis.

In all cases, except for the childhood outcomes, rates are age-standardized to the 2000 US standard million [70].
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
Fig. 15.5 (continued)
The format of each figure provides information on the rate of the health outcome by each of the four designated socioeconomic strata, ranging from CTs with less than 5% of the population below the poverty level to CTs where 20% or more of the population lives below poverty (the federal definition of a “poverty area” [71]). The height of each bar indicates the age-standardized rate (or, in the case of low birthweight and childhood lead poisoning, the proportion); the actual numerical value of rate is provided at the top of the bar, along with a vertical line displaying the rate’s 95% confidence interval (CI). The width of each bar in turn is proportional to the size of the population living in each of the four socioeconomic stratum (<5, 5–9.9, 10–19.9, and ≥20%, respectively, of the population below poverty). Consequently, for those populations living chiefly in the least poor CTs, for example, white non-Hispanics, the width of the bars is greatest for the least poor socioeconomic stratum and thinnest for the high poverty tracts. By contrast, among populations at high risk of living in a poverty area CT, for example, the black and Hispanic populations, the width of the bar is much greater for the high compared with low poverty socioeconomic stratum. The graphic approach to displaying the data in Fig. 15.5 accordingly enables simultaneous presentation of information on the absolute rates, whereas visually facilitating comprehension of the relative and absolute difference across socioeconomic strata and also the population burden, in terms of which socioeconomic stratum has the worst rates and also generates the most cases (because a wide bar with a low rate may yield more cases, in absolute terms, than a thin bar with high rates) [5–9, 72]. Finally, wherever applicable, a dashed line has been included to show the Healthy People 2000 objective for those outcomes for which such an objective was specified [73].

In the case of low birthweight, what stands out first, is that, among the total population there is a clear poverty gradient, with risk of low birthweight two times higher among births occurring in the most versus least impoverished tracts (i.e., 7.5% vs. 3.6%). Second, the Healthy People 2000 goal for low birthweight births was met a decade ahead of schedule in all but the most impoverished areas, which lagged far behind. Third, the racial/ethnic-gender analyses further showed that whereas this pattern held for the white non-Hispanic population, among the black population, an early attainment of the Healthy People 2000 low birthweight objective was not met within any of the socioeconomic strata.

Results are similar for childhood lead poisoning. Within the total population, there was a sevenfold excess among those living in the most versus least impoverished CTs, that is, 33% versus 5%; no Healthy People 2000 objective is shown because none was set. Additionally, the highest proportions of children with lead poisoning were observed among the black girls and boys living in the poorest CTs. Moreover, in every socioeconomic stratum, a higher proportion of black and Hispanic children compared with white children had lead poisoning (except among Hispanics in the poorest CTs, whose rates were similar to those of non-Hispanic whites in the poorest CTs).

Socioeconomic gradients were likewise evident for each of the sexually transmitted infections and also tuberculosis, with persons living in the least poor CTs the
most likely, overall and in each racial/ethnic group, to have the lowest rate of registered cases of the disease, whereas persons in the poorer tracts had higher rates. For example, in the case of syphilis among the total population, the relative risk, comparing persons living the poorest with least poor CTs was 17-fold (38.4 vs. 2.3 per 100,000). Within the total population, moreover, only rates in the least impoverished tracts met the *Healthy People 2000* objectives a decade in advance. This latter finding again chiefly reflected the low rates among the white population, because among both the black and Hispanic populations, rates in none of the socioeconomic strata dipped below the *Healthy People 2000* objective.

Regarding nonfatal gunshot injury, within the total population, the relative risk, comparing persons in the most to least poor CTs was 11-fold, or about 22 versus 2 per 100,000. Of note, this pattern was chiefly driven by the pronounced socioeconomic gradient among the black and Hispanic men, whereby rates were, respectively, 22 and 10.5 per 100,000 among those in the least poor CTs, but 105 and 63 among those in the poorest CTs.

In the case of cancer incidence, we observed the expected socioeconomic gradients. Thus, incidence rates increased with poverty level of the CT for lung cancer and cervical cancer, decreased with decreased poverty level for breast cancer, and did not display a clear-cut socioeconomic gradient for colon cancer. For example, for cervical cancer, within the total population, women living in the poorest CTs were at twofold the risk compared with women in the least poor CTs, that is, rates of 18 versus 9 per 100,000, and this pattern held for both the white and black women (the only groups large enough for meaningful analyses of cervical cancer incidence rates).

Finally for mortality, clear socioeconomic gradients within the total population, with risk highest for persons in the poorest CTs, were evident for all of the outcomes, especially premature mortality, heart disease, diabetes, HIV/AIDS, and homicide, and to a lesser extent, cancer mortality (reflecting in part the different directions of the socioeconomic gradient for such disease as lung cancer vs. breast cancer). For the leading cause of death, heart disease mortality, the excess risk, comparing persons in the most to least poor CTs, was 1.4-fold, resulting in an absolute excess of nearly 100 deaths per 100,000; persons in the least poor CTs were also the furthest along in meeting the *Healthy People 2000* objective. Moreover, the socioeconomic patterning of mortality was consistent across all racial/ethnic-gender groups, with the exception of heart disease mortality among black women (for whom there was no clear socioeconomic gradient).

In other words, for none of these outcomes are there trivial socioeconomic gradients. Yet, in current US public health reports, these gradients are routinely ignored and unreported.

Further underscoring the magnitude of these disparities, Fig. 15.6 shows the population attributable fraction (PAF) in relation to CT poverty. The key message is that for half of the outcomes, over half of all cases would have been prevented if the age-specific rates among persons living in the most impoverished CTs were the same as those of persons living in the least impoverished CTs [5]. To our
knowledge, our Project’s analyses are the first to calculate state-level PAFs in relation to poverty.

Tables 15.5 and 15.6 in turn hint at what these types of analyses could reveal about socioeconomic gradients within racial/ethnic-gender groups and the contribution of socioeconomic inequality to racial/ethnic health disparities. Using the example of premature mortality, an important indicator of social disparities in both health status and access to health services, Table 15.5 shows two key findings. First, whereas almost half the white women and men lived in CTs with less than 5% of persons below poverty, half of the black and Hispanic population lived in CTs with 20% or more below poverty. Second, within each racial/ethnic-gender group, there were marked socioeconomic disparities in premature mortality, with relative risks ranging from 1.6 to 2.8.

Additionally, as shown in Table 15.6, within each economic stratum, a black excess for premature mortality remained apparent. Even so, adjusting solely for the single relatively crude measure of CT poverty reduced the overall age-adjusted twofold black excess risk of premature mortality down to “only” a 40–50% excess. Whereas from an etiological perspective, it would be critical to use more detailed measures of lifetime socioeconomic position to quantify its contribution to observed racial/ethnic disparities in health [48, 51, 52], from the standpoint of monitoring, use of appropriate ABSMs can do much to reveal both socioeconomic gradients in health status within diverse racial/ethnic groups, as well as clarify that racial/ethnic inequalities in socioeconomic position continue to play an important role in generating racial/ethnic health disparities. For this reason, the approach utilized in our Project has been used to frame data analysis and interpretation of both national and state publications on socioeconomic inequalities in health [74, 75].
Table 15.5 Public Health Disparities Geocoding Project: premature mortality rates (death before 65 years of age), by race/ethnicity, gender, and CT poverty level, Massachusetts, 1989–1991 [5]

<table>
<thead>
<tr>
<th>Persons below poverty (CT [%])</th>
<th>N</th>
<th>Percentage</th>
<th>Rate&lt;sup&gt;a&lt;/sup&gt; (95% CI)</th>
<th>IRR (95% CI)</th>
<th>RII (95% CI)</th>
<th>N</th>
<th>Percentage</th>
<th>Rate&lt;sup&gt;a&lt;/sup&gt; (95% CI)</th>
<th>IRR (95% CI)</th>
<th>RII (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White men</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;5</td>
<td>3,203,500</td>
<td>47</td>
<td>212.7 (1)</td>
<td>2.6</td>
<td>(1)</td>
<td>3,234,468</td>
<td>46</td>
<td>127.6 (1)</td>
<td>1.9</td>
<td>(1.1, 1.3)</td>
</tr>
<tr>
<td>5–9.9</td>
<td>2,145,999</td>
<td>31</td>
<td>285.3 (1.2, 1.4)</td>
<td>2.6</td>
<td>(2.5, 2.8)</td>
<td>2,205,174</td>
<td>32</td>
<td>153.2 (1.2)</td>
<td>1.9</td>
<td>(1.7, 2.0)</td>
</tr>
<tr>
<td>10–19.9</td>
<td>983,442</td>
<td>14</td>
<td>356.7 (1.5, 1.8)</td>
<td>2.6</td>
<td>(2.5, 2.8)</td>
<td>1,012,152</td>
<td>14</td>
<td>177.6 (1.2)</td>
<td>1.9</td>
<td>(1.7, 2.0)</td>
</tr>
<tr>
<td>≥20</td>
<td>537,120</td>
<td>8</td>
<td>484.8 (2.0, 2.5)</td>
<td>2.6</td>
<td>(2.5, 2.8)</td>
<td>535,689</td>
<td>8</td>
<td>227.5 (1.5, 2.1)</td>
<td>1.9</td>
<td>(1.7, 2.0)</td>
</tr>
<tr>
<td>Black men</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;5</td>
<td>42,777</td>
<td>11</td>
<td>280.9 (1)</td>
<td>2.7</td>
<td>(1)</td>
<td>34,530</td>
<td>8</td>
<td>151 (1)</td>
<td>1.6</td>
<td>(1.3, 2.0)</td>
</tr>
<tr>
<td>5–9.9</td>
<td>69,978</td>
<td>17</td>
<td>342.2 (0.7, 2.1)</td>
<td>2.6</td>
<td>(2.2, 3.2)</td>
<td>696,663</td>
<td>16</td>
<td>238.8 (0.8, 3.2)</td>
<td>1.9</td>
<td>(1.3, 2.0)</td>
</tr>
<tr>
<td>10–19.9</td>
<td>96,048</td>
<td>24</td>
<td>478.2 (1.0, 2.8)</td>
<td>2.6</td>
<td>(2.2, 3.6)</td>
<td>101,934</td>
<td>24</td>
<td>260.9 (0.9, 3.3)</td>
<td>1.9</td>
<td>(1.3, 2.0)</td>
</tr>
<tr>
<td>≥20</td>
<td>197,895</td>
<td>49</td>
<td>610.6 (1.4, 3.4)</td>
<td>2.6</td>
<td>(2.2, 3.6)</td>
<td>220,539</td>
<td>52</td>
<td>285.4 (1.0, 3.5)</td>
<td>1.9</td>
<td>(1.3, 2.0)</td>
</tr>
<tr>
<td>Hispanic men</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;5</td>
<td>41,931</td>
<td>11</td>
<td>134.6 (1)</td>
<td>2.8</td>
<td>(1)</td>
<td>37,938</td>
<td>9</td>
<td>48.8 (1)</td>
<td>2.4</td>
<td>(2.0, 2.6)</td>
</tr>
<tr>
<td>5–9.9</td>
<td>64,854</td>
<td>16</td>
<td>181.2 (0.6, 3.0)</td>
<td>2.8</td>
<td>(2.2, 3.6)</td>
<td>64,392</td>
<td>16</td>
<td>100.8 (0.6, 7.2)</td>
<td>2.1</td>
<td>(1.7, 3.4)</td>
</tr>
<tr>
<td>10–19.9</td>
<td>81,999</td>
<td>21</td>
<td>281.9 (1.0, 4.4)</td>
<td>2.8</td>
<td>(2.2, 3.6)</td>
<td>84,606</td>
<td>21</td>
<td>109.4 (0.7, 7.6)</td>
<td>2.2</td>
<td>(1.7, 3.4)</td>
</tr>
<tr>
<td>≥20</td>
<td>205,635</td>
<td>52</td>
<td>332.4 (1.2, 4.9)</td>
<td>2.8</td>
<td>(2.2, 3.6)</td>
<td>221,898</td>
<td>54</td>
<td>138.9 (0.9, 8.0)</td>
<td>2.8</td>
<td>(1.7, 3.4)</td>
</tr>
</tbody>
</table>
Turning finally to healthcare disparities, we note that the methods of the Public Health Disparities Geocoding Project can be used with any health database, and not just with public health surveillance records. Indeed, within the health services literature, diverse examples can be found whereby investigators have linked medical record or hospital discharge data to a variety of ABSMs, at diverse geographic levels, to examine healthcare disparities [76, 77]. Types of questions typically asked have included:

1. Who is at greatest risk of having inadequate access to needed healthcare, including screening, preventive care, and treatment? [77–83]
2. What is the magnitude of socioeconomic disparities in health status, health behaviors, and treatment outcomes among patients enrolled in a particular health plan? [84–88]
3. Should data on the socioeconomic composition of health plan members be included as an adjustment factor for comparing health system performance? [89]
4. Are there socioeconomic inequities in performance of procedures, referrals, and other outcomes indicative of healthcare system performance (independent of patient health status)? [78, 87, 90]

Literature on these topics nevertheless remains scant, with ABSMs only just starting to be used by health service researchers to address the lack of socioeconomic data in most medical records [76]. The net implication is that there is ample opportunity for more healthcare systems, researchers, and advocates to use tools like those provided by the Public Health Disparities Geocoding Project to document, investigate, and address healthcare disparities.

For this approach to be best used in healthcare disparities research, however, it will be important to address an important problem: apparently, the most commonly used area-based socioeconomic data for documenting healthcare disparities are ZC-level

<table>
<thead>
<tr>
<th>Persons below poverty (CT [%])</th>
<th>Black/white IRR* (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men</td>
</tr>
<tr>
<td>&lt;5</td>
<td>1.4 (1.3, 1.5)</td>
</tr>
<tr>
<td>5–9.9</td>
<td>1.5 (1.4, 1.7)</td>
</tr>
<tr>
<td>10–19.9</td>
<td>1.3 (1.1, 1.5)</td>
</tr>
<tr>
<td>≥20</td>
<td>1.3 (1.1, 1.6)</td>
</tr>
<tr>
<td>Overall</td>
<td>2.0 (1.9, 2.1)</td>
</tr>
<tr>
<td>Adjusted for percentage below poverty (CT)</td>
<td>1.4 (1.4, 1.5)</td>
</tr>
</tbody>
</table>

*IRR incidence rate ratios; CT census tract; CI confidence interval
*All models adjusted for age, using Poisson regression models

### Implications of the Project for Monitoring and Analyzed Healthcare Disparities
socioeconomic data [76, 83, 86, 89, 90]. In part, this practice appears to have arisen because the ZC is the only address or geographic information provided in hospital discharge records or readily obtainable from health records without the added step and expense of geocoding the address data [42]. Yet, as noted above, use of ZC data should be discouraged on multiple grounds, including the large size and economic heterogeneity of their population and also because of the possibility of introducing serious bias owing to spatiotemporal mismatches between census and ZC data (to the point of reversing the direction of the actual socioeconomic gradient [10]). Compounding these problems, starting with the 2000 decennial census, ZC data are no longer available as a geographic unit for which US census socioeconomic data are available [10, 47]. The US census made the decision to no longer provide these data because, in their words, “carrier routes for one ZC may intertwine with those of one or more ZCs” such that “this area is more conceptual than geographic” ([91], p. 22). To “overcome the difficulties in precisely defining the land area covered by each ZC” [47], starting with the 2000 Census, the US Census Bureau accordingly created a new statistical entity built from census blocks: the five-digit ZIP code tabulation area™ (ZCTA) [92]. Of note, ZCTAs and ZCs sharing the same five-digit code may not necessarily cover the same area (see Table 15.7) [93], such that ZCs obtained by self-report or from addresses in medical records cannot be assumed to correspond to census-defined ZCTAs.

Table 15.7 Technical definitions of and distinctions between ZCs and ZCTAs [47, 92]

<table>
<thead>
<tr>
<th>Definition of ZCTA</th>
<th>Distinction between ZCTA and ZC</th>
</tr>
</thead>
<tbody>
<tr>
<td>“ZCTAs are a new statistical entity developed by the US Census Bureau for tabulating summary statistics from Census 2000. This new entity was developed to overcome the difficulties in precisely defining the land area covered by each ZC. Defining the extent of an area is necessary in order to accurately tabulate census data for that area. ZCTAs are generalized area representations of US postal service (USPS) ZC service areas. Simply put, each one is built by aggregating the Census 2000 blocks, whose addresses use a given ZC, into a ZCTA which gets that ZC assigned as its ZCTA code. They represent the majority USPS five-digit ZC found in a given area. For those areas where it is difficult to determine the prevailing five-digit ZC, the higher-level three-digit ZC is used for the ZCTA code. As the ZC used by the majority of addresses in an area for the ZCTA code is taken, some addresses will end up with a ZCTA code different from their ZCs. Also, some ZCs represent very few addresses (sometimes only one) and therefore will not appear in the ZCTA universe”</td>
<td>“Even though the codes may appear the same, the addresses and areas covered by these areas may not be the same. Data users who wish to compare 1990 and 2000 data are strongly advised to determine and evaluate any coverage differences that exist before making any comparisons. There are several reasons for this caution: The USPS has extensively modified ZCs over the last 10 years. Even though a 1990 ZC matches a Census 2000 ZCTA code, there is no guarantee that these cover the same geographic area. Also, some ZCs in the 1990 data products were discontinued by the USPS, and new ZCs were created; ZCTAs and the 1990 census ZC areas were delineated using different methodologies and therefore may not have comparable coverage area or size; and The Census 2000 ZCTAs will include some dedicated PO box ZCs. All dedicated PO box ZCs were excluded as ZC areas in 1990. The resulting 1990 areas include data for both PO box ZCs and the ZCs that provides street or rural route delivery to the surrounding area”</td>
</tr>
</tbody>
</table>
New interest in improving hospital records, to improve understanding of healthcare disparities \cite{22, 42, 94}, however, could readily lead to improved geocoding of medical records. For example, in the city of Boston, The Mayor’s Task Force on Health Disparities, in conjunction with the Boston Public Health Commission, in 2005, launched an initiative to improve and standardize collection of racial/ethnic and socioeconomic data in medical records, which has secured the participation of all of the largest Boston hospitals \cite{94}. In addition to specifying that educational level should be routinely collected, the Boston Public Health Commission recognizes the utility of having address information routinely geocoded to the CT level. Of note, the US Census Bureau now provides a free online tool to identify any address geocodes, including those for its CT, one single address at a time \cite{95}. Use of this tool could readily be coupled with the input of patients’ addresses at time of enrollment in a health plan or when billing occurs.

**Conclusion: Data, Politics, and Health Inequities**

In conclusion, data on disparities in health status and healthcare are essential, both to understand the magnitude of the problems that are confronted and to increase accountability for – and hence the likelihood of – eliminating these preventable sources of suffering. The continued absence of socioeconomic data in US public health and medical records is a serious problem, one neither innocent nor inevitable. Fortunately, the tools provided by the Public Health Disparities Geocoding Project offer one potential solution to overcoming this obstacle. It is their responsibility, as public health and medical professionals, to end the pernicious cycle of “no data, no problem” \cite{32, 33}. Using available methods and concept, we instead can bring to public attention the existence of socioeconomic disparities in health status and healthcare, within and across diverse racial/ethnic groups as well as show how they contribute to persistent and unacceptable racial/ethnic disparities in health, in conjunction with racial discrimination and other forms of social inequality manifested in each and every economic strata \cite{21, 96}. The goal is to generate knowledge that, if put into action, can inform current efforts to promote social justice and equity in health status and healthcare.

**Acknowledgments** This work was funded by the National Institutes of Health (1 R01HD36865-01), through the National Institute of Child Health and Human Development and the Office of Behavioral and Social Science Research. Principal Investigator, Nancy Krieger.

**References**

34. Krieger N. Shades of difference: theoretical underpinnings of the medical controversy on black-white differences, 1830–1870. Int J Health Serv. 1987;17:258–79.


Chapter 16
Perspective: Title VI, Healthcare Reform, and the Need for a State Antidiscrimination Law

Vernellia R. Randall

Abstract

“It might be that civil rights laws often go unenforced; it might be that current inequities spring from past prejudice and long standing economic differences that are not entirely reachable by law; or it might be that the law sometimes fails to reflect, and consequently fails to correct, the barriers faced by people of color.”

– Derrick Bell

Equal access to quality health care is a crucial issue that the United States (US) is facing. For too long, we have denied too many Americans equal access to quality health care based on race, ethnicity, and gender. Many factors contribute to disparities: cultural incompetence of health care providers, socioeconomic inequities, disparate impact of racially neutral practices and policies, inadequacy of civil rights laws and enforcement, and multiple forms of discrimination. These

1 See Derrick AB, Jr. And we are not saved: the elusive quest for racial justice. New York: Basic Books; 1987) (hereinafter Not saved).

V.R. Randall (* Professor of Law, The University of Dayton School of Law, Dayton, Ohio, USA e-mail: vernellia.randall@notes.udayton.edu
disparities exist in health status, access to health care services, participation in health research, and receipt of health care financing. This disparity in health care is doubly significant given the devastating racial disparity in health status that exists. The combination of racial disparity in health status, institutional racism in health care, inadequate legal protection, and the failure of health care reform to adequately address racial discrimination in health care points to a need for a major civil rights law for health care.

Several federal laws address access to health care: Title XVIII (Medicare), Title XIX (Medicaid), Title IX, and the Hill Burton Act. The only federal laws related to eliminating racial discrimination in health care delivery are Title VI of the Civil Rights Act and § 1557 of the Patient Protection and Affordable Care Act (hereinafter, “Affordable Care Act.”) Racial inequality in health care persists in the United States despite laws against racial discrimination, in significant part because of the inadequacy of Title VI, and the Affordable Care Act has done little to correct the problem.

Keywords Title VI • Medicaid • Racial discrimination • Social Security Act • Hill Burton Act • Civil Rights Act • Disparate impact discrimination • Enforcement • Compliance • Fragmentation • Disaggregation • New laws • Medical testing

---

4 See, e.g., U.S. Commission on Civil Rights I, supra note 2; U.S. Commission on Civil Rights II, supra note 2.
5 Social Security Amendments of 1965, Pub. L. No. 89–97, Titles XVIII, 79 Stat 286; the act does not contain any general anti-discrimination clauses although the implementing regulations require providers and facilities to abide by Title VI.
6 Id.
Title VI of the Civil Rights Act of 1964

On its face, Title VI (with its implementing regulations) should be an effective tool for eliminating racial discrimination. The Civil Rights Act of 1964 provides the legal force for desegregation efforts in health care. Specifically, section 601 of Title VI provides:

No person in the United States, shall, on the grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subject to discrimination under any program or activity receiving federal financial assistance.

In short, Title VI appears to prohibit discrimination of all kinds. Still, nothing in antidiscrimination law is as simple as it might appear. In particular, several problems are presented; among the most significant for this discussion is that the Supreme Court has interpreted Title VI to address intentional discrimination only. Further, regulatory agencies have interpreted Title VI to exclude physicians in private practice, a situation that may have been corrected by the Affordable Care Act. Unfortunately, the Supreme Court has held in Alexander v. Choate that Title VI itself directly reached only instances of intentional discrimination; included in the definition is subtle discrimination. Subtle discrimination is generally considered intentional based in large part on micro-aggressions with the primary difference being the reliance on circumstantial evidence to prove intent. However, the reliance on intent, subtle or direct, is particularly problematic for health care where most discrimination is either disparate impact discrimination or “unthinking or unconscious” discrimination.

The course of treatment physicians … recommend to their patients may be influenced by stereotypical beliefs about the behavior of their patients. Physicians … may believe that poor and minority patients are more likely to break appointments and to misunderstand complex information, and less likely to adhere to their orders. These perceptions may affect – perhaps

13Id.
subconsciously – the decision-making process and lead physicians to refrain from orders that require patient compliance and to hesitate before recommending certain procedures if they assume the patient does not live in an environment that is conducive to the aftercare needed for the best outcomes of the procedure.\textsuperscript{19}

While legal standards for discrimination have not always centered on intent, they do so now.\textsuperscript{20} To prove a disparate treatment claim an individual must show that the defendant intentionally discriminated.\textsuperscript{21} Such a standard means that few of the discriminatory acts that occur in the health care system can be successfully litigated since most occur from “unthinking” or “unconscious” biases.

Psychiatric, psychological, and legal literature generally supports the idea that, in our society, most contemporary discrimination is based more on unconscious bias and stereotyping rather than on conscious bigotry.\textsuperscript{22} As suggested by Professor Lawrence:

Traditional notions of intent do not reflect the fact that decisions about racial matters are influenced in large part by factors that can be characterized as neither intentional – in the sense that certain outcomes are self-consciously sought – nor unintentional – in the sense that the outcomes are random, fortuitous, and uninfluenced by the decision maker’s beliefs, desires, and wishes.\textsuperscript{23}

The problem confronting the legal system is that an individual who holds a negative stereotype about a group is more likely to discriminate against an individual that fits the stereotype.\textsuperscript{24} This stereotype-linked bias is both an automatic process and an unconscious one.\textsuperscript{25} Furthermore, it occurs even among persons who are not prejudiced. According to Professor David Williams, several factors contribute to the unbiased discrimination in health care:

First, healthcare providers are a part of the larger society that views racial and ethnic minorities negatively on multiple social dimensions … Second, research on stereotypes indicates that encounters in the healthcare setting contain ingredients that enhance the likelihood of the use of stereotypes. Stereotypes are more likely to be activated under conditions of time pressure, the need to make quick judgments, cognitive overload, task complexity and when the emotions of anger or anxiety are present … Third, … [physicians view their Black patients] … more negatively than their white counterparts. … Physicians

\textsuperscript{19}See, e.g., Gornick ME. Vulnerable populations and medicare services: why do disparities exist? 2000:43.
\textsuperscript{21}See, e.g., Allen J. Unthinking discrimination, supra note 20.
\textsuperscript{23}Lawrence C, The Id, supra note 22.
\textsuperscript{24}Williams DR. Race, health, and health care. St. Louis Univ Law J. Fall 2003;48:13; see Unequal Treatment, supra note 2.
\textsuperscript{25}Williams DR. Race, health, and health care, supra note 24; see Unequal treatment, supra note 2.
viewed Black patients (compared to their white counterparts) as less likely to adhere to medical advice, less likely to be kind, intelligent and educated, more likely to lack social support, and more likely to abuse alcohol and drugs.26

However, notwithstanding that the discrimination is based on some unconscious or unthinking processes, an individual can change27:

Social psychological research, reviewed here in four major sections, explains that stereotyping, prejudice, and discrimination have (1) some apparently automatic aspects and (2) some socially pragmatic aspects, both of which tend to sustain them. But, as research also indicates, change is possible, for (3) stereotyping, prejudice, and discrimination seem individually controllable, and consequently, (4) social structure influences their occurrence. … The bad news is that people’s habitual use of subjectively diagnostic information, certain information configurations, and perceived covariation sustains stereotypes. … The good news is that people can sometimes control even apparently automatic biases, if appropriately motivated, given the right kind of information, and in the right mood. People therefore can make the hard choice.28

Recognizing the need to get at more than intentional discrimination, the Office of Civil Rights (OCR), which was delegated the responsibility of enforcing Title VI and the Department of Health and Human Services (DHHS) issued interpretive regulations, which provided for disparate impact discrimination29:

A recipient … may not … utilize criteria or methods of administration which have the effect of subjecting individuals to discrimination of their race, color or national origin, or have the effect of defeated or substantially impairing accomplishment of the objectives of the program as respect individuals of a particular race, color, or national origin.30

The regulations defined a recipient as any public or private entity or individual that receives federal financial assistance.31 Federal financial assistance includes federal money awarded through grant, loan, or contract.32 Because of these two definitions, Title VI had the potential of having a broad range effect. Once a program

26Williams DR. Race, health, and health care, supra note 24.
or individual has been determined to be in violation of Title VI, the program or individual “must take affirmative action to overcome the effects of prior discrimination.” The regulations went further and prohibited:

- Criteria or methods of administration, which have the effect of subjecting individuals to discrimination; criteria or methods of administration, which have the effect of defeating or substantially impairing accomplishment of the objectives of the program
- Difference in quality of services
- Differences in quantity or the manner in which the benefit is provided
- Locating services with the purpose or effect of excluding individuals from the benefits of the program

In theory, then, Title VI regulations should improve access to and quality of health care services. Title VI regulations clearly prohibit policies and practices that result in segregation within and between institutions. Title VI’s regulations had the potential of forcing health care practitioners and institutions to evaluate their policies and practices that have a disparate impact (discriminatory effect) on racial minorities. In Alexander v. Choate, the Supreme Court made it clear that a claim seeking a remedy for discrimination based on disparate impact under Title VI must involve a violation of agency regulations promulgated under § 602. Unfortunately, because of Alexander v. Sandoval and unique problems of health care discrimination, Title VI and its regulations are virtually useless.

In Sandoval, in a case argued before the Supreme Court in 2001, the court held in a five-to-four decision that despite a line of Title VI precedents, the disparate impact regulation (discriminatory effect) issued under § 602 could only be enforced through an agency action and not through a private right of action. Since the law requires a conscious discriminatory purpose or intent, individual discrimination claims cannot address the issue of unconscious discrimination and, health-care providers will not be “appropriately motivated” to make the hard choice. Interestingly, some members of congress clearly understand the difference between conscious and unconscious bias. For instance, in its discussion of the American with Disabilities Act (ADA), several members explained that the ADA was intended to address “institutional, structural, and psychological barriers.”

33 45 C.F.R. 80.3(b) (6) (i) (1991).
38 Id.
40 See, e.g., Allen J. Unthinking Discrimination, supra note 20.
Even without the problem with Sandoval, Title VI enforcement has been problematic. First, although required by regulation to produce data, the Office of Civil Rights (OCR) Title VI enforcement effort has produced little consistent data for evaluating Title VI compliance. Second, there has been “little uniformity in how different states handle Title VI requirements, little guidance, little analysis of the information collected by this process, no research and development.” Third, Title VI lacks specific definitions of prohibited discrimination and acceptable remedial action. Fourth, OCR has relied on individual complaints to enforce Title VI. Finally, Title VI would have limited application to health care treatment discrimination since the Department of Health, Education, and Welfare (HEW) interpreted Title VI not to apply to private physicians who received money for treating patients covered under Medicare Part B. Thus under Title VI, physicians would not be recipients of federal financial assistance and consequently would not be covered by Title VI. This particular problem could have been corrected under The Affordable Care Act.

The Patient Protection and Affordable Care Act of 2010

It is a puzzlement, sang Yul Brenner in “The King and I,” as he tried to understand the differences between the East and the West. Indeed, when it comes to prohibiting racial discrimination, the Act is a puzzlement. While there are a number of key provisions of health reform legislation that are likely to have a significant impact on people of color, such as expanded access to health coverage through Medicaid expansions and health exchanges, as well as workforce development, expansions of community health centers, and several specific disparities provisions, the Act does not go far enough. When it comes to eliminating racial discrimination, the new law

---

43 28 C.F.R. § 42.406(a) (1992); 45 C.F.R. § 80.6(b) (1991).
45 See, e.g., Smith DB. Health Care Divided, supra note 9.
46 See, e.g., 45 C.F.R. § 80.3(b) (1991); Watson S. Health care in the inner city, supra note 45.
47 See, e.g., Watson S. Health care in the inner city, supra note 45.
48 Id.
is problematic. Section 1557 of the Patient Protection and Affordable Care Act of 2010\textsuperscript{50} provides:

\ldots \, [A]n individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), \ldots be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under this title (or amendments).\textsuperscript{51}

The problem with the comprehensive health care reform act is that it merely references Title VI without correcting most of the known inadequacy of Title VI in design or in enforcement. The one area of exception may be the extension of antidiscrimination to providers such as physicians by specifically defining contracts of insurance or any program or activity that is administered by an Executive Agency."\textsuperscript{52} For instance, physicians receiving payment from the federal government under Medicare Part B may, under section 1557, be subject to the prohibition against discrimination. Unfortunately, section 1557 failures are much more significant. Section 1557 fails to define the prohibited discrimination in the statute to include both purposeful and effect. Without specific definition of discrimination in the law, the courts are likely to define discrimination as it did under Title VI – intentional only. The Patient Protection and Affordable Care Act provides authority such that “The Secretary [of Department of Health and Human Services] may promulgate regulations to implement this section.”\textsuperscript{53} Under such authority, the Secretary could extend the definition by regulation to include effect discrimination as it does in Title VI. However, such an extension will give no rights of an individual to pursue effect discrimination, since Congress failed to overturn Sandoval and to provide an individual right of action on regulations. Furthermore, the Affordable Care Act fails to assure adequate fines and regulatory enforcement.\textsuperscript{54} Another oversight is the failure of the law to specifically exempt special measures designed to eliminate health and health care disparities as discrimination under the section. Finally, the Affordable Care Act failed to define “an aggrieved person” broadly and failed to allow prevailing plaintiff attorney fees. The discussion of discrimination in health care has been limited. That discussion centered almost entirely around Title VI of the Civil Rights Act\textsuperscript{55} and on assuring economic

\textsuperscript{50} Affordable Care Act, supra note 10.
\textsuperscript{51} Id.
\textsuperscript{52} Id.
\textsuperscript{53} Id.
\textsuperscript{54} Id.
\textsuperscript{55} See, e.g., Watson SD. Reinvigorating Title VI: defending health care discrimination – it shouldn’t be so easy. Fordham Law Rev. 1990;58:939; Smith DB. Health care divided, supra note 9; Smith DB. Addressing racial inequities in health care: civil rights monitoring and report cards. J Health Polit Policy Law. 1998;23:75; Randall VR. Racist Health Care, supra note 5.
access to facilities and providers. Essentially, the health care reform effort failed to reform health care law in a way that would effectively protect patients of color from racial discrimination in health care.

Summary

Taking the “even if” a step further, even if the problems with Title VI enforcement did not exist and Title VI functioned perfectly, the health care industry presents unique problems that would still make Title VI ineffective. Furthermore, the health care system presents several additional problems. First, as with the situation when racial minorities use housing and lending institutions, individuals are, for the most part, totally unaware that the provider or institution has discriminated against them. Similarly, because of the very specialized knowledge required in medical care, individuals can be totally unaware that the provider has injured them. Finally, the health care system, through managed care, actually has built-in incentives that encourage “unconscious” discrimination. Because of these issues, an appropriate legal structure is essential to eliminating discrimination in health care.

Necessary Components of an Effective Health Care Antidiscrimination Act

In an effective public health policy, appropriate state and federal laws must be available to eliminate discriminatory practices in health care. Thus, the crux of the problem is, given managed care, the historical disparity in health care, and “unthinking” discrimination, the laws do not address the current barriers faced by minorities. The executive branch, the legislatures and the courts are singularly reluctant to hold health care institutions and providers responsible for institutional racism. As the United States Commission on Civil Rights found:

There is substantial evidence that discrimination in health care delivery, financing and research continues to exist. Such evidence suggests that federal laws designed to address inequality in health care have not been adequately enforced by federal agencies … [Such failure has] … resulted in a failure to remove the historical barriers to access to quality health care for women and minorities, which, in turn has perpetuated these barriers.57

---


57See, e.g., U.S. Commission on Civil Rights II, supra note 2, 275–276.
A Health Care Antidiscrimination Act should be enacted, which would (1) recognize multiple forms of discrimination, (2) authorize and fund testers, (3) assure fines and regulatory enforcement, (4) require a health scorecard/report for health agencies, providers, and facilities, and (5) require data collection and reporting.

1. Recognize multiple forms of discrimination
Racial disparities in medical treatment rarely occur because of overt, intentional discrimination behavior. Most racial discrimination that occurs in health care is probably the result of subconscious bias, disproportionate impact of policies and practices, and disparate impact. A state law on health care discrimination would at a minimum define discrimination in a way that included: intentional discrimination, subtle discrimination, unthinking discrimination, and disparate impact. The law should define intentional discrimination to include knowledge of disparate impact and failure to take effective steps to reduce impact. Furthermore, any affirmative defenses, such as business necessity, should be limited and narrowly defined.

2. Authorize and fund the use of medical testers
To discourage health care discrimination, an “aggrieved person” should include not only the individual who has been injured, but also one who believes that he or she will be injured, as well as individuals engaged as testers and organizations engaged in testing. In testing, the testing organization sends persons pretending to be patients who share common traits or symptoms except their race to health care facilities or providers to prove that patients of a particular race receive different treatment. This is important because much of health care discrimination goes unnoticed, unsuspected, undetected, or unreported.

Even in cases where discrimination is suspected, the victim will have an almost impossible time developing adequate proof because there will be almost no opportunity to witness better treatment to similarly situated white patients. “Testing” could provide both evidence in the individual case and some accurate empirical data on the overall rate at which discrimination occurs in health care. Testing has

been widely used to enforce Title VIII, \textsuperscript{63} which prohibits discrimination in the sale, advertising, and rental of housing. \textsuperscript{64} However, while use of testers under Title VIII is well settled, it is an issue of great debate in other areas such as employment discrimination under Title VII \textsuperscript{65} and section 1981 of the Civil Rights Act of 1866. \textsuperscript{66} A statute that authorizes the use of testers will bypass that debate in the courts because the Supreme Court has already noted that “Congress may enact statutes creating legal rights, the invasion of which creates standing, although no injury would exist without the statute.”\textsuperscript{67}

3. Provide a private and organizational right of action
An antidiscrimination health care statute would provide for a private right of action and organizational right of action. The private right of action would assure that individuals (including testers) would have standing to sue not only under the statute but also under any implementing regulations, thus avoiding the problem that occurred in federal civil rights enforcement. Furthermore, there are many reasons why limiting enforcement to state agencies may be inadequate. For instance, the agency may not have sufficient staff to devote the resources necessary to enforce the civil rights violations. \textsuperscript{68} Administrative complaints with state agencies may limit some avenues of redress rather than going to court. State agencies may be limited in their capacity to mandate redress for aggrieved plaintiffs. \textsuperscript{69} Without a private right of action, racial discrimination in health care will be impossible to eliminate. \textsuperscript{70}

In addition to the private right of action, an organizational right of action is essential for allowing testing to be carried out more broadly by civil rights organizations. These organizations and testers would have standing to sue and could by that action recoup the costs of testing programs. This would provide the necessary incentive for civil rights organizations to create testing programs and make their existence known to potential victims of discrimination.

\textsuperscript{63}42 U.S.C. s 3604.
\textsuperscript{69}Id.
\textsuperscript{70}Id.
4. Establish an Equality Health Care Council
The act should establish a “Health Care Council,” patterned after Fair Housing
councils. This council could serve several distinct functions, including educating
the public, training health care providers, institutions, and managers, providing
counseling and health care-finding services to individuals, investigating discrimina-
tion complaints – mostly through testing – and pursuing legal remedies.71 Such
councils would provide a focal point: antidiscrimination work in health care.72 It
could easily be an extension of existing state minority health efforts. Thus, when
someone believes she has been discriminated against in a health care facility, she
would have somewhere to turn for help.

5. Prevailing party attorney fees
The health care antidiscrimination statute would provide for attorneys’ fees for a
prevailing party.73 Many federal statutes authorize attorneys’ fees for a prevailing
party.74 The statute should grant prevailing party status when, because of the law-
suit, a party’s ends are accomplished. Under the catalyst theory, the focus is on
whether the party obtained its desired result, despite whether the party obtained a
favorable ruling. Prevailing party attorney fees would help to provide the financial
incentives needed to pursue.75

6. Punitive Damage, in part or in whole, to fund monitoring and assessment programs
Compensatory damages make discrimination victims whole for injuries to their
persons.76 Punitive damages, on the other hand, punish past conduct, teach defen-
dants not to commit these acts again and deter others from similar behavior.77
Similar to split-recovery statutes,78 all or part of the punitive damages should be

71 See, e.g., Haydons SE. A measure of our progress: testing for race discrimination in public
72 See, e.g., Fair Housing Council Finds Discrimination Against Hispanics in dc 66 NO. 40
Interpreter Releases 1154 (October 16, 1989).
73 See, e.g., Miller MD. Catalysts as prevailing parties under the equal access to justice act. Univ
74 See, e.g., Civil Rights Act of 1964, Pub L No 88-352, 78 Stat 259, codified at 42 USC § 2000e-
5(k) (1994); Civil Rights Attorney’s Fees Awards Act of 1976, Pub L No 94-559, 90 Stat 2641,
75 See, e.g., Stanton v Southern Berkshire Regional School District, 197 F3d 574, 577 (1st Cir
1999); Marbey v Bane, 57 F3d 224, 234 (2d Cir 1995).
76 See, e.g., Pogorelec JP. Under what circumstances did congress intend to award punitive damages for
victims of unlawful intentional discrimination under Title VII? Boston Coll Law Rev. Sept
78 As of 2003, 12 states had split-recovery statutes. The 12 states are: Alaska, Colorado, Florida,
Georgia, Illinois, Indiana, Iowa, Kansas, Missouri, New York, Oregon, and Utah.
placed into a fund that would ultimately be used to promote equality health care including discrimination testing.\footnote{See, e.g., Klaben MJ. Split-recovery statutes: the interplay of the takings and excessive fines clauses. Cornell Law Rev. 1994;80:104, 105. Stepanian LM II. Comment, the feasibility of full state extraction of punitive damages awards. Duquenese Law Rev. 1994;32:301, 317.}

7. Require data collection and reporting
Current data collection efforts fail to capture the diversity of racial and ethnic communities in the United States.\footnote{See, e.g., Williams DR. Race/ethnicity and socioeconomic status: measurement and methodological issues. Int J Health Serv. 1996;26(3):483–505; Watson SD. Race, ethnicity and quality of care: inequalities and incentives. Am J Law Med. 2001;27:203.} Data is aggregated information on subgroups within the five racial and ethnic categories and are not collected systematically.\footnote{See, e.g., U.S. Commission on Civil Rights I, supra note 2, 50–52.} Further, racial and ethnic classifications are often limited on surveys and other data collection instruments, and minorities are often misclassified on vital statistics records and other surveys and censuses.\footnote{See Madison-Hughes v. Shalala, 80 F.3d 1121, at 1123 (6th Cir. 1996); U.S. Commission on Civil Rights, “Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs,” (Washington, D.C., 1996), at 246; Marianne Engelman Lado, Unfinished Agenda: the Need for Civil Rights Litigation to Address Race Discrimination and Inequalities in Health Care Delivery, 1. 6 Tex. F. on C.L. and C.R. 1 (Summer 2001).} To fully understand the health status of all individuals, as well as to recognize the barriers they face in obtaining quality health care, it is important to collect the most complete data on underrepresented groups and subpopulations.\footnote{Bagley C. A plea for ignoring race and including insured status in American research reports on social science and medicine. Soc Sci Med. 1995;40:1017–1019.} The lack of data on racial and ethnic minorities makes it difficult to conduct research studies and comparative analyses.\footnote{Williams DR. Race/ethnicity and socioeconomic status: measurement and methodological issues. Int J Health Serv. 1996;26(3):483–505.} Furthermore, the lack of a uniform data collection method makes obtaining an accurate and specific description of race discrimination in health care difficult. The existing data collection does not allow for regularly collecting race data on provider and institutional behavior.\footnote{See, e.g., Williams DR. Race/ethnicity and socioeconomic status: measurement and methodological issues. Int J Health Serv. 1996;26(3):483–505.}

Given the array of potential issues, some researchers have argued that health data should not be disaggregated by race.\footnote{See, e.g., U.S. Commission on Civil Rights I, supra note 2, 50–52.} It could be argued that the use of race in health data promotes and maintains the view that race is a biological concept. It has also been claimed that racial categorizations perpetuate and encourage racial fragmentation. Such views seem potential for harm from the use of race.

However, there are a number of important and compelling reasons for disaggregating health status and health care data by race. First, the use of race is not the cause of racism but the result of racism. That is, individuals have been discriminated
against based on color; established hierarchy and superiority have been based on color; and race is the terminology used to capture this situation. Consequently, racism and racial discrimination will continue to exist (i.e., discrimination based on color) even if terminology changes or ceases to exist. For instance, even though race data is not collected in the European Union in the same way as it is in the United States, racism and racial discrimination continue to exist as a worldwide problem. Here in the United States, even when one controls for socioeconomic status, health status and health care differentials persist.

Second, racism and racial discrimination have implications for every institution and social practice. Health status is impacted by racial discrimination in housing, employment, environment, education, and other institutions. Third, calls not to disaggregate data ignore the power and status differentials that exist among all racial groups. This point is illustrated when one considers the disproportionate percentage of racially disadvantaged who are poor. Fourth, as long as some groups continue to experience discrimination, it is important to monitor their well being. Fifth, to fully understand the health status of all individuals as well as to recognize the barriers they face in obtaining quality health care, it is important to collect the most complete data on “racially disadvantaged” groups, and “subgroups.” The lack of a uniform data collection method makes obtaining an accurate and specific description of racial discrimination in health care difficult, if not impossible. Such data collection has to include collecting data on provider and institutional behavior. “Although not useful as a biological category, race has been and is likely to continue to be an important social category. It is what sociologists call a master status – a central determinant of social identity and obligations, as well as of access to societal rewards and resources. From our earliest health records, race has been an empirically robust predictor of variations in morbidity and mortality. Collecting the appropriate data on race can facilitate ongoing monitoring of the magnitude of differentials, enhanced understanding of their causes, and the development of effective interventions to address them.”

Race matters because racism and racial discrimination matter. Disaggregating data based on race is important because it helps to make the impact of racism and racial discrimination visible and thus allows us to address the root problem.

8. Require a health report card for health agency, provider, or facility
If we are serious about eliminating racial discrimination, the systematic collection and reporting of data from each health care provider on racial disparities in the use

87 Williams DR. Race and health, supra note 2, 322–333.
88 Id.
89 Randall VR. Racist Health Care, supra note 13, 127–194
90 Williams DR. Race and health, supra note 2, 322–333.
91 Id.
of services and the choices of diagnostic and therapeutic alternatives would provide an additional tool in civil rights monitoring.93 The “report card” approach is not new and is being used to “assure accountability, consumer choice, and goal-directed action.”94 Existing and proposed health care “report cards” could be used and only need to be stratified by race.95 As Sidney Watson discussed:

Reporting race-based data on health care is relatively easy once we get over our squeamishness about talking about race and recognize the need for this information. Physicians already gather information on patient race as part of a standard medical history. All this is needed to compile and report racial and ethnic information in a format that protects patient confidentiality and privacy.96

Report cards that reflect racial disparities will provide a strong evidence that racism – “intentional or unintentional, institutional, or individual – is affecting patient care.”97

9. Assure adequate fines and regulatory enforcement
The importance of rigorous enforcement of regulations as a primary vehicle for policing the health services cannot be overemphasized. The collection of data and the development of a report card need the teeth of regulatory enforcement. Thus, a statute which allows significant civil penalty to be assessed for violation of regulations designed to eliminate racial disparities is important to compliance. Current administrative penalty involves termination of funds. Such a step is highly unlikely; consequently, it is the effective equivalent of having no penalty at all. If substantial fines were mandated and collected for violation of antidiscrimination law, such fines could be collected and deposited directly into a restricted account that could be used to eliminate racial disparities.

The question is raised as to whether we should modify existing federal law (Title VI) or adopt a Health Care Antidiscrimination Law on a federal level. The discussion above should answer the first question. Title VI is hopelessly flawed and minor tinkering will not be sufficient to make it an effective tool. As to the question of whether we should create a new federal law, the answer depends on political feasibility.

97Id.
From a political perspective, the antagonism to civil rights makes it highly unlikely such an approach will work. We need only take a look at the Patient Protection and Affordable Care Act of 2010 to get an answer.

**Conclusion**

For an effective public health policy to be established, appropriate state and federal laws must be available to eliminate discriminatory practices in health care. This is the crux of the problem for the legal system: given managed care, the historical disparity in health care, and unthinking discrimination, what is the best way for the legal system to remedy racial disparity in the health care system? It should be clear from the discussion in this chapter that this will not be accomplished via using the Civil Rights Act as it now exists or federal health care reform, such as The Patient Protection and Affordable Care Act of 2010. Construction of new laws at the state and local levels are needed, and governing bodies should be prompted by both their constituents and their legislative members to conceive and pass such laws.
Chapter 17
Quality of Care and Health Disparities: The Evolving Role of the Government

Garth N. Graham

Abstract Over the past 20–25 years, there has been a significant evolution in the role of the Federal government in addressing the problem of health disparities in the United States. In this chapter, the nature of health disparities among minorities and underserved populations in this country, and early governmental approaches to the problem are described in brief. A historical and descriptive overview of the government’s efforts, since 1985, to eliminate health disparities in the United States will be described as well as a description of the potential impact of health reform.

Keywords National Health Disparities Report (NHDR) • National Healthcare Quality Report (NHQR) • Federal poverty level • Indian Health Service (IHS) • Tuskegee Syphilis Experiment • Secretary’s Task Force • Office of Minority Health (OMH) • Centers for Disease Control and Prevention (CDC) • Health Resources and Services Administration (HRSA) • National Institutes of Health (NIH) • Historically Black Colleges and Universities (HBCUs) • National Institute on Minority Health and Health Disparities (NIMHD) • Agency for Healthcare Research and Quality (AHRQ)

An Overview of the Problem

Before 1985, there were few detailed or authoritative analyses that documented the existence of race- or socioeconomic-related inequities in morbidity and mortality among residents of this country published by the federal government. With the release in August 1985 of the “Report of the Secretary’s Task Force on Black and Minority Health” [1], what had been widely recognized through qualitative observation and occasional statistics, was painfully confirmed – the country had a serious problem. The Secretary’s report noted [1] that at the beginning of the twentieth
century, dying “young” was relatively common. In 1900, the average life expectancy at birth for all Americans was 47.3 years. However, blacks died younger on average, with a life expectancy at birth of only 33 years. By the time of the Secretary’s report in 1985, health and longevity had dramatically improved for all Americans. Nevertheless, as the report highlights, a similar pattern of disparities existed. In 1983, life expectancy for whites was 75.2 years, but only 69.6 years for blacks. In 1981, the infant mortality rate for blacks was twice that for whites.

There was a relative paucity of health data available in 1985 for the other minority groups identified in the Secretary’s report – Hispanics, Asian/Pacific Islanders, and Native Americans. Nevertheless, based on a comprehensive review of the information available, the report concluded that a similar pattern of health disparities existed for all these groups. The report identified six areas of particular concern: cancer, cardiovascular disease and stroke, diabetes, infant mortality, chemical dependency, and homicide. Between 1979 and 1981, these six conditions together accounted for more than 80% of the deaths, in excess of that of the white population, for blacks and other identified minorities [1]. In the letter introducing the 1985 report, Department of Health and Human Services (DHHS) Secretary Margaret Heckler called such disparities, “an affront both to our ideals and to the ongoing genius of American medicine,” and emphasized the necessity of working to eliminate this health gap in the United States. In the ensuing 20 years since the landmark report from Secretary Heckler, a variety of public and private programs, entities, and initiatives have been established with the purpose of reducing that gap. Although great improvements in health and health services for all populations have been realized since 1985 [2–5], the problem of health disparities among racial, ethnic, and underserved populations in this country is still a serious one [6–9].

According to the 2009 National Healthcare Disparities Report (NHDR), “… disparities related to race, ethnicity, and socioeconomic status still pervade the American health care system. Although varying in magnitude by condition and population, disparities are observed in almost all aspects of healthcare” [7]. For sizable proportions of measures, racial and ethnic minorities and poor people receive lower quality care. Blacks, Asians, and AI/ANs had worse access to care than whites for one-third (2/6) of core measures considered by the report. Hispanics had worse access than non-Hispanic whites for one-third (2/6) of core measures considered by the report. Hispanics had worse access than non-Hispanic whites for 83% (5/6) of core measures.

Those defined as “poor” (family incomes <100% of the Federal poverty level) received lower quality of care than their “high income” counterparts (family incomes 400% or more of the Federal poverty level); in fact, poor people received worse care than high-income people for 75% (15/20) of core measures and better care for 5% (1/20) of core measures. The largest disparities for blacks, AI/ANs, and Hispanics included the rate of new AIDS cases. The rate for blacks was almost ten times as high as the rate for whites, for Hispanics more than three times as high, and for AI/ANs 1.4 times as high. However, from 2000 to 2007, for blacks, AI/ANs, and Hispanics, this measure was among those with the greatest reduction in disparities for each group (10.2% per year, 2.7% per year, and 4.2% per year, respectively) [7]. As noted in the report, today, just as in 1985, relatively few (and similar) conditions contribute to the majority of observed disparities in mortality for minorities [10]. DHHS had initially identified the areas of cancer, cardiovascular disease, diabetes,
infant mortality, HIV infection/AIDS, and immunizations for special attention in reducing the gap in health outcomes for minorities and underserved populations [9, 11]. The various causes for disparities and barriers to healthcare are myriad and often interrelated. Identifying them completely is difficult and often controversial. Probable causes for disparities include race, class, poverty, culture, diet, and geography. A discussion of the “why” of disparities is beyond the scope of this chapter. It is known that such disparities exist and have always existed. In this chapter, some of the more significant attempts of the US government to eliminate racial and ethnic disparities of health, and what needs to be done in the future will be considered.

**Historical Milestones in the Government’s Response to Minority Health Issues**

*The History and Mission of the Indian Health Service*

One of the earliest governmental efforts on behalf of minority health was the formation of the Indian Health Service (IHS). In the first half of the nineteenth century, minimal healthcare was provided to Native Americans as the responsibility of the War Department, shifting in 1849 to the Department of the Interior [12]. The Synder Act of 1921 allocated Federal funds for health services to recognized Indian tribes [13], and a health division within the Bureau of Indian Affairs was created. This was the forerunner of IHS. At the time, aid was focused on the serious problems of tuberculosis, smallpox, and other contagious diseases, and was often inadequate [12].

The key legislation for governmental support of Indian health was the Transfer Act of 1954 (P.L. 83–568), which transferred health services for Native Americans from the Bureau of Indian Affairs to the Public Health Service [14], thus establishing, in 1955, the IHS. The transfer effectively created the only national health program for civilians in the United States. Today, as an agency within DHHS, the IHS provides a comprehensive health delivery service to close to two million individuals who are members or descendants of federally recognized American Indian and Alaska Native Tribes. The goal of IHS is to provide “comprehensive, culturally acceptable personal and public health services” to Native Americans. IHS supports self-determination for the Tribes, and assists Tribes in developing their own health programs, helps coordinate Federal, state, and local healthcare resources, provides direct healthcare services, offers management training and technical assistance, and serves as an advocate for the health needs of Native Americans [13].

*History and Lessons from the Tuskegee Syphilis Experiment*

The Tuskegee study of untreated syphilis in African American males stands as a powerful episode in the Federal government’s history of addressing minority health issues. For 40 years – between 1932 and 1972 – the US Public Health Service (USPHS), working
with the Tuskegee Institute, carried out a study among a group of 600 poverty-stricken, African American men in Macon County, Alabama, to determine the effects of withholding treatment for syphilis. Besides the needless suffering and adverse personal toll on the study participants and their families, the fallout from the Tuskegee study had a significant impact on later governmental efforts to address minority health issues [15, 16]. In the period before the study began, syphilis was perceived as a major health threat in the United States. Initially, the rationale for the study was based on a hope of proving a need for syphilis treatment programs. Following the 1929 stock market crash, the loss of private financing for development projects at Tuskegee led to government support of the study [16]. What began as a short-term project with specific aims, developed into a 40-year effort that was to yield very little useful information.

Researchers told the participants – 399 had syphilis and 201 did not – that they were being treated for “bad blood.” The men were induced to participate in exchange for free medical exams, free meals, and burial insurance. The subjects were never told the real purpose of the study, and never received proper treatment. In fact, it has been reported that the USPHS hindered with study participants who were drafted into the military from receiving the treatment required of other draftees. And, even when penicillin became accepted as the treatment of choice for syphilis in 1945, the participants went untreated. Instead, the men were kept in the study until they died, and autopsies were performed to examine the physical effects of the disease. Finally, on July 25, 1972, the *Washington Evening Star* exposed the experiment, and the report was quickly carried as front-page news by national papers. In response to the public outcry, a government advisory panel was formed, which concluded that the study was “ethically unjustified.” The study was halted in October 1972. In 1973, the government settled a class-action lawsuit filed by the National Association for the Advancement of Colored People, by agreeing to give more than USD $9 million to compensate study participants and their families, and to provide for their medical care and treatment. “The Tuskegee Health Benefit Program” was established to administer this program under the auspices of the Centers for Disease Control and Prevention (CDC) under whom it remains today [15].

In January 1996, the Tuskegee Syphilis Study Committee met at Tuskegee University to discuss the impact of the study on African American health [17]. The committee concluded, as have others [18], that Tuskegee contributed significantly to African American distrust of government health efforts, as evidenced by low participation by African Americans in clinical trials and organ donation programs. The committee also requested an apology from the President of the United States. In 1997, the US government formally apologized for the study. As one of the outcomes of the apology, DHHS provided funding to establish a center for bioethics in research at Tuskegee University [19]. The Tuskegee debacle did, at least, yield some positive influence on government research practices, most notably in the area of informed consent. The 1974 National Research Act resulted in the creation of the “National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.” This group helped establish basic rules of research conduct and, among other things, regulations that require researchers to obtain voluntary informed consent from study participants. Subsequent bioethics councils were
formed to continue this dialogue, the most recent being the 2001 “President’s Council on Bioethics” [20]. It is hoped that with continued input and advice from minority leaders, and continued discussion of biomedical ethics, increased participation by minority communities in health studies on minority populations will follow, and thus will advance the cause of eliminating health disparities.

A Turning Point in History: The 1985 Secretary’s Task Force on Black and Minority Health

One of the most significant events in the government’s response to health disparities began in 1985 with the release of the Secretary’s Report on black and Minority Health [1] and the subsequent establishment of the Office of Minority Health (OMH) at the DHHS. In April 1984, early into the term as Secretary of DHHS, Margaret Heckler commissioned a “Secretarial Task Force,” under the direction of the then deputy director of the National Institutes of Health (NIH), Thomas E. Malone, to comprehensively examine the health status of blacks, Asian/Pacific Islanders, Hispanics, and Native Americans (including American Indians, Alaska Natives, and Native Hawaiians). As explained in the opening pages of the executive summary, “The Task Force on Black and Minority Health was thus conceived in response to a national paradox of phenomenal scientific achievement and steady improvement in overall health status, whereas at the same time, persistent, significant health inequities exist for minority Americans.”

The DHHS Task Force gathered information and received input from all of its agencies and from health professionals and academics outside the Federal government. Wherein published data was inadequate, the Task Force received data and guidance from advisory groups such as those providing information on Hispanics and Asian/Pacific Islanders. The Task Force reviewed and inventoried all of its department programs as they related to minority health, analyzed national mortality data for over 40 diseases, developed specific measures for mortality and morbidity, and formed subcommittees to specifically examine each of six health priority areas (cancer, cardiovascular disease and stroke, diabetes, infant mortality, chemical dependency, and homicide).

The Task Force report was delivered in just 1 year, and represented the first time that DHHS had ever consolidated information on minority health issues. It provided a discussion of the social, mortality, and morbidity indicators for the four targeted minority groups and a discussion of the impact of the six priority health conditions on those groups.

The Task Force “acknowledged that the factors responsible for health disparities are complex and defy simplistic solutions,” [1] but that those factors were amenable to common approaches for effecting change. To that end, the Task Force made recommendations in six key areas:

1. To launch health information outreach and patient education campaigns to ensure that health education was responsive to the needs of minority populations
2. To enhance delivery and financing of health services in order to increase access to care for minorities
3. To develop strategies within and without the Federal sector to increase the availability of health professionals to minority communities
4. To build capacity of the non-Federal sector to address minority health problems
5. To improve and fully use available sources of health data
6. To adopt a research agenda that would specifically address the problem of minority health disparities

In the letter introducing the report [1], Task Force chairman Malone expressed the hope that the “report should serve not only as a standard resource for department wide strategy, but as the generating force for an accelerated national assault on the persistent health disparities …. One of the significant weapons in that assault, formed in response to the report’s challenge, is the OMH.”

The Federal Office of Minority Health

In December 1985, OMH was established as an entity within the office of the Secretary of DHHS. The role of the office is to advise the Secretary and other branches of government on public health activities that affect minorities, especially African Americans, Hispanics/Latinos, Asian Americans, American Indians, Alaska Natives, Native Hawaiians, and other Pacific Islanders. The mission is to “improve and protect the health of racial and ethnic minority populations through the development of health policies and programs that will eliminate health disparities” [21]. Besides its advisory role, OMH provides educational and research resources to the nation, and cooperates with, operates, and funds a host of programs and initiatives within and outside the public sector.

Educational and Resource Activities

As an educational and resource entity, OMH provides staff minority health liaisons for state and US territorial offices of health, provides minority consultants for each of the ten DHHS regional offices, maintains a listing of pertinent statistics, publications, and health links on the Web site [22], and operates the “Office of Minority Health Resource Center” (OMHRC) [23]. OMHRC was established in 1987 within DHHS and is a national database and referral service for minority health issues. OMHRC offers its services to consumers, health professionals, students, the media, and grant seekers. As it relates to its mission, the agency collects and distributes health information, offers free, customized database and informational searches, and maintains a network of volunteer professionals – the “Resource Persons Network” – who provide advice and technical assistance to local community-based organizations that work in the area of minority health.
Programs and Initiatives

In response to requests from the public, and from the executive and legislative branches of government, OMH supports and coordinates a variety of programs, campaigns, and initiatives geared to implementing policies that could decrease health disparities [21]. Some present and recent examples are White House initiatives (for Historically Black Colleges and Universities (HBCUs), for Tribal Colleges and Universities (TCUs), for educational excellence for Hispanic Americans, and for increasing participation of Asian Americans and Pacific Islanders in Federal programs), and DHHS initiatives such as its Disparities Initiative and its HIV/AIDS Initiative. Some of these initiatives will be discussed in more detail below.

OMH also works to monitor the minority-related goals of the national “Healthy People 2010” program [24], a campaign to increase the quality and longevity of life for all Americans and eliminate health disparities by 2010. Similarly, OMH established the “Closing the Health Gap” educational campaign, the “First National Child Health and Child Welfare Conference” in 2004, and the first “National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health” in 2002 [21]. In 1995, OMH established the Center for Linguistic and Cultural Competency in Health Care (CLCCHC) [25], a “center without walls,” to encourage culturally and linguistically appropriate healthcare for limited English-speaking populations. This program will be discussed further below.

Funding Activities

As a funding entity, OMH administers grants to community- and faith-based organizations. Such grants are geared to enhancing health programs for underserved communities at the local level. OMH has, for example, funded demonstration programs for developing community-based coalitions in support of minority health, programs to build the capacity of local organizations to find funding, and programs to improve the cultural and linguistic competency of health professionals. OMH also funds a variety of cooperative agreements with other national minority organizations, to support research and understanding of the mechanisms that enhance delivery of healthcare to disadvantaged populations.

Other Minority Health Programs Within DHHS

Several of the operating divisions within DHHS have departments directly involved in health disparity issues. The response of these Federal agencies to minority health concerns evolved as a natural necessity as each of these agencies worked to carry out its mandated health mission. IHS has already been discussed and the Agency for Healthcare
Research and Quality (AHRQ) will be discussed later in the chapter. Other key agencies working to decrease the health gap for minorities and underserved populations are the CDC, the Health Resources and Services Administration, and most recently, the National Institute on Minority and Health Disparities (NCHMD) at the NIH.

**Centers for Disease Control and Prevention**

The CDC was founded in 1946 as the “Communicable Disease Center” in a small office building in Atlanta, Georgia, with an overriding mission to fight malaria by killing mosquitoes. In the past 60 years, it has grown to become the primary governmental agency for research into, and prevention and control of, infectious and chronic diseases, injuries, workplace hazards, disabilities, and environmental health threats [26].

The historical threats, such as tuberculosis, syphilis, and hepatitis, initially addressed by the CDC, continue to be of concern for minorities, even as new threats such as HIV/AIDS have emerged. The disproportionate impact of old and new diseases among minorities is well established [11, 27]. In 1988, the CDC instituted its own separate office of minority health in recognition of these disparities, and in response to the landmark 1985 Secretary’s report on disparities [1, 9]. The mission of the CDC Office of Minority Health is to “promote health and quality of life by preventing and controlling the disproportionate burden of disease, injury, and disability among racial and ethnic minority populations” [28]. Examples of CDC programs aimed at benefiting minorities are the Racial and Ethnic Approaches to Community Health (REACH) program and the National Breast and Cervical Cancer Early Detection Program [27].

REACH 2010 was established by CDC in 1999 as its primary effort to eliminate racial and ethnic disparities in health. The program focuses on six areas that affect targeted minority groups (African Americans, Alaska natives, American Indians, Asian Americans, Hispanic Americans, and Pacific Islanders). The key areas are infant mortality, breast and cervical cancer, cardiovascular diseases, diabetes, HIV/AIDS, and child and adult immunizations. REACH 2010 supports local community coalitions that are involved in health education and health promotion. African American and other minority women continue to have higher rates of breast and cervical cancer than do Caucasians, probably owing, in part, to low rates of cancer screening (e.g., mammograms and Pap tests) and treatment [29]. As part of its breast and cervical cancer detection and awareness programs for all Americans, CDC provides underserved women with access to breast and cervical cancer screening services.

**Health Resources and Services Administration**

Health Resources and Services Administration (HRSA), sometimes described as “the nation’s access agency,” has a primary mission to promote access to culturally competent, quality healthcare for all Americans [30]. The agency focuses on
underserved, uninsured, and special needs populations, including rural communities, women, and minorities. Recognizing that lack of access to healthcare is a major factor in causing health disparities among minorities, HRSA established its own “Office of Minority Health and Health Disparities.” Two key HRSA programs aimed at solving these disparities are the health centers program and the Bureau of Health Professions.

Under its Bureau of Primary Health Care, HRSA has administered and expanded a community health center program in response to a congressional mandate and Presidential initiatives. Health centers are public and nonprofit entities that receive Federal funding under the Public Health Services Act of 1996. They differ from other health providers by virtue of their service to local, high-need communities; their provision of comprehensive health in the context of providing access services (e.g., translation and transportation); fees adjusted to patients’ ability to pay; and governance by a community board [31]. Under its Bureau of Health Professions, HRSA promotes a mission of improving “the health status of the population by providing national leadership in the development, distribution, and retention of a diverse, culturally competent health workforce” [32]. As will be discussed below, increasing the numbers of minority physicians and healthcare professionals who serve in minority communities will have great potential for decreasing the gap in health disparities.

**National Institutes of Health**

The National Institute on Minority Health and Health Disparities (NCMHD) at NIH has recently been elevated from a Center to an Institute [33]. The effort initially began in 1990 with the creation of an Office of Research on Minority Health (ORMH). The Office was elevated to a Center in 2000 through the passage of the congressional Minority Health and Health Disparities Research and Education Act of 2000 (Public Law 106–525). NCHMD was established to lead and coordinate NIH research, training, and informational programs that support minority health [34]. Through NIMHD, NIH continues the work of the former NCMHD to improve the visibility of health disparities research, and promotes research that examines why some populations have disproportionately high rates of disease. NIMHD awards grants and contracts independently, and supports research that focuses on basic and clinical research and training related to decreasing health disparities [34].

**The States’ Roles in Eliminating Disparities**

Over the past two decades, there has been growing involvement of the government at both the Federal and state level in the area of health disparities. In 1990, 5 years after the establishment of the Federal Office of Minority Health, there were only five states with offices of minority health – Ohio, Indiana, Missouri, Michigan, and
South Carolina [35]. By 2009, that number had increased to 41 state entities that had offices or infrastructure dedicated to minority populations. The increased importance of states’ roles in eliminating disparities has been called “the New Federalism.” Indeed, state involvement and experimentation has led to national programs such as drug coverage for seniors and health insurance for low-income children [36].

In 1998, a state partnership initiative was started to enhance the capabilities of the individual states to address the disparity issues peculiar to their state [35, 37]. OMH recognized that health disparities often vary by geography and specific population. For example, South Carolina, with a population of elderly African American men, addresses prostate cancer as an important health issue for minorities in that state. Similarly, health departments in California, with its large population of immigrants, must pay particular attention to the cultural and linguistic barriers to healthcare for those communities. Clearly, effective problem solving in the area of disparities requires more than Federal activity. State and local input, awareness, and expertise are crucial. In 1998, initially the states were asked to either address an emerging health-related issue (such as asthma projects in New York and New Jersey), or infrastructure development projects (such as improving data collection, or partnering with grass roots organizations that were already caring for minority health). In its first programs of this sort, OMH funded 25 state offices of minority health [35].

In 1998, OMH also decided to assess minority health infrastructure in eight states and one territory [37]. The resulting report, “Assessment of State Minority Health Infrastructure and Capacity to Address Issues of Health Disparity,” examined the capacity of these entities to address racial and ethnic disparities in priority health areas (cancer, diabetes, cardiovascular disease, infant mortality, substance abuse, HIV/AIDS, suicide, homicide, and unintentional injuries), and across five “crosscutting issues.” Crosscutting issues, which relate to health disparities at all levels [35], were identified as follows: data collection, analysis and reporting, cultural competence, access to healthcare, and health professional development.

The study methods [37] included visiting all nine selected states, and gathering information from at least four key informants at each site. The study found that marketing and educational outreach campaigns were frequent strategies used by state and local agencies to address minority health needs. Stronger linkages were observed between minority communities and local health entities compared with linkages with state agencies. The study also noted that, for minority health organizations, factors that detract from implementing effective health solutions include lack of financial resources, isolation from state agencies, lack of appropriate data, and lack of legislative grounding. The study recommended effective strategies for state and local minority health entities such as improved data collection and dissemination, improved collaborations, technical assistance efforts, and increased funding.

OMH continues to advise states and administer grant programs for state and local minority health entities. Crosscutting issues continue to be important: it is vital that states continue to improve data collection because it is difficult to identify problems and justify expenditures if appropriate data are unavailable. Similarly, state and local agencies cannot adequately address minority health needs without an understanding of potential cultural or other (e.g., language) barriers to access of healthcare. Further, minorities are underrepresented in the health professions, and states can play a role
in increasing minority participation by, for example, sponsoring informational and mentoring programs for minority youth. A study by Trivedi et al. [36] noted that states vary widely in the successes of their capacities to address racial and ethnic health disparities. This study suggests the value of a “state minority health policy report card” to assess important issues such as the insurance gap for minorities, physician workforce diversity, the presence of dedicated offices of minority health in each state, and detailed statistical collection by race and ethnicity.

**Government Support of Minority Educational Institutions and Health Professionals**

One component in the effort to reduce racial and ethnic health disparities is governmental support of programs aimed at increasing the numbers of minority physicians, health professionals, and researchers. Increased diversity within the health provider and research work forces has great potential for improving access to healthcare for underserved populations, especially as racial and ethnic minority populations continue to grow in size throughout the nation [38, 39]. Shortage of physicians in underserved areas is often a problem [40]. Further, minorities generally receive care from health providers of their own race, often because of personal preference, or issues of cultural and linguistic sensitivity [39, 40]. A variety of governmental programs are in existence to support minority health education and awareness.

**Historically Black Colleges and Universities**

Historically Black Colleges and Universities (HBCUs) were defined in the Higher Education Act of 1965 as any historically black college or university that was established before 1964. Presidential Executive Orders in 1980 (Carter), 1981 (Reagan), 1989 (George Bush), 1993 (Clinton), 2002 (George W. Bush), and 2010 (Obama) established and continued Federal programs to strengthen the educational capacities of HBCUs [41]. Since 1981, as required by Executive Order, DHHS has submitted an annual performance and planning document, which outlines DHHS support of, and partnership with, HBCUs including support of health disparities research, minority educational initiatives, and programs to eliminate minority health disparities [42]. The DHHS plan for 2009 described cooperative activities between HBCUs and most divisions and offices within DHHS. Activities were in the areas of research and development, training, technical assistance, facilities and equipment, and scholarship or other aid. Many of these activities support recruitment and training of African Americans in the areas of healthcare delivery and research. For example:

- AHQR continued to fund Excellence Centers for the Elimination of Ethnic/Racial Disparities, such as the center at Morehouse School of Medicine.
- NIH continued to encourage investigators at HBCUs to apply for standard grant funding.
• The National Heart, Lung, and Blood Institute of NIH assisted HBCUs in their research capacities through Research Scientist Development Awards.
• HRSA continued support of workforce diversity through training programs such as AIDS Education and Training Centers, the Advanced Nursing Education Program, Public Health Traineeships, and other programs.
• A variety of agencies provided faculty, student and youth recruitment, and tuition and scholarship aid.

Other Minority Education Initiatives

DHHS also supports health education initiatives for minorities through the Hispanic Agenda for Action, the White House Initiative on Tribal Colleges and Universities (TCUs), and The Asian American & Pacific Islander (AAPI) Action Agenda. In response to a 1994 Presidential Executive Order (Educational Excellence for Hispanic Americans), DHHS instituted a study of its services to Hispanic Americans and recognized the need for improved access to healthcare for this growing population, and the need for increased inclusion of Hispanics within DHHS and within the health workforce [43]. A 2002 Executive Order on TCUs recognizes the crucial role that the underfunded TCUs play in Native American culture. The Office of Minority Health is the lead within DHHS for aiding TCUs in increasing their funding through grants, cooperative agreements, and contracts [44]. The AAPI Initiative, launched by DHHS in 1997, continues the process of identifying health disparities, including those of training, within this population. The tremendous diversity and variation of health needs within the AAPI population poses particular challenges and need for awareness of the issues involved [45].

The Emergence of Quality as a Key Factor in Eliminating Disparities

As the national dialogue on health disparities has continued, the conversation has included, to an increasing extent, the integration of quality improvement measures as a strategy to deal with health disparities. This was particularly noted in 1999 with the congressional mandate [46] to form the Agency for Healthcare Research and Quality (AHRQ). This legislative Act reauthorized the Agency for Health Care Policy and Research (AHCPR), which had been created in 1989, and renamed it as AHRQ [47, 48] to reflect its primacy as a scientific research agency charged with leading Federal efforts to sponsor, conduct, and disseminate “research designed to improve the quality, safety, efficiency, and effectiveness of healthcare for all Americans” [48]. The creation of AHCPR and its reauthorization as AHRQ, represents the developing awareness of lawmakers that healthcare costs were
increasing without equally increasing benefits, and that translation of research into improvements in health delivery and outcomes (such as those needed to decrease disparities) was remarkably slow [49].

AHRQ’s “customers” are patients and clinicians, and, most especially, health decision makers within the governmental, healthcare, and medical communities. Patients and the medical community use the information developed by AHRQ to make informed choices about which health treatments and interventions work and at what cost. And, AHRQ’s research is crucial for the formulation of public and private healthcare policies that are evidence based. The Federal government, by virtue of its political leverage as a mammoth purchaser and regulator of healthcare, has a vested interest and the unique powers necessary to promote quality research and improved decision making, and to decrease racial, ethnic, and socioeconomic disparities in healthcare [50].

AHRQ’s research priorities [48] include promoting patient safety, advancing the use of information technology for coordinating care and researching health outcomes, providing the nation with an annual report card on the state of the nation’s health. In response to concerns about patient safety, such as those raised by the Institute of Medicine [51] that as many as 98,000 patients die yearly from hospital medical errors, AHRQ has established permanent “Centers for Education and Research” to study adverse drug events and patient safety statistics. As will be discussed further below, new information technologies have tremendous potential for improving quality of care for all sectors of the populace, by virtue of providing the means for enhanced and comprehensive data collection, analysis, retrieval, and dissemination. The AHRQ initiative for advancing health information technology provides significant funding to support this technology, especially in rural and underserved areas.

In recognition of vulnerability as a significant component of adverse health disparities, AHRQ has targeted specific populations (the poor, minorities, women, children, the elderly, and individuals with special healthcare needs) as areas of special concern [52]. Clearly, there is a great deal of overlap and interplay between the quality of care in the Nation as a whole and that received by its most vulnerable populations.

Reporting to the Nation

The most public face of AHRQ, and its premier product, is represented by its two highly related, yearly reports on the state of the nation’s health – the National Healthcare Quality Report (NHQR) [3, 4] and the National Healthcare Disparities Report (NHDR) [6, 7]. These reports were mandated by Congress in its 1999 directive [46]. These reports analyze data from over 40 national databases. The NHQR reports on the quality of healthcare as tracked by a number of comprehensive quality measures. The companion NHDR adds the level of equity to the NHQR measures by presenting data on race, ethnicity, and socioeconomic status. The NHDR uses the
same quality measures as the NHQR and adds additional measures of access to care. The wedding of the two documents, as instructed by the congressional mandate, highlights the growing thought that the future of health disparities, at least from a governmental perspective, requires an ongoing discussion about quality of care. The first pair of reports was released in 2003. Much as a student’s school report card will identify areas of strengths and areas that need improvement, the NHQR and NHDR provided a comprehensive analysis of achievement in the nation’s health, as well as the areas that must be targeted for improvement.

These reports represented the first time the US government had ever comprehensively examined the quality of care for the Nation as a whole. The templates for these reports were basically created de novo with design recommendations initially coming from reports commissioned to the Institute of Medicine – the 2001 “Envisioning the National Healthcare Quality Report,” and the 2002 “Guidance for the National Healthcare Disparities Report” [53]. Based on these recommendations, and input received from expert constituencies from within and outside government, final measures were selected by Interagency Work Groups, one for NHQR and one for NHDR. The 2009 NHDR continued to focus on a consistent subset of measures, the “core” measures, which included the most important and scientifically supported measures in the full NHDR measure set. In 2005, the Interagency Work Group selected the core measures from the full measure sets, and findings based on these measures are presented each year. The core measures fell into two categories: process measures, which track receipt of medical services, and outcome measures, which in part reflect the results of medical care.

**NHQR Findings**

The 2009 NHQR defined the delivery of quality of care services as “Quality health care that delivers these services in a way that is safe, timely, patient centered, efficient, and equitable.” The challenges in healthcare quality are noted as follows: “Unfortunately, Americans too often do not receive care that they need, or they receive care that causes harm. Care can also be delivered too late or without full consideration of a patient’s preferences and values. Many times, our system of health care distributes services inefficiently and unevenly across populations” [3]. As noted, the 2009 report was developed using more than 200 measures categorized across four dimensions of quality: effectiveness, patient safety, timeliness, and patient centeredness. The report highlighted that the country does well with acute care in terms of diagnostic and therapeutic intervention but does not do as well with preventive measures and outpatient care. One key example highlighted in the report was noted between the 2008 and 2009 reports; five measures attained overall performance levels exceeding 95%. Four of those five measures related to hospital care for heart attack. In addition, all ten of the worst performing process measures tracked in the 2009 NHQR were measures of outpatient care, and six of those related to preventive services.
NHDR: Reporting on Disparities

A guiding principle of the NHDR methodologies is consistency with existing Federal guidelines, especially with Healthy People 2010 [24] guidelines. The framers of the initial 2003 NHDR gave substantial consideration to define “disparities,” and settled on the broad Healthy People 2010 definition, “all differences among populations in measures of healthcare are considered evidence of disparities,” [6] in contrast to other, more limited descriptions.

Other challenges for understanding disparities within the NHDR were measurement and data collection issues [54]. For example, it was necessary to address and tease out the relative effects of race, ethnicity, and socioeconomic status, because minorities tend to have lower socioeconomic status. Further, national health surveys often do not specifically identify minority or other subpopulations of interest. Gaps in data for desired measures and populations continue to be a challenge.

As reported by the AHRQ [54], “To address challenges posed by inconsistent definitions, measurement problems, and variations in data standards, the general methodological approach of the NHDR is to examine many measures from a variety of national data sources, standardize data and comparisons whenever possible, and apply uniform and rigorous thresholds for identifying differences.” The original NHDR [6] concluded that: “Inequality in quality persists. Disparities come at a personal and societal price. Differential access might lead to disparities in quality. Opportunities to provide preventive care are frequently missed. Knowledge of why disparities exist is limited. Improvement is possible. Data limitations hinder targeted improvement efforts.” The 2009 NHDR [7] expanded on the same themes, concluding that: “All population groups should receive equally high quality of care. Getting into the health care system (access to care) and receiving appropriate health care in time for the services to be effective (quality care) are key factors in ensuring good health outcomes.”

Future Trends and Challenges

Improved Quality of Care Measures and Data Collection

Recent data on the integration of Health Plan Employer Data and Information Set (HEDIS) measures in the Medicare managed care population have again shown that the inclusion of quality care measures along with the recording of racial and ethnic data can effectively lead to the reduction of health disparities [5, 50]. HEDIS [55] measures and the Diabetes Quality Improvement Project (DQIP) [56] are examples of tools that provide standardized measures for the collection of data to rate the quality of care and services provided by healthcare organizations. They are among the recent methods used to meet the long-recognized need for adequate data collection and dissemination in combating health disparities. Almost 25 years ago, the
1985 Secretary’s report noted that improving data collection was a “major area” of importance in any efforts aimed at reducing health disparities [1]. Recently, the 2009 NHDR recognized that gaps in data availability continue to be a problem: for example, lack of statistically reliable estimates for many of the measures for Native Hawaiians, Asians, American Indians, and Alaska Natives. It is crucial that the collection of health statistics, and the use of health “report cards” (such as HEDIS and DQIP), link data points or quality measures to information on race, ethnicity, and socioeconomic status if they are to be of use in reducing health disparities [5, 9, 50, 57]. Such linkage is necessary to specifically understand and identify the “who,” “what,” and “where” of health disparities. Federal and state governments should work together with consumers and the private healthcare sector to effectively address the barriers that exist for linking race, ethnicity, and socioeconomic indicators to healthcare statistics and quality measures [50, 57]. Concerns regarding privacy/confidentiality, potential misuse of data, financial costs, accountability, and reporting consistently arise in relation to the collection of specific data on minority populations [57]. Meeting these concerns is an important challenge for future efforts to reduce health disparities.

**Health Information Technology**

Regardless of the will to assemble healthcare data that relate to minority populations, the means to collect, organize, store, and disseminate such information becomes a limiting factor as the sheer volume and complexity of data continue to increase. The importance of information technology relates not only to researching and reporting on health incomes but also for the coordinating of patient care and safety, and for patient education. In 2004, an Executive Order established the Office of the National Coordinator (ONC) within DHHS [58]. ONC is the government lead for the development, application, and use of health information technology to improve the quality, efficiency, and safety of healthcare in the United States. In 2005, DHHS released a report [59] in conjunction with representatives of the business sector identifying information technology as a “pivotal part of transforming the healthcare system,” with the potential to “drive changes that will lead to fewer medical errors, lower costs, less hassle, and better care.”

In the broader sense, information technology also includes innovations such as electronic health records for patients, and efforts to educate consumers and the health delivery workforce in the uses of information technology to enhance health knowledge and access. The increasing importance of “e-Health” – the electronic exchange of health information by technological means (e.g., Internet, email, computers, and audio visual aids) – is of particular relevance for minorities [60–62]. The role of HIT in potentially reducing disparities is described further in this book.

“Health literacy,” the group of skills necessary to understand, process, and act on healthcare information, can be lower in some populations, such as those with less education, the elderly, and some racial and ethnic groups [62]. Low health literacy,
including the inability to access e-health resources – for example, using the Internet to research a disease or find a physician – can negatively impact an individual’s health [61, 62]. A challenge for future governmental efforts will be to use information technology to support research into healthcare quality and access, and to support the use of e-health technology by vulnerable populations and their healthcare providers.

**Cultural and Linguistic Competency**

Cultural and linguistic competencies in healthcare delivery are simply the abilities of organizations to appreciate, understand, work with, and communicate with populations who have specific cultural and language identities that will impact their access to healthcare. A doctor who has trouble communicating, or understanding the cultural barriers that cause a patient to avoid treatment, will encounter difficulties in trying to address a patient’s needs. Cultural competency has emerged as a crucial element in efforts to eliminate health disparities [63]. As the population of the United States becomes increasingly diverse, healthcare providers will more frequently interact with patients who have differing social and cultural backgrounds. Patient/provider communication positively affects health outcomes, and healthcare providers must be knowledgeable in strategies to improve communication with all populations of patients. Furthermore, vulnerable populations might be unwilling or unable to seek treatment when cultural or linguistic barriers exist. In response to a 1995 congressional mandate (P.L. 101–527), OMH established the Center for Linguistic and Cultural Competence in Health Care. CLCCHC collaborates with Federal agencies and public and private entities to execute its mission. CLCCHC programs promote research on removing language and cultural barriers to healthcare, facilitate information exchange about research in these areas, develop and evaluate demonstration projects that are aimed at removing language and cultural barriers, and provide technical assistance to enhance cultural and linguistic competencies among healthcare providers [25]. Government efforts to support cultural competency in the healthcare system will continue to be an ongoing priority for reducing health disparities.

**Health Reform**

The Patient Protection and Affordable Care Act, PL 111–148 significantly changed the governmental infrastructure addressing minority health. In particular, section 10334 of the law codified the Federal Office of Minority Health in the Office of the Secretary [33]. In addition, this section of the law also authorized existing offices as well as created new offices of minority health at HHS. In particular, the Act authorized offices of minority health at the Centers for Disease Control and Prevention, Health Resource and Services Administration, Substance Abuse
and Mental Health Services Administration, Agency for Healthcare Research and Quality, Food and Drug Administration, and the Centers for Medicare and Medicaid Services. As noted earlier, the law also elevated the National Center on Minority Health and Health Disparities to the National Institute on Minority Health and Health Disparities.

The new law also puts in motion a number of activities to improve federal data collection efforts. In particular, the law stipulates that by no later than 2 years after the date of enactment of this title, any federally conducted or supported healthcare or public health program, activity, or survey (including Current Population Surveys and American Community Surveys conducted by the Bureau of Labor Statistics and the Bureau of the Census) must collect and report data on race, ethnicity, sex, primary language, and disability status, for applicants, recipients, and participants to the extent practicable. The law also contained specific provisions to support the development of model curricula for cultural competency.

Summary

As the nation moves forward into the coming decades, and the population becomes increasingly diverse, the mandate to provide quality healthcare to all Americans will continue to be of importance and will most effectively progress as today’s efforts to eliminate disparities continue and improve. The growing collaboration between Federal and state agencies, and private and academic institutions in using resources and expertise in a common cause holds the greatest hope for achieving health equity for all.

References

Chapter 18
The Association of Black Cardiologists: A Small-Group Success Story in Addressing Healthcare Disparities

Richard Allen Williams and Icilma V. Fergus

Abstract Thirty-six years ago, Richard Allen Williams, M.D., founded an organization consisting primarily of African American cardiologists, and named it the Association of Black Cardiologists (ABC) at its inaugural meeting in Dallas, Texas. The year was 1974. He was joined in this effort by a small number of other black cardiologists who were attending the annual scientific sessions of the American Heart Association. All agreed that the cardiovascular needs of blacks were unmet and were not being adequately addressed by the American Heart Association, the American College of Cardiology, and other prominent medical groups. Despite the fact that hypertension was recognized as a disease that disproportionately affected the African American population, little was being done to increase awareness of this fact or to bring blacks to medical attention. In addition, stroke, often a consequence of hypertension, was uncontrolled, with catastrophic effects in blacks, and coronary heart disease was not generally believed to be an important problem in this population. The ABC was also concerned about the shortage of African Americans trained to treat cardiovascular disease, and one of its objectives was and continues to be to spur efforts to increase the number of African American cardiologists.

With almost no funding and very little moral support, we managed to create an energetic, innovative, efficient, and fiscally sound organization, which is regarded as a model that is arguably the best small minority medical group in the country. Those bragging rights are based upon the impact of a number of community-based programs, which have allowed patients to benefit from the knowledge possessed by professional members and advocates trained by the member cardiologists of ABC. This chapter details some of those programs that represent outreach into the African American communities with the mission of decreasing cardiovascular healthcare disparities among people of color (African Americans).
**Keywords** Cardiovascular • Healthcare disparities • Association of Black Cardiologists (ABC) • Women’s health • Continuing medical education (CME) • Cardiologists in training, community education • “Spirit of the Heart” • REACH • Community Health Advocate Training (CHAT) • Clinical trials • Volunteers

**Internal Structure of the ABC**

The Association of Black Cardiologists (ABC) is a membership body that currently operates from its headquarters in Atlanta, Georgia, in a new state-of-the-art building on 127 acres of land, as well as from a new office based in Washington, DC. ABC is a nonprofit, 501C3 organization governed by a Board of Directors, and is led by a president who is elected by the membership every 2 years. ABC has a staff of 25 talented employees who are specialists in various pursuits such as sociology, business, education, public relations, and many other “people skills” so important for communicating with health clients. ABC was led by an energetic Chief Executive Officer, Dr. B. Waine Kong, who was at the helm for 20 of the organization’s 36 years. Under his leadership, the organization pioneered hypertension screening programs in inner-city barbershops, beauty salons, and churches, and developed something that the American Heart Association and other groups had never had: direct contact with community residents. This has become an important component of achieving success in dealing with people who may be hard to reach or attract to a professional medical office setting. The current CEO is Andre Williams who brings a new business sense to the organization along with a commitment to maximizing efforts to benefit the communities of color that ABC serves.

In addition to its administrative offices and a Board of Directors who provide oversight of all of its functions, ABC has two Centers of Excellence that form the organization’s operational core. They are described as follows:

**The Women’s Center**

Established for the purpose of focusing attention on the unrecognized seriousness of cardiovascular disease in women and in black females in particular, this center received its initial funding through a grant from a large pharmaceutical company. In the past 5 years, it has produced outstanding national as well as local and regional seminars and meetings on the subject, and has raised awareness among practitioners as well as among community residents. There has also been some cross-pollination with the Red Dress program on women’s cardiovascular health sponsored by the American Heart Association, in recognition of the fact that more than 480,000 women in the United States die from cardiovascular diseases each year, and that African American women have a death rate that is almost 70% higher than that in Caucasian women [1].
The Center for Continuing Medical Education and Professional Education

Many fine educational programs that utilize the expertise and unique experiences of ABC’s members and consultants have been developed over the past several years. These are presented on a national, regional, and local basis and are immensely popular and well subscribed to. ABC holds at least three national scientific sessions per year and, through these sessions, it has earned the reputation of being the best resource on the prevention, treatment, and management of cardiovascular diseases in blacks. The Accreditation Council for Continuing Medical Education (ACCME) has recently granted “Accreditation with Commendation” status to ABC, a distinction that is directly due to the untiring and selfless efforts of Luther Clark, M.D., and Cassandra McCullough, formerly Vice President for Extramural Programs and now ABC’s Chief Operating Officer. As a result of their dedicated work, ABC is ranked among the top 5% of accredited providers. It is estimated that more than 300,000 healthcare professionals including clinicians and researchers have been educated through programs offered by the ABC. These programs include national scientific conferences, which have been held annually for the past 32 years during the conventions of the American Heart Association, the American College of Cardiology, and the National Medical Association. There are also regional symposia that are offered throughout the year and feature nationally recognized experts speaking mainly to audiences comprising primary care providers in community settings. Forty symposia were offered in 2005. In addition, several satellite symposia were offered at major cardiology meetings, focusing on best practices in cardiovascular disease, heart disease in women, and multi-modality imaging in ischemic heart disease.

The Center for Continuing Medical Education and Professional Development (CCEPD) also produces many enduring materials such as journal supplements, interactive audio CD-ROMs, clinical reference tools, and Web courses.

Financial Status

The ABC has operated on fiscally sound business principles since its inception in 1974, and it continues to maintain a solid financial status.

Cardiologists-in-Training Program

Enabling the development of young doctors undergoing fellowship or postgraduate training in Cardiology is an important and integral part of the ABC mission. The organization sponsors special sessions for scientific abstract presentations at ABC conferences and presents awards to outstanding investigators. A Cardiologists-in-Training (CIT) representative sits on the ABC Board of Directors, and efforts are
made to assist potential trainees in obtaining positions at various institutions. With support from various sponsoring companies, ABC has been able to make a small number of fellowship awards annually.

Special ABC Initiatives

**Community Education Projects**

ABC’s mission to reduce and/or eliminate healthcare disparities in communities of color means that the organization is committed to engaging people from the grassroots level. The statistics show that African Americans continue to lead all racial groups in chronic diseases, particularly cardiovascular disease. ABC has created and embraced several programs that have been very successful in making an impact on healthcare disparities. These special community programs are directed by Icilma V. Fergus, M.D.

1. CHOICES is a faith-based program in which ABC provides training in cardiovascular screening to lay health promotion specialists to screen for hypertension, diabetes, dyslipidemia, obesity, and other health problems. In 2005, over 3,800 individuals were screened and 14,000 received information and education about cardiovascular conditions that may affect them.

2. REACH is tied to the national goals of substantially reducing cardiovascular disease by the year 2010. It involves an intensive training program for community residents, enabling them to become health promotion specialists. The training is carried out in conjunction with churches, barbershops, and beauty salons. Training in cardiopulmonary resuscitation, blood pressure measurement, biometrics, nutrition, and other functions has been conducted for hundreds of individuals.

3. “Spirit of the Heart” Weekends are programs that are conducted across the nation in major metropolitan arenas in a unique format. They engage community residents in various national locations for a 3-day period during which they attend a number of events related to cardiovascular disease. The Community Leaders Forum is held on a Friday evening. This forum provides an opportunity to educate, empower, and mobilize influential members of the community so that they can engage in increasing and improving access to cardiovascular care. On Saturday, the next day, Health Risk Assessment Screenings provide screening services to attendees who are referred for further medical attention when appropriate. In 2010, ABC partnered with the BET foundation to provide a powerful women’s health component that includes workshops and a panel of practitioners in addition to the screening. Patient education on a variety of health topics is also conducted. A spiritual health encounter occurs on Sunday. So far, this program has reached over 50,000 lives in cities around the country. In keeping with the ABC “Seven Steps to a Healthy Heart,” the Spirit Weekend includes “Messages from the Pulpit” with a faith-based health education sermon. In 2009 alone,
ABC screened close to 2000 community members and reached more than 100,750 personal contacts through the “Spirit of the Heart,” which is a trademark program invented by ABC.

4. ABC Project HOPE embodies our Katrina Relief efforts. ABC raised $300,000 under the leadership of Keith Ferdinand, M.D., and much of this money was used for the direct support of Katrina victims and organizations involved in the relief effort.

5. For the last 3 years, ABC has engaged in a new program, which is the Community Health Advocacy Training (CHAT) in conjunction with the National Heart, Lung and Blood Institute (NHLBI). The purpose is to prepare the advocates (CHAs) to implement community educational activities in the community. The curriculum includes the ABC’s “Seven Steps to a Healthy Heart,” NHLBI’s “With Every Heartbeat is Life” curriculum, and advocacy through health policy training. The program is an intense but fun 2½ days of training followed by issuance of a certificate to the participant. To date, ABC has trained almost 400 CHAs and recruited 2,500 CHAs from communities where the programs are held.

ABC continues to partner with various organizations to increase awareness of cardiovascular disease and its risk factors. Last year, ABC participated with Daichi Sankyo Incorporated (DSI) in a campaign to enlighten the public about hypertension and barriers to achieving and maintaining a normal blood pressure. A survey titled “My Pressure Points” was conducted in which 500 African Americans were interviewed about their knowledge and awareness of certain key points regarding hypertension. (This survey is available on the Web site at www.abcardio.org) In addition, ABC and DSI jointly engaged in a radio media campaign that reached nearly 40 million people. ABC has also partnered with Boeringher Ingleheim (BI) this year to release a DVD geared to educating the lay public about managing their lives with hypertension.

**Participation in Clinical Trials**

It is well recognized that African Americans are under-represented in research studies and trials provide evidence-based data on which clinical decisions regarding treatment are made. The ABC has been making a strong effort to remedy this problem by partnering with researchers to recruit subjects for various investigations. Some examples are:

1. The ABC Study of Hypertension, which was a multicenter, randomized, double-blind placebo-controlled investigation of the efficacy of candesartan cilexetil in the treatment of hypertension in blacks.
2. The African American Heart Failure Trial (A-HeFT), referred to above, was co-sponsored by ABC to determine the safety and efficacy of a fixed-dose combination of isosorbide dinitrate in attempting to reduce mortality from heart failure in blacks. More than 1,000 patients were recruited by ABC and the investigators.
The study was scientifically rigorous and resulted in a 43% reduction in mortality; this led to approval of the study product by the Federal Food and Drug Agency (FDA) for public use.

3. The ARIES Trial was the first prospectively designed study of dyslipidemia in African Americans. It employs statin therapy. ABC members constituted 44% of the investigators, and ABC recruited half of the patients. The principal investigator, Keith Ferdinand, M.D., is the Chief Science Officer for the ABC.

Other ABC initiatives include development of a practice management system involving electronic medical records (EMR), which will be mandatory for medical practices in the not too distant future. ABC advocates the EMR system because it has the potential for improving patient management and decreasing healthcare disparities. It will also enable the development of a data warehouse and central repository of information (handled in accordance with HIPAA regulations), which will serve as a valuable resource for determining disease patterns and outcomes of prevention and treatment among racial and ethnic groups.

Member Participation and Volunteer Involvement

The key to the long-term successful operation of a nonprofit organization is vigorous volunteerism. Hundreds of ABC members have given unselfishly of their time and expertise without any financial reward, to participate in the many programs offered by the organization, to serve on committees, to help with fund-raising and special events, and to become officers and trustees. The members are the backbone of the ABC, and their importance cannot be minimized. They consist of 660 mostly African American cardiologists, a group that includes healthcare professionals from several non-black races and ethnicities. The membership is also multi-disciplinary in that it includes medical professionals who are from diverse backgrounds, such as cardiovascular nurses, primary care providers, cardiovascular radiologists and cardiac imaging practitioners, cardiopulmonary specialists, neurologists, and cardiologists. There are also members from a number of foreign countries, especially African and Caribbean nations. The ABC believes that anyone who has an interest in improving the cardiovascular health of African Americans and others should be a member.

Conclusion

The Association of Black Cardiologists was a vision many years ago of what might be done to improve the cardiovascular status of a specific population subgroup, the African American community. This organization serves as an example of what can be done by inspired, determined people working together to eliminate healthcare disparities. Through dedicated work, that vision of “treating the hearts of a diverse America” has become a reality. Although the job certainly is not finished, the ABC
has demonstrated that there is light at the end of the tunnel. Much remains to be
done, including efforts to increase the pool of black cardiologists above the 2% of
the general cardiologist population that currently exists. Although this is a daunting
goal, it is achievable. As the old African American expression goes, “we ain’t what
we oughtta be, but thank God almighty, we ain’t what we was!!”

Reference


In the United States, disadvantaged and minority populations are disproportionately affected by asthma (Gold and Wright, Annu Rev Public Health 26:89–113, 2005; Asthma and Allergy Foundation of America and National Pharmaceutical Council, Ethnic disparities in the burden and treatment of asthma. Washington, DC, 2005). Relative to wealthier and white populations, they have higher asthma prevalence and experience more serious impacts such as severe attacks leading to emergency department visits and hospitalizations (Aligne et al., Am J Respir Crit Care Med 162: 873–7, 2000; Litonjua et al., Pediatr Pulmonol 28(6):394–401, 1999; Weiss and Gergen, Chest 101(June suppl):362S–7S, 1992; Call et al.,


Low-income children and children of color are more likely to live in substandard housing. Living in substandard housing leads to exposure to allergens and higher rates of allergen sensitization (Eggleston, Immunol Allergy Clin North Am 18:75–84, 1998; Huss et al., Ann Allergy 72(2):173–7, 1994; Kitch et al., Environ Health Perspect 108(4):301–7, 2000). Features of substandard housing such as excessive moisture and dampness, poor ventilation, crowding, pest infestations, deteriorated carpeting, and structural deficits are associated with high levels of indoor asthma triggers (Hyndman, Making connections between housing and health. Putting health into place. Syracuse, NY: Syracuse University Press, pp. 191–207, 1998). Exposure to combustion products from unvented stoves can induce asthma symptoms (Eisner et al., Thorax 57:973–8, 2002). A strong parallel thus exists between exposure to asthma triggers and the differential exposure of disadvantaged populations to hazards in the outdoor environment (e.g., toxic waste dumps or freeways) – a hallmark of environmental racism (Northridge and Shepard, Am J Public Health 87(5):730–2, 1997).

Keywords  Asthma  •  Substandard housing  •  Allergens  •  Disadvantaged and minority populations  •  Cockroaches  •  Home visits  •  Community health workers  •  Education  •  Intervention  •  Buildgreen standards  •  Breathe Easy Homes (BEH)  •  Environmental racism

Social features of the environment of disadvantaged populations [1], including exposure to violence [2], contribute to asthma morbidity. Social stressors interfere with adherence to asthma control regimens and may directly affect airway function [3].
The effectiveness of interventions may be reduced in populations affected by disparities if the interventions are not culturally appropriate and do not account for low literacy levels among the affected groups.

Suboptimal medical care occurs more commonly among disadvantaged groups, including lower use of anti-inflammatory medications, less continuity of care, and lower rates of pulmonary function and allergy testing [4–6]. Lack of insurance and logistical barriers reduce access to primary care and medications, leading to crisis-oriented emergency department use [7]. Persons with less education and limited English proficiency have more difficulties in navigating the health system to obtain needed services. Adherence to medical regimens may be lower among people with limited education [8].

Over the past 2 decades, knowledge of how to reduce exposure to indoor asthma triggers has increased dramatically [9–25]. While approaches targeting individual triggers have met with limited success [26], comprehensive approaches addressing multiple triggers and the total housing environment have been more successful both in preventing asthma and reducing morbidity [9, 27]. Given the important role allergens play in producing asthma inequities, decreasing them has emerged as a major goal.

Home-based education and support has emerged in recent years as an effective strategy for reducing indoor asthma triggers, improving medical aspects of asthma management, lowering psychosocial stress, and improving asthma-related health outcomes [27–37]. A strategy based primarily on education and behavior change, however, is limited in its ability to reduce exposures due to adverse housing conditions.

Therefore, a complementary strategy is to address substandard housing conditions related to asthma. Approaches include remediation of existing housing deficits to bring homes in line with healthy homes guidelines and construction of new “asthma-friendly” homes. Several sets of guidelines for such homes are available [38], such as The Seven Principles of a Healthy Home from the National Center for Healthy Housing [39], the U.S. Green Building Council’s LEED for Homes [40], the National Association of Home Builders’ NAHB Green Home Building Guidelines [41], Enterprise Community Partner’s Green Communities Criteria [42], the U.S. Environmental Protection Agency’s (EPA) Energy Star with Indoor Air Package [43], and the American Lung Association’s Health House Builder Guidelines [44]. The recommendations include designing the foundation and building envelope to prevent water intrusion, incorporating efficient and effective ventilation methods, using hard surface flooring materials, and employing products that minimize emission of volatile organic compounds.

This chapter describes how we have implemented these two strategies of home visits and housing improvements in Seattle, Washington, to improve asthma control among low-income children with asthma. Taken as a whole, the Seattle interventions constitute a continuum of strategies that operate at multiple socio-ecologic levels: home visits at the individual and interpersonal levels, remediation or construction to develop asthma-friendly housing at the physical environmental level, and advocacy for healthy homes policies at the policy level (Fig. 19.1).
Community Health Worker Home Visits

The Seattle-King County Healthy Homes I Project (1997–2001)

The Healthy Homes I Project provided home visits by community health workers (CHWs) to reduce exposure to indoor asthma triggers and asthma morbidity among children living in ethnically diverse, low-income households [33, 45, 46]. A 1-year long, high-intensity intervention was delivered by a CHW. During the first home visit, the CHW conducted a structured home environmental assessment by walking through the home with the caregiver. Each assessment finding generated specific actions for caregiver, family members, and CHW based on a standard set of best practices (see Table 19.2). When advising the family on moisture and mold, for example, the CHW suggested to families that they ventilate the unit properly, avoid fish tanks and plants, clean mold with detergent solution, heat all rooms and closets, dry water-damaged objects promptly or discard them, repair leaks, install a vapor barrier in a crawl space, vent dryers, close windows during seasons of high outdoor spore levels, and keep humidity below 50%. The CHW role was to educate, demonstrate, assist in getting landlord repairs as appropriate, and refer the caregiver to a Public Health Environmental Inspector as needed. The CHW and caregiver prioritized actions and prepared a mutually agreed-upon plan. The CHW made an average of seven additional visits to encourage the caregiver to complete their plan, provide additional education, and offer social support. Families were given resources to reduce exposures, such as an allergy-control pillow and mattress.
encasement, low-emission vacuum, commercial-quality door mat, cleaning kit, referrals to smoking cessation counseling, roach bait, and rodent traps. Families were offered assistance with roach and rodent eradication and advocacy efforts for improved housing conditions. They were also referred to free skin-prick allergy testing at multiple clinic sites and special asthma fairs.

**The Community Health Workers**

A distinguishing feature of the Healthy Homes Project was its use of a CHW. The CHWs shared language, ethnicity, culture, and a personal or family experience with asthma with participants. They completed 40 h of training with follow-up continuing education, followed a protocol and manual, and discussed challenging cases with other team members and a nurse clinical supervisor. The CHWs served as role models in demonstrating actions to reduce exposures, such as vacuuming and cleaning mold. In addition to information and instrumental support, they provided social support through a caring, empathetic attitude, genuine interest in the well-being of the families and knowledge of resources [47]. Each CHW carried a caseload of between 40 and 80 clients at any one time, completing about 10 visits per week.

**The Project Participants**

Project participants were urban, low-income, ethnically diverse families that included a child, 4–12 years of age, with persistent asthma whose caregiver was verbally proficient in English, Spanish, or Vietnamese. Participants were recruited from community and public health clinics (65%), local hospitals and emergency departments (27%), and through referrals from community residents and agencies (8%). Of the 274 eligible and interested families, 214 completed the intervention (78%). Seventy-five percent of their homes had at least one asthma trigger present, while 36% had two or more.

**The Home Assessment**

Central to the Healthy Homes intervention was the comprehensive home environmental assessment. The assessment consisted of a verbal questionnaire and a visual inspection of the home with family members.

The CHW asked caregivers about indoor asthma triggers, for example, dust, roaches, rodents, pets, mold, tobacco smoke, air pollution, and irritants. A second set of questions queried caregivers about practices that increase exposure to triggers, including the use of humidifiers, tobacco use, and the handling of toxic materials. Further questions addressed practices and resources that reduce exposures,
Box 19.1 Elements of the visual assessment

Site: pooling of water, surface grading leading to water flow towards home, debris, and garbage, extensive overgrowth of vegetation abutting home.

Building envelope and exterior: leaks, gaps in doors that enable pest entry or water incursion, broken or inoperable windows, bulging walls or sagging rooflines, foundation cracks, damaged or missing trim or flashing, and problems with gutters.

Ventilation: dirty air filters, inadequate whole house and spot ventilation.

Living area: leaks, condensation, water damage, mold, cracks, inadequate ventilation, deteriorated carpeting, dust, peeling paint, mold, presence of unvented fuel-fired space heaters, inadequate food preparation, storage and disposal facilities, pests, pets, tobacco products, hazardous chemicals and products, clutter.

such as household cleaning and dust control, food storage, use of low-emission vacuums, removal of carpets, use of allergy-control bedding covers, washing bedding and stuffed animals, increasing ventilation, and adequate home heating to reduce moisture and mold control. The CHW and participant then walked through the home to complete the visual inspection (Box 19.1 describes items included in the visual assessment). Portions of the assessment were repeated at subsequent visits to assess progress in resolving problems or address new concerns.

The Action Plan

Following the assessment, the CHW developed an initial home action plan that described protocol-specified actions to address the triggers and behaviors found by the assessment (see Table 19.1). The CHW and caregiver prioritized actions that were most feasible and of most interest to arrive at the family’s individualized plan. Working with families during the following year, the CHW monitored and reinforced behaviors, adjusting plans as needed. The CHW adhered to standard protocols with allowances to adapt and meet the needs and values of their clients. One suggestion, for example, was that Buddhist clients substitute electric candles for incense at their household alters.

As we implemented the project, we learned that not all households could implement the recommended actions or address the conditions leading to trigger exposure. Mites, for example, are killed when bedding is washed with hot water at a temperature of 130°C. When measuring the temperature of hot water in homes, however, the CHW found that 74% had temperatures below 130°C. Not all homes with visible mold were able to eliminate it through cleaning practices. Although we
<table>
<thead>
<tr>
<th>Exposure</th>
<th>Action</th>
<th>Community health worker</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Asthma trigger</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moisture</td>
<td>Use ventilation properly, avoid fish tanks and plants, clean mold with</td>
<td>Educate, demonstrate, assist in getting landlord repairs as appropriate, refer to</td>
</tr>
<tr>
<td></td>
<td>detergent solution, heat all rooms and closets, dry water-damaged</td>
<td>Public Health Environmental Inspector as appropriate</td>
</tr>
<tr>
<td></td>
<td>objects promptly or discard, repair leaks, install vapor barrier in</td>
<td></td>
</tr>
<tr>
<td></td>
<td>crawl space, vent dryers, close windows during seasons of high outdoor</td>
<td></td>
</tr>
<tr>
<td></td>
<td>spore levels, keep humidity &lt;50%</td>
<td></td>
</tr>
<tr>
<td>Dust</td>
<td>Vacuum and dust, use double-layer vacuum bags and low-emission</td>
<td>Educate, demonstrate, provide with low-emission vacuum with dirt finder, vacuum</td>
</tr>
<tr>
<td></td>
<td>vacuums, use doormats and remove shoes</td>
<td>bags, “green” cleaning kit, mop and bucket, gloves, door mat</td>
</tr>
<tr>
<td>Mites</td>
<td>Vacuum and dust, wash bedding weekly in 130°C+ water, replace or</td>
<td>Educate, provide, and install allergy-control bedding covers</td>
</tr>
<tr>
<td></td>
<td>vacuum/steam clean upholstered furniture, carpet and drape removal,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>keep humidity &lt;50%</td>
<td></td>
</tr>
<tr>
<td>Roaches</td>
<td>Clean counters and dishes daily, store food in sealed containers,</td>
<td>Educate, use IPM methods (caulk and foam to seal small defects, Abamectin gel bait,</td>
</tr>
<tr>
<td></td>
<td>clean up clutter, remove garbage daily, eliminate water sources</td>
<td>boric acid, vacuuming and cleaning pre- and post-eradication), repeat if roaches persist</td>
</tr>
<tr>
<td></td>
<td>(leaks, etc.)</td>
<td>after 3 months, provide food storage containers</td>
</tr>
<tr>
<td>Rodents</td>
<td>Clean counters and dishes daily, store food in sealed containers,</td>
<td>Educate, seal defects with mesh and foam, provide glue boards, and snap traps or</td>
</tr>
<tr>
<td></td>
<td>clean up clutter, remove garbage daily, and remove outdoor excessive</td>
<td>Contrac Blox (bromadiolone 0.005%) in kitchen</td>
</tr>
<tr>
<td></td>
<td>vegetation</td>
<td></td>
</tr>
<tr>
<td>Tobacco smoke</td>
<td>Quit smoking. Encourage other household smokers to quit or smoke</td>
<td>Assess stage of change, counsel, refer to free telephonic smoking cessation program,</td>
</tr>
<tr>
<td></td>
<td>outside using smoking jacket</td>
<td>provide HEPA(^a) air filter for nonsmokers exposed to ETS</td>
</tr>
<tr>
<td>Pets</td>
<td>Remove from home or keep outside bedroom, vacuuming and carpet</td>
<td>Educate, provide HEPA(^a) air filter for sensitized participants</td>
</tr>
<tr>
<td></td>
<td>removal, bedding covers</td>
<td></td>
</tr>
<tr>
<td>Viral infections</td>
<td>Hand washing, influenza immunizations</td>
<td>Educate</td>
</tr>
<tr>
<td>NO(_x)</td>
<td>Ventilate kitchen</td>
<td>Educate on combustion sources</td>
</tr>
<tr>
<td>Wood smoke</td>
<td>Avoid using fireplaces and wood stove unless air tight and properly</td>
<td>Educate</td>
</tr>
<tr>
<td></td>
<td>ventilated</td>
<td></td>
</tr>
<tr>
<td>Irritants</td>
<td>Dispose of properly and switch to less irritating alternative, ventilate if must use</td>
<td>Encourage use of safer alternatives</td>
</tr>
<tr>
<td>Occupational take-home hazards</td>
<td>Identify potentially hazardous work or hobbies</td>
<td>Educate on hazard reduction, occupational medicine referral if appropriate</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^a\)While controversy continues regarding the efficacy of various interventions to reduce mite exposure and related morbidity, we believe there is sufficient evidence to justify inclusion of simple measures for mite-sensitized persons

\(^b\)Use of HEPA filters is controversial. Current evidence suggests they may be effective in reducing exposure to pet allergens and tobacco smoke
provided free telephone smoking cessation counseling and nicotine replacement patches, only 20% of smoking caregivers quit. The suggestion to smoke outside the home with a smoking jacket was useful in reducing indoor smoking. Most caregivers became more effective cleaners. Providing simple tips such as cleaning on a schedule, giving oneself a reward for cleaning, and doing a little bit each day seemed helpful, as did providing a vacuum with a HEPA filter and safe cleaning supplies. While some participants did increase ventilation in their homes, others felt unsafe with open windows. It was difficult for pet owners to give up their animals, rendering ineffective a recommendation to remove pets from the home.

We were unable to address most of the structural conditions associated with exposure to asthma triggers, since 86% of participants were renters. Moisture problems were present in 77% of homes, contributing to exposure to mites, molds, and roaches. Eliminating roaches was difficult in homes in multiunit structures that had structural defects that allowed pest entry. Most homes (85%) had carpets, but few families were able to remove them as they were in rental units. In some cases, tenants were afraid to approach landlords because of fear of retaliation. In other cases, a CHW assisted tenants in approaching landlords. However, landlords usually did not make suggested improvements, such as removing deteriorated carpets, installing ventilation fans, or eliminating sources of water intrusion. The Seattle Housing Authority (SHA) immediately repaired unhealthy conditions and gave priority to eradicate roaches in participant homes. We worked closely with SHA to put the participant families who were waiting for housing on priority lists for housing that met Healthy Homes criteria.

**Intervention Effects**

We assessed the benefits of the CHW multi-visit high-intensity intervention relative to a low-intensity intervention consisting of a single CHW visit and provision of bedding encasements using a randomized, parallel group study design. At the end of the project, all low-intensity group members received the same benefits as did members of the high-intensity group.

The high-intensity intervention yielded significantly greater benefit in caregiver quality of life \((P = .005)\). Urgent health services use declined significantly more in the high-intensity group \((P = .026)\). Symptom days decreased more in this group but the difference between groups was not significant \((P = .138)\). The high-intensity group showed greater and statistically significant improvement in all three primary outcome measures. The child’s asthma symptoms days decreased by 4.7 days while caregiver quality of life score increased by 1.6 points (a change of 0.5 point is clinically significant) [48]. The proportion of urgent health services use decreased absolutely by 15%. In the low-intensity group, symptom days also decreased significantly by 3.9 days and the caregivers’ quality of life scores improved by 1.0 point. Gains in health outcomes and behaviors in the high-intensity group persisted for 6 months after the intervention ended. The frequency of actions to reduce dust
Breathing Easier in Seattle: Addressing Asthma Disparities

exposure and the use of bedding encasements increased more in the high-intensity group. Neither group reduced exposure to pets and smoking in the house.

The reduction in urgent health services use led to a reduction of $201–334 per child in the high-intensity group and $185–315 per child in the low-intensity group when comparing the 2 months prior to the intervention with the final 2 months of the intervention year.

While we showed that home visits to address indoor asthma triggers are effective, the standard mode of providing asthma education is clinic-based asthma education from an asthma educator. To support the wider use of the new home visit approach, we next investigated whether home visits yield benefits in asthma control beyond traditional clinic-based education.

The Seattle-King County Healthy Homes II Project (2002–2006)

The Seattle-King County Healthy Homes II Project addressed the question of whether the addition of in-home asthma self-management support from community health workers (CHWs) would yield additional benefits in asthma control beyond those produced by in-clinic support from an asthma nurse. Participants included 309 children with asthma with demographic features similar to those enrolled in HH-I.

CHW Home Visits

Like HH-I, home visits addressed asthma triggers and provided social support and advocacy for clients (e.g., housing issues, insurance coverage). In addition, CHWs helped participants improve their skills in the medical aspects of asthma management, such as use of medication, managing an exacerbation with the help of an action plan, and improving access to medical care.

CHW clients received one intake and an average of 4.5 follow-up visits over the course of a year, as well as interim telephone communication. At the intake visit, CHWs reviewed asthma control, medical self-management and trigger avoidance practices, and access to medical care. Based on this assessment, a home visual inspection and allergy testing results, CHWs developed a set of protocol-driven client and CHW actions. At follow-up visits, CHWs assessed progress and reviewed a core set of educational topics (medication use, action plans, effective use of the medical system, medical adherence, and trigger reduction) [49–52]. They employed motivational interviewing methods to encourage participant behavior change [53]. CHWs fit allergen-impermeable bedding encasements on the child’s bed [54, 55] and supply a low-emission vacuum with power head and embedded dirt finder [56–58], 2-layer microfiltration vacuum bags [59], a high quality door mat, a cleaning kit, and plastic medication boxes.
Clinic-Based Asthma Education

A nurse conducted a structured intake during an appointment at the clinic that she used in conjunction with allergy test results to develop a client-specific asthma management plan. She also prepared an asthma action plan [60] that was reviewed by the patient’s medical provider. Education began at the initial visit and the nurse offered clients three follow-up clinic visits at 3-month intervals. Most participants had one follow-up visit. The nurse made referrals to additional resources such as social workers and school nurses and assisted clients in accessing their medical providers. If a child failed to keep appointments, the nurse attempted to make telephone contact. All study participants received spacers and allergen-impermeable bedding encasements and children seven and older received a peak flow meter.

Care Coordination

The nurse sent visit notes to providers and contacted them directly as needed. The CHW and nurse discussed mutual clients as needed. The CHW sent home visit reports to providers and communicated directly with them as issues arose.

Intervention Effects

HH-II was a randomized, controlled, parallel group study, similar in design to HH-I. Adding in-home visits resulted in clinically important and statistically significant increases in symptom-free days. While symptom-free days increased in both groups, CHW visits yielded 24 additional symptom-free days per year. Home visits yielded modest increases in caretaker quality of life in both groups. The increase was statistically greater in the Nurse + CHW group relative to the Nurse-only group. Urgent health service utilization decreased in both groups, with 30% lower utilization in the Nurse + CHW group, although the addition of CHW visits did not reduce utilization significantly. Participants in the Nurse + CHW group adopted an average of 2.0 new behaviors compared to 1.3 in the Nurse group, a significant difference. The difference was attributable to increased trigger control actions rather than medical self-management actions.

Although the evidence for the effectiveness of multifaceted, in-home, tailored interventions for asthma is strong [21], home interventions are limited in their ability to modify the relationship between housing conditions and asthma outcomes. As noted earlier, behavioral interventions cannot eliminate substandard housing conditions, such as water intrusion or lack of ventilation systems that result in exposure to asthma triggers. As substandard housing is often the only housing available to low-income populations, we developed two programs to improve housing quality.
**Improved Housing**


The *Better Homes for Asthma Project* attempted to assess whether the remediation of structural deficiencies related to exposure to asthma triggers adds *additional* benefit to the 1-year intervention provided by the CHW model. Using a randomized controlled trial approach with a delayed remediation control group, we assigned 34 homes to two groups. The early intervention group received both structural remediation and CHW visits for 1 year. The late intervention group received only CHW visits during the first year, followed by remediation. The average cost for remediation was $4,529 per unit.

**Participants and Selection of Homes**

Participants were families in households with incomes less than 125% of the poverty level, and with children ages 2–17 years with persistent asthma. To identify eligible housing units, we conducted a review of housing code violations for structural conditions, an exterior visual inspection, and an in-home screening assessment to determine whether the home was too deteriorated for the scope of the program (maximum of $9,000 in estimated repairs). Unit owners (landlords) had to agree to participate in and abide by the conditions of the program, including a promise not to raise the rent for at least 1 year. Eligible residents had to agree to remain in the unit for 1 year to assure adequate time for evaluation of health impacts. We sent 854 families information about the study and 398 families responded. We made 115 visual assessments, conducted 43 baseline in-home screening assessments, and randomized 34 homes.

**The Assessment**

All homes received a detailed inspection by a public health expert in housing who identified conditions associated with exposure to asthma triggers. The housing expert used the results of the inspection to develop a specific remediation work order for each home.

**The Intervention**

Table 19.2 describes the types of interventions performed on the 21 homes. We selected interventions appropriate to the conditions in each home from among those listed in the table.
Table 19.2  Menu of housing remediation options

<table>
<thead>
<tr>
<th>Description</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vent clothes dryer to exterior [A]</td>
<td>Install an outside air duct from exterior to air return system for combustion furnaces [B]</td>
</tr>
<tr>
<td>Seal basement concrete if moisture probe indicates high moisture content [B]</td>
<td>Install flue liner [B]</td>
</tr>
<tr>
<td>Crawlspace – remove debris, make rodent-proof [B]</td>
<td>Mold remediation – hard surfaces: clean, disinfect, and dry. Seal surfaces from which mold was removed [A]</td>
</tr>
<tr>
<td>Crawlspace – Seal/cover soil with poly [A]</td>
<td>Mold remediation – absorbent surfaces: remove extensive mold or water-damaged material. Replace drywall if wet &gt;48 h, wood if mold penetrates &gt;3 mm. Remainder: clean, disinfect, dry, and vapor barrier seal [A]</td>
</tr>
<tr>
<td>Crawlspace – seal from house air [A]</td>
<td>Clean evaporator pan under refrigerator [A]</td>
</tr>
<tr>
<td>Downspout – assure adequate runoff away from house (only if moisture problem in basement/crawlspace) [A: wet walls; B: other]</td>
<td>Seal all wall openings, especially in kitchen and baths [B]</td>
</tr>
<tr>
<td>Gutter – redirect flow to functioning downspout [B]</td>
<td>Repair dry floor drain traps if sewer gasses found [A]</td>
</tr>
<tr>
<td>Wood-earth contact – assure 6” minimum gap [B]</td>
<td>Repair drains if standing water [B]</td>
</tr>
<tr>
<td>Caulk windows [A]</td>
<td>Repair plumbing leaks</td>
</tr>
<tr>
<td>Caulk wood siding vertical seams [A]</td>
<td>Install range hoods that vent directly to exterior [A: gas; B: electric]</td>
</tr>
<tr>
<td>Caulk door seams [A]</td>
<td>Undercut all bedroom and bathroom doors [A]</td>
</tr>
<tr>
<td>Seal roof and chimney flashing if evidence of interior leaking [A]</td>
<td>Install quiet, continuously operating whole house exhaust ventilation system [A]</td>
</tr>
<tr>
<td>Check furnace chimney draft and if inadequate, check cleanout opening [A]</td>
<td>Assure that one window per room can open and install security stop [A]</td>
</tr>
<tr>
<td>Repair or replace leaky chimney flue [B]</td>
<td>Remove bird, rodent, or insect debris from attic [A]</td>
</tr>
<tr>
<td>Install pleated filter in forced air heating system [A]</td>
<td>Seal openings from interior space into attic [B]</td>
</tr>
<tr>
<td>Check return and supply ducts (only if in garage, crawlspace, or attic) for leaks [B]</td>
<td>Seal tub/wall surround joint and toilet/floor spaces [A]</td>
</tr>
<tr>
<td></td>
<td>Remove child’s bedroom, basement, bath, and kitchen carpet [A]</td>
</tr>
<tr>
<td></td>
<td>Install CO monitor [A]</td>
</tr>
</tbody>
</table>

Limitations

We encountered substantial difficulties implementing this project, resulting in too few participants who completed the study to allow meaningful analysis. Recruitment and retention of families was difficult. Some tenants did not want to go through the inconvenience of renovations when they did not own the property and saw long-term benefit only for the landlord. Others did not see remediation as a valuable benefit or were skeptical that their homes would really be repaired for free. Some families moved immediately before or soon after repairs were made. It may be more effective to recruit property owners rather than tenants.
Securing landlord participation was also difficult. It may be more feasible to work with homeowners or with nonprofit housing agencies rather than individual landlords.

Working with the remediation contractors also brought challenges. Securing adequate mold insurance (which protects the contractor from mold-related health claims) was a barrier; in Seattle this costs several thousand dollars a year. The contractors had to be capable of implementing all the repairs on the menu (Table 19.2); it would have been simpler to use a shorter list of interventions focusing on ventilation, flooring, and simple weather intrusion control. However, contractor availability was not the primary issue; securing the participation of families and landlords and getting clients and homes ready for the contractor were more significant barriers.

The project was based in the county health department. As the county had little experience in managing housing remediation, the contracting process was hampered by bureaucratic complexities and inefficiencies. Partnering with a community agency to oversee working with contractors may be more efficient.

These factors allowed us to enroll only 34 homes. With attrition of participants (dropping out of study or moving) and refusal by landlords to allow repairs, we remediated only 21 homes, and only 15 families completed exit data collection 1 year after remediation.

The Breathe Easy Homes Program (2003–2007)

In 2000, the Seattle Housing Authority (SHA) received a $35 million HOPE VI grant to replace deteriorating public housing built in the 1940s at the High Point public housing site with new, mixed-income housing. Congress created the Urban Revitalization Demonstration (HOPE VI) program in 1992 to address concerns about families living in extreme poverty in public housing [61]. Designed initially as a rebuilding endeavor, HOPE VI also promoted social change in public housing by seeking to eliminate pockets of concentrated poverty in public housing sites by developing mixed-income communities [62].

The High Point community is located on 120 acres in West Seattle, 6 miles from Seattle’s downtown. The original 716 units were built for Boeing World War II workers and became public housing in the 1950s. Redevelopment began in 2004 and will be completed in 2012. The site will be home to nearly 1,700 families, including 891 living in affordable units for low-income people. An additional 790 housing units are being sold at market rate to independent and assisted-living seniors, single families, and the general population. High Point was the first large-scale development in the country to feature low-impact sustainable design in an urban setting. The site includes housing with BuildGreen™ standards, an innovative natural drainage system to protect local salmon habitat, new municipal infrastructure systems, neighborhood facilities, connections to walking trails, and 20 acres of land for parks, open spaces, and playgrounds.
At the time of site deconstruction, High Point was a community of minority and immigrant residents made up of 36% African-Americans, 29% Asian/Pacific Islanders, 18% white, and 17% other races. Most Asian residents were immigrants from Southeast Asia who began to arrive in the United States in the late 1970s. The Black population grew by 20% between 1994 and 1998 as East Africans from Ethiopia, Somalia, and other countries immigrated to Seattle in the early to mid-1990s. An estimated 61% of household heads were not born in the United States and did not speak English as their first language. The net impact was a marked shift from those whose first language was English to those that spoke a language other than English at home.

A community activist and resident of High Point, who has upper respiratory allergies, raised the idea of building asthma-friendly homes as part of the redevelopment with a project architect. The architect and other project managers embraced the idea. At that point, the SHA and its community partners had already begun to conceive of High Point as a model of environmental health and sustainability. Their vision was to improve access to transit choices, make widespread use of soft drainage techniques and minimally impervious surfaces to improve water quality in nearby Longfellow Creek, build a network of open spaces and trails to encourage active living, and incorporate state-of-the-art resource conservation elements in housing unit design. The project manager contacted us to see if we would partner with SHA, architects, and residents in designing asthma-friendly units, provide tenants with CHW services to support residents in preventing accumulation of asthma triggers in the new homes, and evaluate the impact of the new homes on asthma outcomes. We therefore had an opportunity to assess whether moving into a new Breathe Easy Home (BEH) provides additional benefits in controlling asthma beyond those offered by CHW home visits [63].

During the first phase of construction (2005–2006), the contractor built 35 homes with special features designed to reduce the impact of asthma. We anticipated that this number of homes would provide housing for the estimated number of families affected by asthma that move into the new community during phase I. SHA, with support from the Enterprise Foundation, has built 25 additional Breathe Easy Homes during the second phase of construction.

The Participants

Initially, we intended to offer Breathe Easy Homes to people with asthma who were living in the old High Point community prior to the HOPE VI project. Our goal was to make a right of return possible for the original residents of the community, many of whom had been temporarily relocated as a result of site demolition and construction. Not all residents wished to return, however, so we made additional recruitment efforts through local hospitals, clinics, asthma specialists, flyers, and word-of-mouth. A family was eligible for a Breathe Easy Home (BEH) if it included a child, 2–17 years of age, with persistent asthma confirmed by a health provider. Families also had to meet SHA eligibility criteria for public housing that included low-income verification, passing credit and criminal background checks, and a willingness to abide by new lease requirements specific to the asthma-friendly homes.
The Breathe Easy Homes

The team designing all the homes at High Point reviewed international and local programs for recommendations on building green, energy-efficient homes suitable to the Pacific Coast maritime climate, including BuildGreen™ of King and Snohomish Counties and SeaGreen: Greening Seattle’s Affordable Housing. The team also discussed the project with local building consultants and architects.

All homes in the redevelopment use a BuildGreen™ design. BuildGreen™ is an industry-driven voluntary program that promotes “green” building practices to reduce the impact that building has on the environment while choosing healthy building materials. For High Point, this includes advanced framing with increased energy efficiency, airtight drywall installation, Energy Star™ compliant argon-filled windows ($U<0.35$), low-emission finishes, and sealed cabinets and cement board exterior siding to reduce the moisture hazard (Table 19.3).

The design team and public health developed a set of enhancements to the basic design to include in the Breathe Easy Homes (BEH) (Fig. 19.2 and Table 19.3). The exterior envelope is made of a durable modified rain screen with air and moisture-tight construction exceeding local building code to minimize failures that might lead to excessive moisture conditions known to trigger asthma. The foundation is enhanced through the addition of insulation to prevent condensation and water intrusion. Steps were also taken to reduce wetting of materials during

<table>
<thead>
<tr>
<th>Table 19.3 Features of Breathe Easy Homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>All High Point Homes feature</td>
</tr>
<tr>
<td>Gas-fired high-efficiency closed-loop boiler for both on-demand domestic hot water and radiant baseboard heaters to reduce heating bills</td>
</tr>
<tr>
<td>Quiet whole house fan with 2-speed timing switch to remove moisture</td>
</tr>
<tr>
<td>Filtered fresh air intake ports in all living spaces and bedrooms to improve indoor air quality</td>
</tr>
<tr>
<td>Airtight drywall installation to reduce moisture penetration and inhibit mold growth</td>
</tr>
<tr>
<td>Low E coated and argon-filled Energy Star. 33 maximum U-value vinyl windows to reduce heating bills and block UV rays</td>
</tr>
<tr>
<td>Low off-gas vinyl flooring with recycled content in baths and kitchens</td>
</tr>
<tr>
<td>Low VOC paint throughout</td>
</tr>
<tr>
<td>Sealed cabinet construction to reduce emissions</td>
</tr>
</tbody>
</table>
construction and an interior drying step was conducted prior to drywall installation. To insure low energy use, there is an exterior drainage plane behind durable cement board siding, over taped and sealed rigid insulation, over high R-value blown-in insulation in a wall constructed of 2 × 6 advanced framing. Other exterior design elements are walk-off mats and shoe storage at the entry to minimize the entry of contaminants into the homes. The cost for the exterior upgrade is approximately $1250 per unit.

The team felt that it was important to minimize or eliminate the use of carpets, since they may attract and hold contaminants that are known to trigger asthma. Hard surface flooring materials such as wood, tile, or linoleum generally cost more than carpet. We chose Marmoleum™, a linoleum-like surface comprised of linseed. The team also selected low/no emission, nontoxic finishes and materials to minimize exposure to irritants that can trigger asthma. The cost for this group of upgrades is an estimated $3250 per unit.

An upgraded Energy Recovery Ventilation System with dedicated supplies of fresh air to each bedroom and the main living area includes a variable speed fan that runs continuously providing 1/3 air changes per hour in the home. The energy-efficient system has a high-efficiency (HEPA) filter that removes most particulates and allergens (MERV 15) and provides 1/3 air changes per hour. The heating system includes a hydronic (hot water) radiant baseboard system rather than forced air that minimizes dust circulating in the air. Spot ventilation in all bathrooms and kitchen areas is provided, with humidity sensitive controls in bathrooms with showers. The cost for this group of upgrades is $2,500 per unit.

---

**Fig. 19.2** Breathe Easy Home design and construction elements
A landscape design team developed plans to reduce outdoor asthma triggers in yards and outdoor spaces. The maintenance design includes plants with low allergen ratings and Integrated Pest Management strategies to minimize or eliminate the use of toxic pesticides.

**Home Visits by Community Health Workers**

CHWs helped families learn about their new homes, provided education using our established protocols, and gave them allergen-proof bedding and a pillow cover for the child’s bed, a vacuum with a high-efficiency (HEPA) filter, doormat, and bucket of environmentally friendly cleaning supplies as in the previously described studies. The staff of SHA developed a Mutual Housing Agreement with specific guidelines to help residents maintain their units in an asthma-friendly condition. While similar to those for the standard homes, the agreement specifically prohibits smoking or furry pets inside homes, for example. The guidelines are reviewed by the CHW during the educational visits.

**Intervention Effects**

We assessed the impact of BEH on clinical outcomes with a quasi-experimental study design. The historical comparison group was drawn from participants in our prior Healthy Homes II study. This design tested the hypothesis that living in a BEH home adds clinical benefits beyond those conferred by education and self-management support alone. The CHW conducted a home assessment through direct observation and an interview with the caretaker, as described above, to collect data on the presence of triggers and on housing conditions. We assessed exposure to asthma-related allergens in three different subsets of homes by collecting samples of house dust from the child’s bedroom floor: (1) in the old home 1 year prior to moving into the BEH home, (2) in the old home just before moving into the BEH home, and (3) after 1 year in the BEH home. It was not always feasible to collect dust samples in a home and therefore the data are from a convenience sample that includes different homes at each time point. We measured concentrations of dust mite (Der p1) and cat (Fel d1) allergens and ergosterol (an estimate of fungal mass).

The clinical response after 1 year of living in a Breath Easy Home was dramatic. The primary outcomes of children’s asthma symptom-free days in the past 2 weeks and caretaker quality of life improved significantly among those living in a BEH. Rescue medication use, activity limitation, symptom nights in the past 2 weeks, and urgent clinical visits in the past 3 months all decreased. Lung function measured by FEV₁ improved.

An analysis comparing changes within the BEH group to those observed in the comparison group showed no significant differences in outcomes, although the degree of improvement in the BEH group was greater for all measures except FEV₁ and nocturnal asthma symptoms.
Exposure to mold, dampness, and rodents in the home within the BEH group decreased dramatically and significantly, while smoking in the home and roaches showed large but nonsignificant declines. The reduction in moisture-related hazards was particularly notable, with no visible mold or evidence of water damage, condensation, leaks, or drips after 1 year in the BEH. Rodents were eliminated and a combined trigger score measuring the average number per home was close to zero. The average number of hazards per home (presence of rodent, roach, pet, mold, moisture, or smoking inside the home) decreased from 1.5 in the old homes to 0.03 in the Breathe Easy Homes. Analysis of cross-sectional descriptive dust data showed a pattern of lower levels of fungi, and mite and cat allergen in the BEH homes.

In summary, the BEH families experienced improvements in a wide range of clinical outcome and trigger exposure measures. However the results, while better than those occurring among the HH-II families who received in-home asthma education visits alone, were not statistically different. At a modest cost, home design and construction can incorporate asthma-friendly features that improve the lives of children and families living with asthma. This study suggests, but does not prove, that moving into a healthier home adds benefits beyond those conferred by in-home asthma education alone.

Lessons Learned

Over the past 13 years, we have had the opportunity to try a spectrum of approaches to addressing inequities in asthma health outcomes related to housing conditions. Some of the strategies were successful, while others fell short of our goals. We conclude this chapter with a discussion of some of the lessons learned.

Home Visits by Community Health Workers

*Home visits by CHWs are effective in reducing exposure to asthma triggers and improving asthma-related health inequities.* In particular, we found that the CHW may have an advantage in working with low-income, minority clients. Because they share community, culture, ethnicity, language, and life experiences with the families, they can bridge the gap between community members and health agencies and institutions and develop trusting relationships. Clients may be more likely to heed their advice and learn new skills as the CHW models effective trigger control behaviors. They tailor their support to a family’s needs and priorities by assessing their readiness to take action and by understanding the family’s cultural and community context. They help families with concerns extending well beyond asthma, such as housing, domestic violence, and employment, in order to bring the family to a place where it could focus on asthma. The CHW tends to function more
Breathing Easier in Seattle: Addressing Asthma Disparities

as a peer and coach than a more distant professional. Providing asthma education in the home offers several advantages over clinic-based approaches, particularly among populations affected by asthma disparities. These populations face significant logistical and psychosocial barriers to attend asthma classes or clinic-based asthma education. Home visits may be the only way to reach many of these patients.

Evidence now supports the effectiveness of multiple methods for provision of asthma self-management support, including home visits by community health workers and other health professionals, clinic-based individual education and group education. Perhaps an optimal strategy is to offer patients options for self-management support, recognizing that many patients may choose not to participate in classes or go to clinic for asthma education while others may not desire a visitor in their homes.

A less intensive CHW intervention may be a useful alternative to a full year, multi-visit program. Our projects, like others, suggest that a single visit produces benefits in asthma control, although not as much as a more intensive intervention. It may be more feasible to disseminate and fund a less expensive, simpler program even if outcomes are not quite as good. We have reduced the number of visits during the year of participation from nine in our early projects to four in our current work.

Resources and incentives for caregivers are important. Providing caregivers with tools, such as vacuums, bedding encasements, and cleaning supplies, to carry out their home action plan is an important part of the intervention. Monetary rewards, such as gift certificates, proved highly useful for encouraging participants to complete challenging tasks, such as regular cleaning and mold removal. Acknowledging the satisfaction that parents feel from seeing their actions benefit their families is another powerful incentive.

Addressing multiple triggers is necessary. Our interventions support the value of strategies aimed at reducing exposure to multiple indoor asthma triggers rather than focusing on a single trigger, consistent with the many single intervention studies that have failed to show an effect [20].

Integrating support for reducing exposure to triggers and self-management of the medical aspects of asthma control is desirable. Controlling asthma requires practice of a complex set of skills, including proper use of medications, managing exacerbations, and using the medical system effectively as well as reducing exposure to triggers. Our later projects have emphasized an integrated approach to home-based asthma support that includes all these elements.

These interventions can provide CHWs with marketable and sustainable skills. The CHWs developed a new set of marketable skills, such as client counseling and motivational interviewing, scheduling and organizational practices, home environmental assessment and hazard reduction, along with the discipline to work autonomously. They earned living-wage jobs with benefits along with acquiring specialized knowledge. Many of them worked in the field for 5 years or longer. Others moved to other public health jobs where the skills and connections to community were valued.

Sustainable funding is needed to bring the benefits of home visits to more households. Home visiting programs across the nation are struggling with a core issue:
how to fund their programs. Most health insurers do not reimburse for home visits. Most health departments and community agencies lack resources to support programs of meaningful size and reach. Until insurers support home visits, until insurance purchasers ask them to do so, and until government has sufficient resources to hire home visitors or contract with community agencies to do so, many families will not receive the benefits of home visits. The recent reforms in health-care financing may provide an opportunity to secure sustainable funding.

Healthy Housing

*Improving housing conditions is an important strategy for eliminating health disparities.* The vast majority of participants in all three projects lived in homes with unhealthy conditions. Lack of affordable housing and discrimination in housing markets give low-income people and people of color few options to seek healthy housing. Many have a limited understanding of what makes for unhealthy home conditions. Yet evidence from our work [64] and the literature [65] demonstrates that living in substandard housing is associated with poor health, be it asthma, depression and stress, or lead poisoning.

*It is difficult to remediate privately owned housing occupied by low-income tenants.* Landlords may be interested in eliminating water damage, but are often reluctant to invest in their properties by removing carpet and increasing ventilation, particularly if they own multiunit dwellings. A common refrain is that, “I can’t give one tenant something that I don’t give to all the others.” Renters are not invested in the property improvements and frequently move before benefits accrue. For these and other logistical reasons, we were not successful when we tried to implement our Better Homes for Asthma program to locate and remediate substandard houses where low-income children with asthma lived. While this approach was conceptually appealing, it may not be feasible to implement on a scale broad enough to make a significant impact on asthma disparities. An evaluation of the remediation approach, this time in a single public housing development, is in progress in the Viking Apartments in Worthington, MN [66].

*We had more success in partnering with a public housing agency to build new affordable, asthma-friendly housing.* The Seattle Housing Authority approached us with the idea for the BEH Project and remains enthusiastic about its goals. Unlike private sector landlords, the Housing Authority actively participated in efforts to improve housing quality. Residents are supported in a consistent manner by SHA rather than the varied level of interest expressed by private landlords. An ongoing concern is that household composition and income may change over time, causing families to become ineligible for Breathe Easy Homes.

*Incentives and regulations may be necessary to make healthy housing more widely available.* To move the healthy housing concept beyond demonstration projects, builders and owners need motivation to incorporate healthy homes principles as they maintain older homes and build new ones. Certification of new construction as “healthy,” promotion of healthy homes concepts in the housing market,
and tax and energy cost incentives may motivate some. Training all professionals that inspect homes (e.g., sanitarians, plumbing or electrical inspectors) in healthy homes practices so that they may in turn educate homeowners and renters could be useful. Incorporating healthy homes principles into local housing codes and enhancing housing inspection and code enforcement may also be necessary.

**Conclusion**

Disproportionate exposure to indoor asthma triggers is an important contributor to asthma-related inequities. Living in substandard housing is a circumstance all too common among low-income people and people of color who may lack skills for reducing exposure, exacerbating the consequences. We have described the value and challenges of providing in-home support from community health workers and building new asthma-friendly public housing as strategies to reduce exposure to asthma triggers. In-home support is effective for helping people gain skills to successfully reduce exposure to triggers as well as improve skills in the medical components of asthma self-management. Remediation of existing, privately owned housing appears to be fraught with logistical obstacles and may not be a practical approach. Construction of asthma-friendly public housing units is feasible. In conclusion, housing-focused interventions have potential to reduce asthma disparities and deserve wider study and implementation.

**References**


Chapter 20
Breast and Prostate Cancer Healthcare Disparities

Elise D. Cook

Abstract For most cancers, African Americans have the highest incidence and mortality rates of all racial or ethnic group in the USA. In 2005, the death rate for all cancers combined was 33% higher for African American men and 16% higher in African American women than for white men and women, respectively, excluding basal and squamous cell skin cancers and carcinomas in situ (American Cancer Society, Cancer facts & figures for African Americans 2009–2010. Atlanta: American Cancer Society, 2009). The higher cancer incidence in blacks is driven specifically by the higher rate in black men. Cancer incidence is slightly lower in black women than white women.

Just over 150,000 new cases of cancer were expected to be diagnosed among African Americans in 2009 (American Cancer Society, Cancer facts & figures for African Americans 2009–2010. Atlanta: American Cancer Society, 2009). The most commonly diagnosed cancers for men of this race are prostate (34%), lung (16%), and colon and rectum (10%). Among African American women, the most common cancers are breast (25%), lung (12%), and colon and rectum (11%).


Keywords Socioeconomic status • Cancer prevention • Screening disparities • Treatment disparities • Clinical trial data • Triple-negative breast cancer • Biological aggressiveness • Prostate-specific antigen (PSA) • Genetic polymorphisms • Social determinants of health • Patient navigation • Susan G. Koman for the Cure • National Human Genome Institute

E.D. Cook
Associate Professor, Department of Clinical Cancer Prevention, MD Anderson Cancer Center, University of Texas, Dallas, TX, USA
e-mail: edcook@mdanderson.org
Breast Cancer in African American Women

Invasive breast carcinoma is the most commonly diagnosed cancer in women in all racial groups in the USA. Breast carcinoma is the second leading cause of cancer mortality in women after lung cancer, but is the leading cause of cancer mortality in African American women. Although African American women of all ages are diagnosed less often with breast cancer than white women are, the former are more likely to die from this disease because their mortality rate is much higher. An estimated 19,500 new cases of breast cancer were expected to occur among African Americans in 2009 [1]. Overall, the incidence is 10% lower in African Americans than whites, but among women under age 40, the incidence is higher in African Americans. More than 6,000 deaths from breast cancer were expected to occur among African American women in 2009 [1].

The 5-year relative survival rate for breast cancer diagnosed in 1996–2004 was 77% among African Americans and 90% among whites. This difference can be attributed detection at a later cancer stage and a lower survival rate within each stage among African American women [1]. Just 51% of breast cancers are diagnosed at a local stage among African Americans, whereas 62% among whites are discovered early. In addition, within each stage, the 5-year survival rate is lower for African Americans than whites [1]. In addition, African American and white women receive disparate treatment [2]. Finally, breast tumors tend to be more aggressive in African American women; factors associated with socioeconomic status may influence the biologic behavior of breast cancer [3].

Breast Cancer Prevention Disparities

Breast cancer can be prevented using one of two strategies. The first strategy includes improving modifiable risk factors such as avoiding weight gain and obesity, engaging in regular physical activity, minimizing alcohol intake, and avoiding postmenopausal hormone replacement therapy. The second strategy uses chemoprevention (tamoxifen or raloxifene) for women at high risk for invasive breast cancer. The latter strategy is not of much benefit to African American women because they are less likely than white women to use tamoxifen and raloxifene and thus do not receive the same overall benefit from chemoprevention. The lower use of chemoprevention is related to the lower risk attributed to African Americans by the breast cancer risk assessment models used to determine whether a woman is a candidate for chemoprevention [4].

Breast Cancer Screening Disparities

In addition to breast cancer prevention measures, women can undergo screening to detect cancer early. The most commonly accepted recommendations for breast cancer screening include an annual mammogram for women 40 years of age and older.
Patients at high risk for invasive breast cancer may require additional screening modalities such as an earlier age at baseline mammogram or the addition of breast magnetic resonance imaging or breast ultrasonography. Women with a strong family history of breast cancer or multiple cancers should consider genetic testing as well. Unfortunately, African Americans are less likely to receive adequate mammographic screening than whites, which may partially explain the higher prevalence of advanced breast tumors among the former [5].

Breast Cancer Treatment Disparities

African American women with breast cancer are less likely than white women to receive radiotherapy, chemotherapy, or hormonal therapy [6]. The disparity in appropriate treatment for breast cancer most likely impacts survival. Determining the causality of the lower survival rate is difficult because of the effects of differences between African Americans and whites in socioeconomic status, long- and short-term treatment, and the level of aggressiveness of the breast cancer type.

Albain et al. [7] reviewed 19,457 cases of cancer among adults, 2,308 of whom were African American, from 35 Southwest Oncology Group (SWOG) randomized phase III clinical trials conducted from 1974 to 2001. Despite enrollment uniform stage, treatment, and follow-up, the survival rate of patients with sex-specific (breast, ovarian, and prostate) cancer was lower for African Americans than for whites. Albain et al. were criticized for not obtaining better information on patients’ socioeconomic status or following the patients long term. For example, Montaya and Kent [8] stated that solving the puzzle of differential survival outcomes by race requires that ambient exposures, life experiences, and clinical treatment over multiple generations be analyzed with as much care as all other factors. Because these factors had not been controlled for, the use of race as a reliable proxy for human variation presents serious impediments to accurate interpretation [8]. In addition, the criticism from Rosenberg et al. [9] was that the all-cause mortality rates observed in the SWOG studies may reflect an initial period of comparable cancer care provided by the trials followed by a longer period of overall care received in the general medical community. If this were so, it is not clear how the SWOG study can illuminate racial differences in breast tumor biology free of the effects of racial differences in access to health care. Regardless, consistent access to quality care is a crucial issue for cancer-specific and all-cause mortality [9].

In 2000, Dignam [10] reviewed key studies and several randomized clinical trials of the National Surgical Adjuvant Breast and Bowel Project (NSABP), which looked into the disparity in the survival rate of African American and white women with breast cancer. In most studies reported in the literature, the stage of disease at diagnosis did not fully account for differences in outcome between the racial groups. When additional factors were taken into account, however, the prognoses between races became more similar. Results from these clinical trials similarly indicated that when the stage of disease and treatment were comparable, the outcomes for African Americans and whites did not differ markedly. However, Yusef et al. [11] pointed out
that using clinical trial data has certain disadvantages: a lack of detailed socioeconomic data, small numbers of African American participants in many of the studies, and an inherent danger in retrospectively examining trial results in patient subsets, which may lead to spurious findings. Therefore, until more African American patients are enrolled in clinical trials and more information on socioeconomic status is collected, the review of trial data to determine whether similar treatment leads to similar survival rates is flawed.

In a comprehensive, national cohort of Medicare patients, approximately 65% of African American women and 74% of white women received radiotherapy after breast-conserving surgery for invasive breast cancer [12]. The disparities varied by geographic region. For example, African Americans in the northeastern and southern USA were the least likely to receive radiotherapy [12]. African American women are also less likely to receive guideline-recommended adjuvant therapy; marital status, income by census tract, and health insurance appeared to be the primary mediators of this difference. Given that radiotherapy usually requires daily hospital visits for 6 weeks, it is not surprising that married women (marital status is a proxy for social support) were more likely to receive adjuvant therapy for their breast cancer. These findings are supported by other studies that have shown that marital status may be an important predictor of not only the receipt of adjuvant therapy, but also the stage of the cancer at diagnosis due to lack of screening [13].

To ascertain the reasons underlying treatment omission, Bickell et al. [14] conducted interviews with surgeons who were treating 119 women who had not received guideline-recommended adjuvant therapy. A third of the omissions were attributable to surgeons’ perceptions that treatment was not indicated, a third to the refusal of the patient to accept treatment recommendations, and a third to system failures. System failures occurred more frequently among minority women [14].

Biological Causes of Breast Cancer Disparities; triple-negative breast cancer is defined as the absence of estrogen and progesterone receptor expression as well as the absence of ERBB2 amplification. It is characterized by its biological aggressiveness, a worse prognosis, and lack of a therapeutic target [15]. Triple-negative breast cancer disproportionately affects women of African descent. Carey et al. [3] evaluated 496 incidences of invasive breast cancer from the Carolina Breast Cancer Study and found that premenopausal African American women were more likely to develop basal-like breast tumors (a triple-negative breast cancer) than postmenopausal African American and non–African American women.

Triple-negative breast cancer has been classified into four subgroups (luminal, ERBB2, normal breast, and basal-like) that have distinct gene expression patterns and phenotype characteristics (Table 20.1). Triple-negative breast cancer shares features with basal-like breast cancer, the most aggressive subgroup with the worst outcome (Table 20.2). Because these subgroups can be determined only in the research setting, clinicians use the triple-negative definition as a proxy for basal-like breast cancer [15]. Aggressive morphologic features associated with the basal-like subtype included markedly elevated mitotic count, geographic tumor necrosis, and pushing margin of invasion [16]. Triple-negative breast cancer lacks the receptive that are targeted by the most promising anti-estrogen drugs such as tamoxifen,
Table 20.1  Breast tumors classified into four groups based on gene expression patterns

<table>
<thead>
<tr>
<th>Subgroup</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Luminal</td>
<td>High expression of many genes expressed by breast luminal cells, including ER and CK 8/18</td>
</tr>
<tr>
<td></td>
<td>No over-expression of ERBB2</td>
</tr>
<tr>
<td>ERBB2</td>
<td>Over-expression of the oncogene ERBB2</td>
</tr>
<tr>
<td></td>
<td>Low levels of ER expression and of almost all of the other genes associated with ER expression, a feature they share with basal-like tumors</td>
</tr>
<tr>
<td>Normal breast</td>
<td>Expression of genes distinctive of basal epithelial and adipose cells</td>
</tr>
<tr>
<td></td>
<td>Low expression of the luminal cells gene cluster</td>
</tr>
<tr>
<td>Basal-like</td>
<td>High expression of CK 5/6 and 17, laminin, and fatty acid binding protein 7</td>
</tr>
<tr>
<td></td>
<td>Failure to express ER and most of the other genes usually co-expressed with it</td>
</tr>
</tbody>
</table>

Adapted from Livasy et al. [16]

ER endoreticulum, CK cytokeratins

Table 20.2  Clinical features of triple-negative breast tumors

<table>
<thead>
<tr>
<th>Feature</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient characteristics</td>
<td>Younger age at diagnosis</td>
</tr>
<tr>
<td></td>
<td>African origin</td>
</tr>
<tr>
<td></td>
<td>BRCA1 mutation carrier</td>
</tr>
<tr>
<td>Tumor characteristics</td>
<td>Ductal invasive carcinoma</td>
</tr>
<tr>
<td></td>
<td>Rare histologies (medullary, metaplastic)</td>
</tr>
<tr>
<td></td>
<td>Negative for estrogen receptor, progesterone receptor, and human epidermal growth factor receptor 2</td>
</tr>
<tr>
<td></td>
<td>Elevated mitotic count</td>
</tr>
<tr>
<td></td>
<td>Tumor necrosis</td>
</tr>
<tr>
<td></td>
<td>Pushing margin of invasion</td>
</tr>
<tr>
<td></td>
<td>Large and high-grade tumor</td>
</tr>
<tr>
<td></td>
<td>Axillary node involvement</td>
</tr>
<tr>
<td>Treatment and prognosis</td>
<td>Chemosensitive</td>
</tr>
<tr>
<td></td>
<td>No known targets</td>
</tr>
<tr>
<td></td>
<td>Poor prognosis (trend of relapse first 3 years)</td>
</tr>
<tr>
<td></td>
<td>Aggressive relapse</td>
</tr>
</tbody>
</table>

Adapted from Livasy et al. [16]

raloxifene, and aromatase inhibitors; it also lacks the human epidermal growth factors 2 that are targeted by the drug trastuzumab. Therefore, some of the most commonly used and effective drugs are rendered useless for women with triple-negative breast cancer.

Morris et al. demonstrated that breast carcinomas in African American patients appear to be more aggressive than in Caucasian patients due to multifactorial differences. These investigators compiled pathology data from the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) database regarding stage, histologic grade, and estrogen receptor (ER) expression in breast carcinomas diagnosed in 197,274 African American and Caucasian patients between 1990 and
2000, and the same information, along with nuclear grade, Ki-67, c-erb-B2, and p53 expression, in 2,230 African American and Caucasian patients diagnosed at Thomas Jefferson University Hospital between 1995 and 2002. Immunohistochemical markers were assayed in paraffin-embedded, formalin-fixed tissue stained with hematoxylin and eosin using antibodies to these proteins, with differences in expression analyzed by the chi square test. In both databases, more African American patients presented with advanced stage tumors and higher histologic (P<.001) and nuclear grade (P<.001) than Caucasian patients. African American patients had less ER positivity (51.9% vs. 63.1%; P<.001) but significantly higher Ki-67 (42.4% vs. 28.7%; P<.001) and p53 expression (19.4% vs. 13.1%; P<.05) than Caucasian patients with all stages of disease. In addition, the triple-negative breast cancer phenotype was more common in African American patients than in Caucasian patients (20.8% vs. 10.4%; P<.0001), and was associated with higher histologic and nuclear grade (P<.0001). African American patients with breast carcinomas are more likely than Caucasian patients to present with tumors that are of a later stage and higher grade, with higher Ki-67 expression and more ER negativity, thereby highlighting a greater need for early screening among African American women [17]. Molecular studies that may explain these differences, and correlations with survival, have been proposed to identify therapeutic targets.

Prostate Cancer in African American Men

Among all races and ethnicities in the USA, African American men bear the largest burden of prostate cancer. About 27,100 new cases and nearly 3,700 deaths from prostate cancer were expected to occur in African Americans in 2009. Although approximately 90% of African Americans and whites are present in local and regional stages, the incidence rate is about 60% higher and the mortality rate 240% higher in African Americans than whites [1]. One likely contributing factor to this disparity is that prostate cancer grows more rapidly and is more aggressive in African Americans [18]. The risks for prostate cancer include older age, African American race, and high intake of dairy and calcium. Studies of whether folate level, testosterone level, exposure to dioxin, and a high-fat diet are risks have been inconclusive, although a high-fat diet is associated with progression of prostate cancer to advanced stages [19].

Prostate Cancer Prevention Disparities

The prostate cancer prevention studies using finasteride, dutasteride, selenium, and vitamin E did not have the power to detect differences in effect for racial subgroups. Overall, dutasteride and finasteride prevented prostate cancer while selenium and/or vitamin E did not.
**Prostate Cancer Screening Disparities**

Prostate cancer screening with a digital rectal examination and a prostate-specific antigen (PSA) blood test is wrought with controversy. Recent results from the US Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial (PLCO) showed no significant difference in prostate cancer mortality between cohorts of various races and ethnicities who did or did not undergo screening [20]. Confounding issues included low numbers of African American men (only 4% of the study population), high numbers of men in the control group who had received prostate cancer screening before entering the trial (44%), and improvements in therapy for prostate cancer during the course of the trial. A follow-up report from this study will be presented when the cohort reaches 13 years [20]. In contrast, the European Randomized Study of Screening for Prostate Cancer, which is evaluating the effect of screening with the PSA test every 4 years among men in seven European countries, has so far shown that this screening regimen reduces the rate of death from prostate cancer by 20% compared with no PSA testing at all but was associated with a high risk of over-diagnosis [21]. A follow-up report is planned for this study as well. Since neither the USA nor the European study had a sufficient number of black men enrolled to conduct subset analyses, it is difficult to say whether the overall study findings apply to them. Although the US Preventive Health Services Task Force does not advise for or against prostate cancer screening, health-care providers who care for African American men still recommend screening because of the relatively high death rate from prostate cancer in this population [22].

**Prostate Cancer Treatment Disparities**

African American men are less likely than whites to have their prostate cancer staged and to receive surgical treatment [22]. African American men are more likely to have a lower socioeconomic status than white men; a lower status appears to affect the risk of death from prostate cancer [23]. However, even when access to care is equal, such as in a health maintenance organization, African American men are less likely than white men to be offered treatment with curative intent and are more likely to be offered watchful waiting. This difference was not due to patient age, tumor grade, cancer stage, or presence of comorbid conditions. [24] Medical record review revealed that the difference was due to physician recommendation rather than patient compliance.

**Biological Causes of Prostate Cancer Disparities**

Site-specific prostate cancer susceptibility loci in men have been mapped to chromosomes 1q24–25 (HPC1), 1q42.2–43 (PCAP), 1p36 (CAPB), Xq27.2 (HPCX), 20q13 (HPC20), 17p (ELAC2/HPC2), 8q24, and 8p. For susceptibility
loci *BRCA2* and *BRCA1* the development of prostate cancer appears to be linked to a syndrome that includes malignancies such as breast cancer [25]. Table 20.3 lists genetic polymorphisms that affect susceptibility to prostate cancer and disproportionately affect African American men.

**Table 20.3** Sample of altered genetic polymorphisms and variants of key genes in cancer pathways that alter susceptibility to prostate cancer across races

<table>
<thead>
<tr>
<th>Gene</th>
<th>Cancer pathway</th>
<th>Racial heterogeneity of gene mutations and expressions</th>
</tr>
</thead>
</table>
| CYP3A4 | Androgen deactivation | G variant  
- Considerably more common among AAs (>50%) than CAs (<10%), Hispanics, or Asians  
- In AAs, strongly associated with PCa with aggressive characteristics at diagnosis  
- After prostatectomy, an increasing number of copies is associated with worse progression-free survival among CAs but not among AAs  
- Considerably more common among AAs (>50%) than CAs (<10%), Hispanics, or Asians |
| EphB2 | Tyrosine kinase receptor/ tumor suppressor | K1019X mutation  
- Higher prevalence in AAs with a family history of PCa (15.3%) than in CA controls (1.7%)  
- Threefold higher risk for PCa among AAs who carried at least one copy of the allele and had a family history of PCa than healthy AAs |
| BCL-2 | Apoptosis | – Positive association between increased cancer proliferation and BCL-2 in prostate tumors in AAs but not in CAs |
| AR | Possibly alteration of androgen receptor DNA-binding affinity and/or its response to androgens, non-androgenic steroids, or anti-androgens | Germline androgen receptor (A1675T) (T559S) substitution mutation  
The first androgen receptor germline mutation in an AA family with a history of PCa |
| Unnamed gene located on chromosomes 5 and 8 | rs7729084, rs12474977, and rs4367565 | AA ancestry associated with prostate cancer susceptibility loci |

Adapted from Hatcher et al. [26], Hu et al. [27], and Bock et al. [28]

AA African American, CA Caucasian American, PCa prostate cancer
Solutions to Disparities in Breast and Prostate Cancer Health

The social determinants of health are the conditions in which people are born, grow, live, work, age, and obtain health care. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels, which are themselves influenced by policy choices [29]. The World Health Organization’s report on the social determinants of health made several recommendations for closing the health equity gap: (1) improve the daily living conditions; (2) tackle the inequitable distribution of power, money, and resources; and (3) measure and understand the problem and assess the effects of the action taken [29].

The Deep South Network for Cancer Control is a sustainable community infrastructure developed to promote cancer health awareness and minority recruitment to clinical trials, recruit and train minority investigators, and develop and test cancer control strategies to eliminate disparities between African Americans and whites [30]. The solutions to racial disparities in breast and prostate cancer health include patient education, reduction of patient mistrust of the medical system, social support, increasing the numbers of minority health-care providers, and research on the biology of and treatment for these cancers [31].

As health-care professionals, we should lead the way in providing public education on cancer health education, especially for prostate and breast cancers, the most common cancers among men and women, respectively. Education would cover the risks and benefits of cancer prevention, screening, and early detection. For example, the National Cancer Institute’s video intervention “The PSA Test for Prostate Cancer: Is it Right for Me?” has been used successfully to improve prostate cancer awareness in African American men with different levels of health literacy who are considering PSA screening [32]. Minority populations demonstrate a low level of awareness about therapies proven to reduce the risk of breast and prostate cancers. Unfortunately, these therapies are not without adverse side effects. For some men and women at high risk developing breast or prostate cancer, these treatments can reduce their risk and save lives. Education of high-risk individuals is the key to starting the process of informed decision making.

The knowledge and beliefs of patients about treatment and their mistrust of the medical system are mutable factors associated with the underuse of effective adjuvant therapies for cancer. Physicians may improve a patient’s cancer care by ensuring that discussions about adjuvant therapy include a clear presentation of both the benefits and the risks of treatment and by addressing the patient’s trust in and concerns about the medical system [33].

Urologists can reduce health-care disparities by providing accurate staging of prostate cancer after diagnosis for all men, and especially for minority and older men [22].

Breast and prostate cancers often require a series of treatments, such as daily hospital visits lasting for several weeks for radiotherapy or weekly visits lasting for months for adjuvant chemotherapy. African American patients, especially those who have poor social support, are vulnerable to system failure and can fall through the cracks, resulting in insufficient treatment. Dr. Harold Freeman developed the
concept of patient navigation in 1990 to improve patient access to cancer treatment. Initially the navigators were members of the community they served, allowing them to personally relate to their patients [34]. Since its inception, patient navigation has morphed into heterogeneous programs with a variety of navigation styles and programs encompassing screening, diagnostic testing, treatment, and quality-of-life issues. Navigation has been shown to improve access to care, decrease patient anxiety, and increase patient satisfaction among urban minority women who have had abnormal mammographic results [34, 35]. Tracking and feedback registries enhance the ordering and completion of oncology consultations for African American and other minority patients, thus increasing the odds of completion of recommended adjuvant therapy and reducing the traditional health-care disparities faced by minority patients with cancer [36]. For example, in a 2009 study of the effect of race on pathologic complete response rates and survival outcomes for 471 women (100 of whom were African American) with triple-negative breast cancer treated at The University of Texas MD Anderson Cancer Center, race did not significantly affect the response or patient survival rate. Although the median follow-up was only 24.5 months, this study showed that appropriate treatment can yield similar results in African American and white women with triple-negative breast cancer [37].

Although 12% of the US population is African American, only 2% of oncologists are. The Susan G. Komen for the Cure/American Society of Clinical Oncology (ASCO) Diversity in Oncology Initiative was designed to increase the number of minority oncologists in the USA. This program provides $70,000 in loan repayment for oncologists of any race or ethnic group who practice in underserved areas for 2 years, mentor-guided clinical rotations in oncology for minority medical students, and travel awards for minority residents who attend the society’s annual meeting [38]. Research has shown that more minority than white medical students say they would spend their post-residency professional careers serving underrepresented minorities [39]. The National Surgical Adjuvant Breast and Bowel Project (NSABP) provides a Minority Investigator Travel Award to increase the participation of underrepresented minority investigators at the organization’s meetings and a Minority Mentoring Program to develop more minority investigators (Personal Communications). In addition, the Glickman Urological and Kidney Institute’s Minority Men’s Health Center (MMHC) at the Cleveland Clinic is dedicated to addressing the health needs of minority men by involving the community, providing cultural sensitivity training for health-care providers, and providing patient access to care. The center also engages and encourages minority youth to consider a career in the health professions [40].

The biological factors for breast and prostate cancer health disparities must be addressed through research. For example, in collaboration with Howard University, investigators at the National Human Genome Research Institute and a predominantly African American group of urologists established the African American Hereditary Prostate Cancer (AAHPC) Study Network to evaluate the linkage of hereditary prostate cancer in African American families with at least four affected members [41].
Finally, disparities in breast and prostate health can be addressed through research on new or better treatments that will improve the outcomes for African Americans. Current treatments and new therapeutic options for breast cancer include the use of platinum compounds, epidermal growth factor receptor antagonists, anti-angiogenics, and poly ADP ribose polymerase inhibitors. Advances in research are promising and new types of active drugs will become a reality in the near future, making possible a better outcome for African Americans with breast cancer [42]. As of May 2010, there are 60 open studies of triple-negative breast cancer [15].

The Impact of Health-Care Reform on Disparities in Breast and Prostate Health Care

Changes mandated by the Obama administration that are expected to take effect by 2012 will likely improve the financial situation for many people affected by cancer [43].

- Health-care insurers will not be able to cancel a policy when a person is diagnosed with cancer. People with cancer will not have to be afraid of being dropped from their plan due to this diagnosis. Annual and lifetime limits on health-care benefits will be prohibited.
- Cancer care can be very expensive, and currently a person can easily reach the benefit limit allowed in a given year. The patient would then be forced to pay out of pocket for further cancer care or, if he or she is unable to afford it, would receive no care at all.
- Senior citizens will receive a $250 rebate to help with the Medicare prescription “doughnut hole” of $3,454.
- Newly created health-care plans must cover preventive health-care services and require no co-pays. Breast, prostate, and colorectal cancer screening will be completely covered. Existing plans will have to provide 100% coverage (and no co-pays) of preventive health care by 2018.
- A new program has been created to encourage companies to provide medical benefits for employees who retire between 55 and 64 years of age [43].

Currently, clinical breast exams are not covered under Medicare; they will be covered under the health reform plan. A new annual wellness visit that provides a personalized prevention plan services, including a health risk assessment, will be provided under Medicare.

The biggest problem with the new health-care bill is that not all citizens will be covered. As health-care providers, we must do all we can to ensure that every American with cancer has access to appropriate care.

Acknowledgment The author would like to acknowledge the significant contribution to this chapter by Edith P. Mitchell, M.D., F.A.C.P., Clinical Professor of Medicine and Medical Oncology, Kimmel Cancer Center at Thomas Jefferson Medical School.
References

Abstract  As we shift from documenting health-care disparities to implementing solutions to eliminate them, health information technology will play a critical role. Health information technology can alert physicians to deviations from evidence-based guidelines, improve clinical decision-making at the point-of-care, and support population-based management of health care (Custodio et al., J Health Care Poor Underserved 20:301–7, 2009). Telemedicine applications can improve access to specialist care for patients in remote and underserved areas (Fricton and Chen, Dent Clin N Am 53:537–48, 2009). Novel devices can provide close monitoring for high-risk populations. In short, health information technology (IT) can drive our efforts to monitor and reduce health-care disparities.

The 2009 American Reinvestment and Recovery Act’s (ARRA) HITECH provisions contain over $2 billion in programs and over $20 billion in incentives to support the adoption and “meaningful use” of Health Information Technology (Blumenthal, N Engl J Med 362:382–5, 2010). The Recovery Act also includes over $7 billion in grants to improve the availability of broadband technology in underserved areas. Together, these programs will lay the foundation for America’s health IT infrastructure. They will also give us a new modality to monitor, manage, and correct health disparities.

As with the diffusion of any new technology, there is always the risk that uneven access to electronic health records (EHR) by certain types of patients and providers will create new disparities in health. While the current data do not indicate that providers or patients of particular ethnic or racial groups are more or less likely to adopt or have access to electronic health records, careful attention must be paid to ensure that underserved patient populations are the beneficiaries of the clinical
improvements that health information technology can enable. This chapter summarizes our current state of knowledge about health IT adoption among underserved communities and outlines a vision for how broad adoption and use of health information technology can limit or correct health-care disparities. It describes the federal HITECH Act programs and also addresses how the federal government is working to ensure that the benefits of health IT are widely distributed to underserved populations.

**Keywords** Underserved populations • Health information technology (HIT) • Electronic health records (EHR) • Demographic information • Fragmentation • Clinical decision-making • Quality improvement • “Meaningful use” • Patient engagement • Information exchange • Beacon Community program • Incentive payments

---

**Current State of Adoption of EHR in Underserved Communities**

One key methodological challenge to tracking and monitoring electronic health record (EHR) adoption among providers who deliver care to vulnerable population is our inability to adequately identity providers who deliver care to vulnerable populations, as data is sparse on the race or ethnicity of physicians, case-mix or payer-mix of physician practices, and demographic profiles of patient populations. This challenge is coupled with even more limited data sources on electronic health record adoption.

To date, most surveys about health information technology (IT) adoption provide modest insight into adoption in minority and low-income communities. The best review of the data on this subject was completed in a joint project by the George Washington University, Massachusetts General Hospital, and Robert Wood Johnson Foundation. In subanalyses of the National Ambulatory Medical Care Survey (NAMCS) data and data from Federally Qualified Community Health Centers (CHC), there were no findings of any major disparities in EHR adoption by physicians or clinics that see disproportionate numbers of underserved patients [1]. Some preliminary data demonstrated that physicians serving a greater proportion of Medicaid patients are significantly less likely to have EHRs relative to physician practices with fewer Medicaid patients. However, more investigation is needed to understand the factors contributing to and underlying these findings [2].

As federal policies and programs make electronic health records more commonplace, it will be necessary to develop reporting mechanisms to be able to track adoption and use across different patient and provider populations.
A Vision: The Potential for Health IT to Mitigate Disparities

Health IT has extraordinary potential to improve our ability to track and improve health-care disparities. We describe four potential approaches: (1) practice level information management, (2) provider decision-making, (3) managing fragmentation, and (4) supporting patient engagement.

Practice Level Information Management

Even as physicians have become increasingly aware of the disparities in health-care service delivery and outcomes, they are often unable to identify or document the disparities that exist in the care of their own patients. In paper-based systems, it is costly and time-consuming to query and systematically analyze the quality of care delivered, as physicians must laboriously review written charts one by one to evaluate the care delivered. Often the demographic data needed to identify and manage disparities are not collected or documented properly in paper-based systems [3].

Advanced electronic health records will allow physicians and nurses to rapidly evaluate their practice patterns on a regular basis. Highly structured records – with rich patient demographic and identifying data – allow physicians to generate composite measures characterizing the care of the different populations they serve, as well as identify specific outlier patients whose care requires optimization. The provider becomes a proactive agent in the management of his/her patients. Early studies of electronic health record adoption in Community Health Centers (CHC) suggest that electronic health records can significantly facilitate quality improvement efforts [4].

In cancer care, Houston, Texas-based MD Anderson Cancer Center has undertaken an ambitious pilot project of implementing highly structured medical records for head and neck cancers [5]. Because the record system is attuned to the condition treated and standardized across all providers, doctors will be able to track individual and group process and outcomes performance measures in real time. Information about specific racial, ethnic, and demographic groups – and their outcomes – is readily accessible to clinicians for use (Hanna E., Medical Director, Multidisciplinary Head and Neck Center, 2010, Personal Communication). Accordingly, tracking the care of specific populations – and identifying areas for improvement – is easy for providers.

Remarkably, health IT may also change a provider’s approach to medical education. While many practitioners participate in generic continuing education, health IT may allow practitioners to establish their individual educational needs based on practice patterns, making continuing medical education more personalized and productive. Practitioners who identify disparities in their care might elect to study and understand the patterns in their care. Several medical boards, such as the
American Board of Internal Medicine and the American Board of Family Practice, have taken steps to incorporate practice audits as a skill necessary for maintaining board-certification. Electronic health records will facilitate this approach to continuing medical education.

**Provider Decision-Making: Integrating Patient Information at the Point of Service**

With an ever-expanding body of medical interventions and an endless supply of new data about their use, it is challenging for providers to make evidence-based decisions about whether and when to apply and withhold these treatments. Factors specific to individual patients, such as their demographic information and medical history and medications, have a significant impact on what care should be delivered but are often inadequately considered by treating providers when paper charts are unavailable. Because data in electronic health records are always available, EHRs support better clinical decision-making.

In the setting of reliably recorded electronic health records, clinical information systems can also provide point-of-service decision support by analyzing the information specific to each clinical encounter. So far, computerized physician order entry systems have shown significant promise by providing physicians with alerts as they prescribe tests and medication. While there have been few document applications to date of using decision support to reduce disparities, one could imagine how a decision support system could be implemented to ensure higher prescribing rates of medications for patients of racial, ethnic, and gender groups who are being undertreated for particular conditions. The possibilities for using decision support to improve care of underserved populations using enhanced decision support seem endless.

The challenge, of course, with decision support systems is making sure that the support provided is appropriate and well-chosen for the patient and receiving physician. A poorly designed support system could overwhelm providers or, worse, make them complacent about managing complex medical decisions by excessively implementing alerts.

Technology failure is not an indictment of health IT’s potential to reduce disparities. Instead, it represents a possible failure of implementation. How the technology is implemented – the managerial challenge of introducing safeguards, changing workflows, and auditing quality – is critically important to success in putting health IT to work in improving health-care disparities.

**Managing Fragmentation: Organizing Clinical Information**

A key deficiency that contributes to disparities in access to care is fragmentation. Provider groups and physicians often exist in isolation of each other. Patients seek care across multiple sites and seek alternate opinions and diagnostic and therapeutic
approaches, but studies are repeated frequently, increasing cost and potentially imposing unnecessary risk to patients when interventions are repeated. Emergencies can be ill-managed because the treating providers lack information available elsewhere in the patient’s records. Underinsured and undeserved patients without access to regular primary care are particularly at risk for this latter concern [6].

In a wired health system, a treating provider will be able to privately and securely query all of a patient’s health records – from all of his/her points of care – and obtain a synthesized health record of all points of contact. The Recovery Act’s HITECH provisions stipulate broadened protections for privacy and security of data transmission to ensure that sensitive patient data will not fall into the wrong hands. Care that takes place across a variety of settings – home, physician offices, and hospitals – can be centrally documented, but securely viewed and transmitted across a health system. The Nationwide Health Information Network (NHIN) and an initiative of our office, the Office of the National Coordinator for Health Information Technology (ONC), aim to provide hospitals and doctors’ offices with a common platform and set of protocols for private and secure information exchange. The NHIN is in its infancy, but already includes a number of large providers such as Kaiser Permanente, the Cleveland Clinic, and the Veterans Administration among its members.

The Indian Health Service (IHS), the federal service that provides care to Native Americans, currently uses a Resource and Patient Management System (RPMS) to provide comprehensive support of clinical and administrative functions with the Indian Health Services. The RPMS stores data on approximately 90% of clinical encounters occurring within IHS clinical facilities, including tribally administered and urban clinics. A National Patient Information Reporting System (NPIRS) facilitates aggregated reporting of care that occurs across the Indian Health Service (IHS) [7]. Collection of information across the NPIRS allows for some parts of patient records to be amalgamated.

Properly organizing and presenting the collected information has the potential to limit disparities – by better documenting what a patient has and has not received. Developing methods of streamlining and organizing health information will be a critical challenge as more information about patients is placed in electronic form.

Supporting Patient Engagement

An informed patient is an empowered patient, but even sophisticated customers of health care often have incomplete or inadequate information and understanding about their health. Electronic health records may provide platforms and portals through which underserved patients can better manage their own personal health to eliminate disparities in their care.

Supplied with carefully tailored, specific health information, patients will have the means to improve their own care. They will use health information systems to securely report and to track their medication compliance, their diet and exercise, or
other personal contributions to their care and health. For their part, providers will develop registries of patients, populated using information from electronic health records, to broadcast targeted information about relevant medical conditions and treatments to their patients.

For several years now, Appleton, Wisconsin-based ThedaCare has had electronic health records that are fully transparent to patients through a patient portal, “MyThedaCare.” The portal offers access to physician notes, lab results, medication refills, and appointment scheduling [8]. Patients – many of whom are in rural areas served by critical access hospitals – use the secure site to report any problems or results such as blood pressures or blood sugars to providers, making them a part of the patient’s permanent medical record. While doctors were initially resistant to using the site to interface with patients because the associated care would not be reimbursed, most have fully adopted the system because it has improved speed and ease of information exchange that otherwise might have taken place in extra visits or phone calls.

A key issue with patient-facing health IT is variability of interest in use among underserved or minority patients, as well as health literacy. At Kaiser Permanente, researchers found that racial minorities used personal health records and patient portals less than nonminority counterparts [9]. Differences in education, income, and Internet access did not account for the disparities in PHR registration by race. Others have raised the issue that underserved and vulnerable patients are precisely the least likely to have computers and use them for their health [10]. While patient-facing health information technology has the potential to improve care that is delivered, it will be important to monitor whether underserved patients use these technologies – and establish approaches to make sure that they do.

Overview of HITECH Act Programs

Despite the potential for electronic health record technology to eliminate disparities and improve overall quality of care, adoption rates of electronic health record systems have been low. According to estimates from the 2009 National Ambulatory Medical Care Survey (NAMCS), 43.9% of the physicians reported using all or partial EMR/EHR systems in their office-based practices. About 20.5% reported having systems that met the criteria of a basic system, and 6.3% reported meeting criteria for a fully functional system (see Fig. 21.1; [11]). In addition to the costs of the software, medical practices and hospitals have resisted systems because of the change in workflows that they require. Electronic health record systems require fundamental modifications to how clinicians deliver and document care to patients.

To ease the costs and challenges associated with transitioning from paper to electronic systems, President Obama and the Congress authorized billions of dollars in incentive payments to doctors and hospitals and $2 billion in discretionary programs to create infrastructure supports for EHRs (see Figs. 21.2 and 21.3). The approach they authorized to qualify for the incentive payments was to reward physicians not

NOTES. Any EMR/EHR is a medical or health record system that is either all or partially electronic (excluding systems solely for billing). The 2009 data are preliminary estimates (as shown on dashed lines), based only on the mail survey. Estimates of basic and fully functional systems prior to 2006 could not be computed because some items were not collected in the survey. Fully functional systems are a subset of basic systems. Starting in 2007, the skip pattern after the all or partial EMR/EHR systems question was removed. Includes nonfederal, office-based physicians. Excludes radiologists, anesthesiologists, and pathologists.
SOURCE: CDC/CHS, National Ambulatory Medical Care Survey

Fig. 21.1 Health IT adoption

Fig. 21.2 HITECH Act overview (Blumenthal [12])
S.H. Jain and D. Blumenthal

merely for adopting record systems but for achieving stages of “meaningful use” of electronic health records. To qualify for the full amount of incentive payments – up to $44,000 for a Medicare provider; up to $63,750 for a Medicaid provider; and millions of dollars for a hospital – an eligible provider or hospital must fulfill the requirements of all three stages of Meaningful Use. Stage 1 focuses on collecting critical data elements in electronic form, sharing key information with other providers and with patients, and reporting quality measures to the government. The proposed evolution of Meaningful Use in stages 2 and 3 would emphasize rewarding providers for using EHRs to improve processes of care and outcomes, respectively (see Fig. 21.4). After 2015, providers are subject to penalties to their Medicare reimbursement if they do not demonstrate that they are meaningful users.

To help overcome nonfinancial obstacles of implementing and becoming meaningful users of health information technology, the Office of the National Coordinator for Health IT (ONC) used the $2 billion in available discretionary funds to launch several essential programs. To address providers’ technical and logistical problems associated with implementation, the government has committed almost $650 million under the HITECH Act to the creation of a network of 60 Health Information Technology Regional Extension Centers (RECs). Focusing initially on primary-care

<table>
<thead>
<tr>
<th>OBSTACLE</th>
<th>INTERVENTION</th>
<th>FUNDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial Resources</td>
<td>Medicare and Medicaid Incentive Program: incentive payments to “meaningful users”</td>
<td>Up to $27 billion*</td>
</tr>
<tr>
<td>Technical Assistance</td>
<td>Regional Extension Centers: Up to 70 regional extension centers will help providers through the process of selecting and implementing electronic health records</td>
<td>$643 million</td>
</tr>
<tr>
<td>Human Resources</td>
<td>Workforce Training Programs: Several distinct programs to support the education of up to 45,000 new health IT workers</td>
<td>$118 million</td>
</tr>
<tr>
<td>Exchange</td>
<td>Health Information Exchange: State programs to ensure the development of health information exchange within and across their jurisdictions</td>
<td>$564 million</td>
</tr>
<tr>
<td></td>
<td>National Health Information Network &amp; Standards and Certification: Create a common platform for health information exchange; develop interoperability specifications</td>
<td>$54.3 million</td>
</tr>
<tr>
<td>Technology</td>
<td>Strategic Health Information Technology Advanced Research Projects: Fund projects focused on breakthrough advances in health IT</td>
<td>$60 million</td>
</tr>
<tr>
<td>Breakthrough Examples</td>
<td>Beacon Communities Program: 15 demonstration communities in which clinicians, hospitals and consumers demonstrate how electronic health records can achieve breakthrough improvements in care</td>
<td>$235 million</td>
</tr>
</tbody>
</table>

* Estimate based on providers’ achievement of meaningful use

Fig. 21.3 Obstacles to health IT implementation and interventions
providers in small practices in underserved areas and on critical access hospitals, these centers will offer advice on which EHR systems to purchase and then assist physicians and hospitals in becoming meaningful EHR users by assisting with workflow changes. The RECs will specifically work to assess needs, select, and negotiate with system vendor or reseller, implement project management, and institute workflow changes to improve clinical performance and ultimately outcomes. Past experience has shown that robust local technical assistance can result in effective implementation of EHRs and quality improvement throughout a defined geographic area [13]. Regional Extension Centers will deliver help implementing electronic health record systems to the providers and hospitals that need it most.

To address the lack of infrastructure for the exchange of health information, the federal government is channeling more than $560 million in HITECH Act monies to state governments to lead the development of exchange capabilities within and across their jurisdictions. Furthermore, the ONC is accelerating ongoing work to create a national infrastructure, the Nationwide Health Information Network. The data standards established under the new regulation will also promote information exchange by facilitating communication among parties sharing health information.

To address shortages in trained health IT workers, ONC has awarded $118 million in grants to community colleges and universities. These programs are expected to train over 45,000 new workers who are skilled in health information technology implementation.

Finally, the ONC is launching the Beacon Communities program to generate and disseminate evidence about the use of health IT to enable sustainable improvements in health care cost, quality, and population health. The Beacon Community Program includes $250 million in awards to 17 communities, many of which have committed health IT resources to reduce disparities in care and improve the quality of services delivered to underserved populations. The Louisiana Public Health Institute, for example, is working in post-Katrina New Orleans and surrounding communities to use health IT to improve access to smoking cessation and diabetes care.

Fig. 21.4  The three stages of Meaningful Use
As another example, the University of Hawaii at Hilo will work with rural, medically underserved communities on the big Island of “Hawaii” to implement a region-wide HIE and Personal Health Record that will facilitate culturally competent care for at-risk native Hawaiians, the elderly, pregnant women and infants, and non-English speaking residents. The University of Hawaii aspires to use its Beacon funding to achieve a 25% reduction in health disparities.

**Meaningful Use and Health Disparities**

At the time of press, only the first of three stages of meaningful use had been fully defined through the federal rule-making process. A meaningful user of health IT would use health IT to: (1) improve quality, safety, efficiency, and reduce health disparities; (2) engage patients and families in their health care; (3) improve care coordination; (4) improve population and public health; and (5) ensure adequate privacy and security protections for personal health information.

The definition of Meaningful Use stage 1 requires physicians to use electronic health record systems to record patient demographic data. This requirement represents an important first step for physicians to reduce health-care disparities. For the first time, as a requirement for receiving incentive payments, participating in the meaningful use program, physicians will have to document the racial and ethnic identities for the patients that they serve (see Fig. 21.5). While recording this information will not reduce disparities by itself, the ability to track patients by race and ethnicity offers a first opportunity to use health IT broadly to identify and record health-care disparities. It will represent a major advance for the disparities field by facilitating research into disparities and, more importantly, practice level improvement and tracking.

Given the process and outcomes orientation of Stage 2 and Stage 3 Meaningful Use, these stages represent additional opportunities to include measurement and alleviation of disparities as requirements for demonstrating “meaningful use.” The Health IT Policy Committee that advises the definition of “Meaningful Use” has convened meetings on the subject of disparities and is actively considering ways in which this new policy instrument can be used to improve care of underserved patients and populations. Several groups – such as National IT Collaborative for the Underserved, the NAACP, and the National Medical Association – have identified this opportunity and have been working towards additional consideration of the needs of minority patients and physicians in “Meaningful Use.”

**Federal Efforts to Minimize Disparities in Access to Health IT**

One of the key risks of advancing health IT adoption and meaningful use is that expanded adoption of health information technology, in addition to helping to alleviate health-care disparities, will create new disparities. Despite the broad availability
### Summary Overview of Meaningful Use Objectives

<table>
<thead>
<tr>
<th>Objective</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core set</td>
<td></td>
</tr>
<tr>
<td>Record patient demographics (sex, race, ethnicity, date of birth, preferred language, and in the case of hospital stays, date and preliminary cause of death in the event of mortality)</td>
<td>More than 50% of patients’ demographic data recorded as structured data</td>
</tr>
<tr>
<td>Record vital signs and chart changes (height, weight, blood pressure, body mass index, growth charts for children)</td>
<td>More than 50% of patients 2 years of age or older have height, weight, and blood pressure recorded as structured data</td>
</tr>
<tr>
<td>Maintain up-to-date problem list of current and active diagnoses</td>
<td>More than 80% of patients have at least one entry recorded as structured data</td>
</tr>
<tr>
<td>Maintain active medication list</td>
<td>More than 80% of patients have at least one entry recorded as structured data</td>
</tr>
<tr>
<td>Maintain active medication allergy list</td>
<td>More than 80% of patients have at least one entry recorded as structured data</td>
</tr>
<tr>
<td>Record smoking status for patients 13 years of age or older</td>
<td>More than 50% of patients 13 years of age or older have smoking status recorded as structured data</td>
</tr>
<tr>
<td>For individual professionals, provide patients with clinical summaries for each office visit; for hospitals, provide an electronic copy of hospital discharge instructions on request</td>
<td>Clinical summaries provided to patients for more than 50% of all office visits within 3 business days; more than 50% of all patients who are discharged from the inpatient department or emergency department of an eligible hospital or critical access hospital and who request an electronic copy of their discharge instructions are provided with it</td>
</tr>
<tr>
<td>On request, provide patients with an electronic copy of their health information (including diagnostic test results, problem list, medication lists, medication allergies, and for hospitals, discharge summary and procedures)</td>
<td>More than 50% of requesting patients receive electronic copy within 3 business days</td>
</tr>
<tr>
<td>Generate and transmit permissible prescriptions electronically (does not apply to hospitals)</td>
<td>More than 40% are transmitted electronically using certified EHR technology</td>
</tr>
<tr>
<td>Computer provider order entry (CPOE) for medication orders</td>
<td>More than 50% of patients with at least one medication in their medication list have at least one medication order entered through CPOE</td>
</tr>
<tr>
<td>Implement drug–drug and drug–allergy interaction checks</td>
<td>Functionality is enabled for these checks for the entire reporting period</td>
</tr>
<tr>
<td>Implement capability to electronically exchange key clinical information among providers and patient authorized entities</td>
<td>Perform at least one test of EHR’s capacity to electronically exchange information</td>
</tr>
<tr>
<td>Implement one clinical decision support rule and ability to track compliance with the rule</td>
<td>One clinical decision support rule implemented</td>
</tr>
<tr>
<td>Implement systems to protect privacy and security of patient data in the EHR</td>
<td>Conduct or review a security risk analysis, implement security updates as necessary, and correct identified security deficiencies</td>
</tr>
<tr>
<td>Report clinical quality measures to CMS or states</td>
<td>For 2011, provide aggregate numerator and denominator through attestation; for 2012, electronically submit measures</td>
</tr>
</tbody>
</table>

**Menu set**:

<table>
<thead>
<tr>
<th>Objective</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implement drug formulary checks</td>
<td>Medication reconciliation is performed for more than 50% of transitions of care</td>
</tr>
<tr>
<td>Incorporate clinical laboratory test results into EHRs as structured data</td>
<td>More than 40% of clinical laboratory test results whose results are in positive/negative or numerical format are incorporated into EHRs as structured data</td>
</tr>
<tr>
<td>Generate list of patients by specific conditions to use for quality improvement, reduction of disparities, research, or outreach</td>
<td>Generate at least one listing of patients with a specific condition</td>
</tr>
<tr>
<td>Use EHR technology to identify patient-specific education resources and provide those to the patient as appropriate</td>
<td>More than 10% of patients are provided patient-specific education resources</td>
</tr>
<tr>
<td>Perform medication reconciliation between care settings</td>
<td>Medication reconciliation is performed for more than 50% of transitions of care</td>
</tr>
<tr>
<td>Provide summary of care record for patients referred or transitioned to another provider or setting</td>
<td>Summary of care record is provided for more than 50% of patient transitions or referrals</td>
</tr>
<tr>
<td>Submit electronic immunization data to immunization registries or immunization information systems</td>
<td>Performed at least one test of data submission and follow-up submission (where registries can accept electronic submissions)</td>
</tr>
<tr>
<td>Submit electronic syndromic surveillance data to public health agencies</td>
<td>Performed at least one test of data submission and follow-up submission (where public health agencies can accept electronic data)</td>
</tr>
</tbody>
</table>

**Additional choices for hospitals and critical access hospitals**:

<table>
<thead>
<tr>
<th>Objective</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Record advance directives for patients 65 years of age or older</td>
<td>More than 50% of patients 65 years of age or older have an indication of an advance directive status recorded</td>
</tr>
<tr>
<td>Submit electronic data on reportable laboratory results to public health agencies</td>
<td>Perform at least one test of data submission and follow-up submission (where public health agencies can accept electronic data)</td>
</tr>
</tbody>
</table>

**Additional choices for eligible professionals**:

<table>
<thead>
<tr>
<th>Objective</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Send reminders to patients (per patient preference) for preventive and follow-up care</td>
<td>More than 20% of patients 65 years of age or older or 5 years of age or younger are sent appropriate reminders</td>
</tr>
<tr>
<td>Provide patients with timely electronic access to their health information (including laboratory results, problem list, medication lists, medication allergies)</td>
<td>More than 10% of patients are provided electronic access to information within 4 days of its being updated in the EHR</td>
</tr>
</tbody>
</table>

*This overview is meant to provide a reference tool indicating the key elements of meaningful use of health information technology. It does not provide sufficient information for providers to document and demonstrate meaningful use in order to obtain financial incentives from the Centers for Medicare and Medicaid Services. The regulations and filing requirements that must be fulfilled to qualify for the Health IT financial incentive program are detailed at www.cms.gov*

**These objectives are to be achieved by all eligible professionals, hospitals, and critical access hospitals in order to qualify for incentive payments.**

**Eligible professionals, hospitals, and critical access hospitals may select any five choices from the menu set.**

---

**Fig. 21.5** Summary overview of Meaningful Use objectives (Blumenthal and Tavenner [14])
of incentive payments, some types of physicians may be more or less inclined or prepared to take advantage of them. Minority physicians or physicians who serve underserved patients may be fast adopters of health IT or, alternatively, may be less likely to adopt it. Encouraging research from the pre-HITECH era – suggests that providers serving racial and ethnic minorities adopt health IT at a rate similar to providers treating nonminorities. However, one study found that some minority patients were less likely to have primary-care physicians using EHRs, compared with privately insured white patients [15]. In addition, surveys of federally funded Community Health Centers showed that CHCs serving the most poor and uninsured patients were less likely to have functional EHRs [16].

The goal of the Office of the National Coordinator for Health IT (ONC) is to ensure that lack of access to health IT does not become a new type of disparity. Accordingly, the ONC has implemented several key initiatives towards this end.

First, the incentive payments available for Medicaid providers are greater than incentive payments available to non-Medicaid providers. Medicaid providers can qualify for up to $63,750 in total incentive payments by achieving Meaningful Use as opposed to the $44,000 maximum for providers who seek incentive payments from Medicare. In addition, unlike providers who become Medicare meaningful users, Medicaid eligible providers can receive $20,000 (out of the $63,750) simply to acquire or upgrade their systems to prepare for becoming meaningful users. Such upfront payments are not available under the Medicare part of the program. The larger and more flexible payments available to Medicaid meaningful users reflect a federal recognition of the greater burdens, financial and otherwise, associated with serving their vulnerable populations.

Second, the Regional Extension Centers are specifically tasked with supporting providers that are more likely to need assistance becoming “meaningful users” of health IT. Pursuant to requirements of the HITECH Act, priority will be given to providers that are primary-care providers (physicians and/or other health-care professionals with prescriptive privileges, such as physician assistants and nurse practitioners) in any of the following settings: (1) individual and small group practices (ten or fewer professionals with prescriptive privileges) primarily focused on primary care; (2) Public and Critical Access Hospitals; (3) Community Health Centers and Rural Health Clinics; and (4) other settings that predominantly serve uninsured, underinsured, and medically underserved populations. Accordingly, greater assistance is available to many of the physicians who care for our most vulnerable patients.

Third, the Health Information Technology Research Center (HITRC) will work with all Regional Extension Centers to form a collaborative learning network (consortium) that is facilitated by the HITRC. Lessons learned by all Regional Centers about effective practices in provider implementation and use of EHRs, and in supporting priority primary-care providers, will be shared through the HITRC across Regional Centers and with the public. As lessons are learned about serving minority providers and providers who serve underserved populations, they will be disseminated to all of the 60 Regional Extension Centers through the HITRC.

Fourth, the ONC is working with the Office of Minority Health in the Department of Health and Human Services to implement a disparities mitigation strategy.
In addition to convening federal officials to focus and advise ONC on issues related to health IT, disparities, and underserved populations, this strategy includes targeted communication to providers about the role of health IT in alleviating disparities; specialized stakeholder engagement around serving minority physicians and underserved patients; and careful tracking of health IT adoption among minority physicians and medically underserved areas.

Finally, the HIT Policy Committee (HITPC) that is chaired by the National Coordinator for Health IT, and advises on the definition of meaningful use, is actively considering the role of health IT in alleviating and managing health-care disparities. Recommendations from the HITPC are likely to influence the definitions of Meaningful Use in stages 2 and 3.

Taken together, these efforts will increase the likelihood that the benefits of health IT are broadly available to the patients and providers who need it most.

Conclusion

In early 2009, President Barack Obama boldly proclaimed, “Now is the time to … computerize the health-care records of every American within five years, saving billions of dollars and countless lives in the process.”

As President Obama suggested, electronic health records have the potential to dramatically improve health-care delivery to all Americans. However, they have particular import for our most vulnerable populations – the poor, the uninsured, and patients who have been historically underserved by our health-care delivery system.

The HITECH Act was written with keen awareness of this potential, and it empowered the Office of the National Coordinator for Health Information Technology (ONC) to ensure that health IT is deployed effectively and evenly for the benefit of all Americans. While the risks of creating new health-care disparities are clear, ONC is proactively implementing solutions to minimize this possibility. The availability of larger incentive payments for Medicaid providers, coupled with access to Regional Extension Support for high-priority providers, is the key element to support the responsible deployment of health information technology throughout the nation.

The test of our success will be in 5 years when we measure and study both whether the benefits of health IT are broadly available to patients and whether it is being effectively used to improve the care delivered to the society’s most vulnerable patients.

References

Chapter 22

Remote Area Medical®: Pioneers of No-Cost Health Care*

Stan Brock and Amanda Wilson

Abstract This chapter explores Stan Brock’s unique system for the delivery of free health care to the underserved in American communities. Readers will learn about the roots of Remote Area Medical®, more commonly known as RAM, and how the organization has developed and expanded programs to serve those in need around the world and in the United States. Over the course of a quarter century, Stan Brock has led numerous teams of volunteer health practitioners to places where basic health care has become inaccessible for those who live there. From the world’s most remote locations to urban landscapes, learn how one man’s dream of providing free care has become a reality.

Keywords Access to medical care • Volunteer doctors, free clinics • Remote Area Medical • RuralAmerica • Reach Across AMerica • Free healthcare delivery • Underserved • Uninsured • Unemployed • Medical • Dental • Vision

When I formed Remote Area Medical® (RAM) in 1985, it was not the culmination of years of academic study, anthropological research, or in-depth analyses of public health systems. Rather, the nonprofit now known to many by the acronym RAM was borne of necessity a half century ago. It was an idea brought forth from desperation, from a survival instinct amplified by time spent in an unforgiving remote location inhabited primarily by tribes who lived and died without the aide of modern medical technology.

*For more information about Remote Area Medical® and our programs, please go to: www.ramusa.org.

To learn more about the origins of Remote Area Medical®, you can read All the Cowboys Were Indians, by Stan Brock.

S. Brock
President/CEO, Remote Area Medical, Knoxville, TN, USA
e-mail: stanbrock@ramusa.org
The Roots of Remote Area Medical®

In 1953, I was an adolescent of British birth and upbringing in a post-World War II era, in search of meaning, or novelty, or myself in British Guiana, South America. As a boy on the verge of manhood, seeking acceptance from the Wapishana Indians on the world’s largest tropical cattle ranch, I found myself fending off sickness, injury, or even death at every turn. In Guyana (as it is now known), the wilderness of the tropical rainforest lies alongside the harsh savannas that accommodate the Dadanawa Ranch, and those two worlds are never entirely separate from each other for the vaqueros (cowboys) who live and work there. The geographical duality of the unfamiliar home I had claimed for myself presented the locals with a host of infectious diseases, insect infestations, and fatal injuries that might be survivable in a more developed culture, but often meant death for my new friends and neighbors. And although I experienced my fair share of near-fatal encounters as a vaquero over the course of the next 15 years – I survived malaria, dengue fever, numerous wild animal attacks, and various encounters with Longhorns and mustangs without the help of a doctor – I can pinpoint the exact moment that the idea for Remote Area Medical® first entered my mind:

I was still relatively new to the ranch, and I was determined to gain the approval of the vaqueros who taunted me daily, only I had chosen to do so by attempting to ride the one wild horse that had already killed two men – his name was Cang, “the Devil.” He was a flea-bitten gray with an ugly head and ears almost as long as a mule’s. He was 700 pounds of kicking, biting, bucking fury, and he did not take kindly to my attempt to ride him. The torturous scene that ensued after I (surprisingly) successfully saddled Cang was a blur of twisting rage, speed, and pain, and took a turn for the macabre when he crashed into an immoveable fence and I was fired with cannon-like force over Cang’s head. I came down hands first, arms akimbo, tucked my chin in, and did a forward roll on my back. Onlookers described Cang’s subsequent headstand as an impressive feat of acrobatics! No doubt I too would have been impressed, only unfortunately for me I was just about to be turned into a human pancake. Seven hundred pounds of bone and muscle came down on top of me with a devastating wallop. The air rushed out of my lungs and I felt my ribs collapse; my vision was a star-spangled sea of red. My ribs were cracked, that I knew for certain. I’d felt them cave in when Cang landed on top of me. To make matters worse, I was 350 miles away from the nearest doctor in Georgetown, and there were only two ways of getting there. One involved a 30-day trek on foot through the forest and the other was by chartered aircraft. Suddenly I felt a pain and fear that compounded my physical aches: the uncertainty of what would happen to me without access to medical care.

Yes, the instinct to survive in such conditions is fierce and not just for oneself. It occurred to me at some point during the encounter with Cang that designing an all-volunteer health and veterinary program for such desolate places might very well make life easier for a whole lot of people. And even after leaving the ranch to pursue other career opportunities, I still yearned to bring to my companions in the remotest regions of Guyana the security of access to doctors and basic medical care. But my vision had expanded – I had visited other countries, other continents, where whole civilizations were left to suffer and die from illnesses that were easily treatable,
Remote Area Medical

if only medical professionals were within reach. I was determined to fulfill my
dream of providing free health care to those in areas where there is no access,
through the efforts of volunteer medical professionals. The organization would cre-
ate a network of volunteer doctors, nurses, dentists, optometrists, and other medical
practitioners who would travel to remote areas of the world and provide free care to
indigenous peoples. By the mid-1980s, I had settled in Tennessee and after years of
reflecting, creating, and revising my dream, I was finally able, in 1985, with the help
of friends and neighbors who shared my goal, to form Remote Area Medical®.

A Dream Transformed

The original intent of Remote Area Medical® was to bring medical care to remote
regions of the world, where access to hospitals and health practitioners was simply not
an option. As such, the organization operated its first expedition in Mexico, among the
Huichol Indians. However, when a local television station in east Tennessee filmed a
short program about what our volunteers were doing in Mexico, local communities
began to take notice. Relatively soon after, I was asked if I would organize a similar
effort in a nearby community, where the local hospital was being closed down, and the
county’s only dentist was leaving town. For these, and a variety of other reasons, resi-
dents were unable to seek the necessary care to address their basic dental needs, and
in 1992, RAM (as we have been called since the founding of the organization) coordi-
nated its first US expedition in Hancock County, TN. While there, a volunteer team of
two dentists, two dental assistants, one nurse, and a small number of general volunteers
treated 52 patients in 2 days, working from two dental chairs.

From that one clinic, word of what RAM had been doing spread like wildfire. Requests for free clinics poured in from surrounding counties, and I quickly realized
that the inaccessibility of health care is not something that affects only the inhabitants
of third-world countries and far-away lands, but it is a very real dilemma for anyone
who cannot afford to pay for a visit to a physician, a dentist, or an optometrist. And
so, Remote Area Medical® embarked upon a new journey – developing a program to
address the needs of those in the rural United States who are unable to obtain basic
dental, vision, and medical care – as a result of multiple factors that often affect the
plight of the socio-economically depressed even in the world’s richest country.

Rural AMerica Program

The primary purpose of the Rural AMerica program was (and still is) to provide
vision and dental care to those in rural communities who are underserved – the unin-
sured and underinsured, the unemployed and underemployed, and those who simply
cannot afford to pay for the rising cost of health care. The roots of RAM’s Rural
AMerica program are planted deeply in Appalachia, where our work began in 1992.
But the need in rural Appalachia quickly began to outgrow the ability to provide
services: RAM has always depended upon volunteers for the services provided at
clinics (or expeditions), and volunteers have always been limited by the amount of time they could offer. To add to the strain placed on those professionals and volunteers already giving their time, expeditions were being requested more often. One major obstacle that stood (and still does stand) in the way of scheduling more clinics was the inability of health practitioners to cross state lines to provide free care.

When the TN legislature became aware of RAM and asked how they could help RAM provide more services at more clinics in the coming years, this licensure concern was brought to their attention. The result of that conversation was the TN Volunteer Health Care Services Act, passed in 1995, which allows a licensed health practitioner from any state to come into Tennessee to provide free care at a clinic conducted by a nonprofit organization. Finally, 10 years after its formation, RAM would begin to grow into the network of volunteer dental, vision, and medical practitioners I had envisioned decades earlier.

By 2007, Remote Area Medical® had expanded its services beyond Tennessee’s borders: clinics were being hosted in Virginia on an annual basis, including the largest regularly scheduled RAM clinic in Wise, VA (a 2½ day clinic). Although Virginia’s laws regarding out-of-state practitioners were not as open as in Tennessee, certain healthcare providers could be recruited from other states to staff the many volunteer positions necessary for executing a successful clinic. Today, the Wise, VA RAM expedition has evolved over the course of 11 years, from a relatively small clinic held in an airport hangar to an expansive clinic held on the county fairgrounds, with an impressive array of medical services made available by the region’s healthcare agencies and providers. It was (and remains) the result of teamwork among volunteers, guided locally by RAM volunteer Teresa Gardner of St. Mary’s Health Wagon.

Overall, the development of the Rural AMerica program has been remarkable. Compared to the first US expedition in Hancock County, TN, our rural weekend clinics can currently treat up to 800 patients in 1½ days, with a team of dozens of volunteer dental, vision, and medical practitioners. Although those who have followed RAM’s progress throughout the years may have noticed the apparent growth of the organization, they were not the only ones.

Reach Across AMerica

RAM expeditions had caught the attention of the long-running CBS television news program “60 Minutes.” In January of 2008, a team of journalists led by Scott Pelley and producers Henry Schuster and Rebecca Peterson attended a RAM clinic in Knoxville, TN. Two months later, the footage they captured aired on CBS, and RAM, known up to that point primarily by a growing number of impoverished folks in southern Appalachia, became known nationwide. In the months that followed, RAM quickly learned that hundreds of thousands of inner city residents were as financially remote from adequate medical care as the most geographically isolated Amazon dwellers. Calls began to come in to RAM Headquarters from across the nation requesting our services, even from as far away as Alaska.
In response to those requests, we have developed the *Reach Across AMerica* program, designed to drastically expand our services. In 2009, RAM responded to a request from Los Angeles, California, and conducted an 8-day clinic there, treating upwards of 6,000 patients – a rather large patient number, but far less than we could have done had California allowed volunteer practitioners to help from outside the state. 2009 also saw RAM return to service among the Native Americans, conducting a clinic in Fort Duchesne, Utah, for the Ute Indian tribe. Since that time, we have returned to California and continue to seek ways to address the complicating issue of practitioners crossing state lines. Fortunately, California legislators, along with some in other states, are recognizing the important work that can be done to improve the health of those in need: California is currently considering legislation to allow out-of-state licensed professionals, and Oklahoma has passed legislation to approve temporary charitable licenses for those certified outside of the state. These programs cost the government and the taxpayer nothing. Although allowing licensed practitioners to freely cross state lines to provide free care for the underserved is not a solution to America’s healthcare crisis, it is a quantum leap in the right direction.

**RAM Expeditions**

In 25 years, RAM has conducted over 600 expeditions, both in the United States and abroad. The nature of the expeditions has varied over the years, based upon needs and resources available. True to its roots, RAM is active in other countries, including Guyana, Haiti, Dominican Republic, Honduras, Guatemala, East Africa, India, Nepal, and others. However, the most frequent expeditions occur in the United States and consist of dental, vision, and basic medical services and take place over the course of a weekend. Each month, volunteers provide these services in communities where RAM has been invited to help. And while each clinic may last only 2–3 days, literally months of hard work go into planning each one.

The host community, a group usually led by a health council or other local organization and guided by experienced RAM personnel, lines up local logistics and volunteers, recruiting as many professionals as possible. Then, the day before the clinic is scheduled to begin, RAM brings experienced volunteer clinic administrators and the necessary equipment to be set up at a prearranged location, often depending upon the help of local nonmedical volunteers. Professional volunteers offer as much time as they are able during the expedition.

**RAM Services**

RAM offers a variety of services at its expeditions, all at no cost to the patient or the taxpayer. Following is a brief description of each of the services provided.
**Dental**

Dental care is one of the most important services offered at expeditions, and RAM’s dental services have provided relief to thousands of patients over the years. Patients often arrive at clinics with serious dental problems that threaten their overall health. However, in a single visit, many of these conditions can be treated and improved. The RAM dental program has evolved from offering only emergency extractions to include restorations, cleanings, and fluoride treatments. Our volunteer network has a number of very dedicated dentists whose hard work helps to make each expedition a success.

**Vision**

Vision care is another key service provided to patients at RAM clinics. This service includes a basic vision screening, refracting, and eye exam. If a patient requires glasses, they receive a prescription and in most cases a brand new pair of glasses made in our mobile eyeglass lab before leaving the clinic. The primary purpose of RAM’s vision care team is to provide people with eyeglasses to improve their present circumstances and to better see the world around them. For some, a pair of glasses may allow them to drive more safely, to gain employment, or to better perform their current job. For others, reading glasses will allow them to read more comfortably or thread a needle for the first time in years. In an effort to determine if there are eye conditions or diseases that require further attention, volunteer ophthalmologists and optometrists perform thorough exams, including intraocular pressure checks to screen for glaucoma.

**Medical**

Because RAM clinics are mobile in nature, the number and type of medical services available at expeditions varies and is usually limited to routine medical screenings, including diabetes testing, mammograms, and pap smears. In some instances, minor surgical procedures can be performed.

**Remote Area Medical Volunteer Corps and the RAM Mission**

In all of its programs, RAM seeks to provide relief to those in need of basic health care – whether that care is dental, optical, or medical in nature. Remote Area Medical® is a 501(c)(3) charitable organization with no paid employees using an airborne force of volunteers dedicated to serving mankind, providing free health care, veterinary services, and technical and educational assistance in remote and rural areas of the United States and around the world. Currently, more than 60% of RAM’s work is done in the United States.
The RAM Foundation

The Remote Area Medical Foundation is a 501(c)(3) publicly supported charity providing administrative and fund raising services for the Remote Area Medical Volunteer Corps. Established in 1996, the Foundation was created to develop a sustainable financial and practical infrastructure designed to carry RAM’s unique methods of free healthcare delivery into the distant future. The RAM Foundation is committed to developing and implementing strategies for the proliferation of Remote Area Medical® programs. Always the aim is to help relieve suffering, cure disease, restore sight, and enhance the lives of thousands of impoverished and isolated people and their animals every year. While the RAM Volunteer Corps will remain all-volunteer, the Foundation’s structure will offer career opportunities in social service and nonprofit management.

RAM Resources

First and Foremost

RAM’s most important resource is our volunteer pool. Over the years, over 48,000 volunteers have participated in RAM expeditions and activities. Also vital to the success of our programs are our donors and supporters, who make it possible for RAM to continue providing free services; it is they who have allowed us to elevate our standard of care to near state-of-the-art, expand our equipment inventory to treat hundreds of people a day, and extend our reach beyond the shadow of the Smoky Mountains of Tennessee. Without the active participation of our volunteers and donors, RAM would still be a dream.

The RAM Fleet

Aircraft

One of the unique aspects of Remote Area Medical® is the ability to use aviation to increase RAM’s effectiveness as providers of no-cost health services to people in need. Using a number of planes, from as large as the C-47/DC-3 to as small as a Cessna 150, RAM can carry people and equipment into areas that are difficult to reach by road. The flagship of RAM’s air fleet is the historic C-47/DC-3 that flew paratroopers to the Normandy landings during the D-Day invasion. It has been used by Remote Area Medical® to carry 6,000 lb of much-needed medical supplies to Baton Rouge and Sulphur, Louisiana, during RAM’s Katrina response expeditions. It has also been used to carry relief supplies to Haiti in the wake of the earthquake
that devastated that country in January 2010. Use of the C-47/DC-3 has been generously donated by Michael Hogan. Other planes include a Beech 18, a Cessna 206, and the most recent addition to the RAM hangar, a King Air C-90. The King Air was donated by Rena and Sami David of New York and allows expedition planners and clinic managers to quickly reach expedition sites.

**Ground Vehicles**

RAM operates a collection of trucks and trailers to move equipment and supplies to and from expedition sites. The *Rural AMerica* and *Reach Across AMerica* programs also operate two mobile optical labs; carry a full inventory of new eyeglass frames along with most common lens prescriptions; and have the equipment and supplies to support 20 vision exam lanes and over 70 dental stations, complete with portable chairs, drill/suction, and various tools and instruments. One of the optical labs is located on the lower deck of RAM’s new *Reach Across AMerica* truck – a retrofitted race care hauler, now used to transport (on its upper deck) the dental and vision equipment and supplies necessary to set up exam stations for a RAM clinic.

**Looking to the Future**

As we reflect upon 25 years of service, we remain mindful of the more than 415,000 patient encounters that have been made possible by the hard work and dedication of nearly 50,000 volunteers, of the 65,000 animals that have received free medical treatment, and of the hundreds of thousands of folks who will queue at our clinics until America finds a solution to the healthcare crisis. We look toward a future of continuing to provide free care to those in need, and we remain hopeful that our ability to do so will increase as restrictions on practitioners crossing state lines decrease. We have seen folks in places like Tennessee, Kentucky, Oklahoma, California, Virginia, Illinois, and elsewhere address this most important issue that affects the capacity to provide free care on a large scale. With the lasting support of volunteers and donors, Remote Area Medical® will continue to expand our free programs until every American and indeed every global citizen is assured access to the medical care their families need.
Chapter 23
Principles for Eliminating Racial and Ethnic Disparities in Health Care Under Healthcare Reform

John Z. Ayanian and Richard Allen Williams

Abstract The elimination of racial and ethnic disparities in health has become a national priority in the United States (U.S. Department of Health and Human Services, Healthy people 2010: understanding and improving health, 2nd ed. Washington, DC: U.S. Government Printing Office, 2000). These disparities have many causes and potential solutions. In the landmark Unequal Treatment report, the Institute of Medicine reviewed and highlighted racial and ethnic disparities in health care as an important factor contributing to disparities in health outcomes (Institute of Medicine, Unequal treatment: confronting racial and ethnic disparities in health care. Washington, DC: National Academy Press, 2002). This report concluded with a strong call for action to eliminate racial and ethnic disparities in the US healthcare system. Since 2003, the federal government has issued an annual National Healthcare Disparities Report to monitor racial, ethnic, and socioeconomic disparities in access to care and quality of care. Whereas the initial report released by the federal Department of Health and Human Services generated considerable controversy and debate about the content and interpretation of key findings (Bloche, N Engl J Med 350(15):1568–70, 2004), subsequent reports have become a useful tool for tracking national trends in disparities across a wide array of quality measures. In 2004, this report found that lower quality of care was experienced by African Americans for two-thirds of measures, by Hispanics for one-half of measures, and by American Indians/Alaskan Natives for one-third of measures (Moy et al., Health Aff (Millwood) 24(2):376–87, 2005).

In this chapter, five principles are presented to guide policy makers, health care leaders, and healthcare professionals seeking to reduce and ultimately eliminate racial and ethnic disparities in health care. These principles are based on clinical and policy experience, the research literature on healthcare disparities, and findings and recommendations of key reports from the Institute of Medicine (Unequal treatment: confronting racial and ethnic disparities in health care. Washington, DC: National

J.Z. Ayanian (✉)
Professor of Medicine and Health Care Policy, Harvard Medical School, Professor of Health Policy and Management, Harvard School of Public Health Boston, Massachusetts, USA
e-mail: ayanian@hcp.med.harvard.edu

Academy Press, 2002) and the American College of Physicians (Groman and Ginsburg, Ann Intern Med 141(3):226–32, 2004). The principles have been refined with input from an advisory committee of clinical and academic leaders in minority health care convened by the Minority Health Institute. The principles address aspects of access to care and quality of care that are especially important for minority populations in the United States, including African Americans, Latinos, Asian Americans, Native Hawaiians and other Pacific Islanders, and American Indians and Alaska Natives. These principles have become more timely and attainable with passage of the federal Patient Protection and Affordable Care Act (PPACA) that was enacted by Congress and signed by President Obama in March 2010.

**Keywords** Health insurance coverage • Medicaid eligibility • Healthcare workforce • Patient-centered care • Racially concordant physicians • Cross-cultural education • Race/ethnicity data • Geocoding • Core aims • Quality improvement • Healthcare Effectiveness and Data Information Sets (HEDIS) • Consumer Assessment of Healthcare Providers and Systems (CAHPS)

**Principle 1: Provide Insurance Coverage and Access to High-Quality Care for All Americans**

Rates of health insurance coverage differ substantially by race and ethnicity for children and adults under 65 years of age in the United States (Fig. 23.1). Compared with white Americans, African Americans, Asian Americans, and Pacific Islanders are about twice as likely to be uninsured, and Latinos, Native Americans, and

![Fig. 23.1 Probability of being uninsured by race and ethnicity, US nonelderly population, 2008](image-url)
Alaska Natives are approximately three times as likely to lack insurance. Nearly all elderly Americans are covered by the Medicare program, but elderly individuals in minority groups are less likely to have private supplemental insurance coverage that enhances access to physicians and hospitals [2].

The adverse consequences of lacking health insurance for individuals, families, and communities have been well documented in a series of reports from the Institute of Medicine and a recent systematic review [3–8]. Uninsured adults and children are less likely to have a regular source of primary care and less likely to receive effective health services. Studies of several national cohorts have demonstrated that uninsured adults experience higher overall mortality rates [9–11] and are more likely to die of conditions, such as hypertension, diabetes, breast cancer, and HIV infection, for which early detection and effective treatment can clearly improve outcomes [10, 12, 13]. Approximately 80% of uninsured Americans are members of working families [4]. However, the proportion of people with no insurance is particularly high among low-income minority families because private insurance is either unavailable to low-wage workers or premiums are prohibitively expensive (e.g. >10% of annual household income). Therefore, public insurance programs, such as Medicaid and the State Children’s Health Insurance Program, play a crucial role in providing coverage for minority individuals.

Under the Patient Protection and Affordable Care Act of 2010 (PPACA), eligibility for state Medicaid programs will be substantially expanded to cover all adults with incomes up to 133% of the federal poverty level. As a result, 16 million low-income adults will become newly eligible for Medicaid by 2014. This expansion will eliminate very inconsistent rules for eligibility that vary widely by state, especially in the South and Southwest where Medicaid eligibility for low-income adults has been historically most restrictive. Expanded and more uniform Medicaid eligibility will be particularly beneficial for African Americans and Hispanic Americans in these regions if the expanded eligibility is coupled with more effective efforts to enroll those who are newly eligible for Medicaid coverage.

Minority Americans will also have improved access to private insurance coverage through new state health insurance exchanges that will be created by 2014 under federal healthcare reform. Gaining insurance coverage is associated with substantial reductions in racial, ethnic, and socioeconomic disparities in control of hypertension, diabetes, and hyperlipidemia [14]. These disparities in risk factors contribute to increased morbidity and mortality from cardiovascular, cerebrovascular, and renal disease among African Americans and Hispanic Americans.

In addition to providing insurance coverage for all Americans, clinicians and hospitals that provide care to minority Americans must be well supported to deliver high-quality care. Because of geographic residential patterns and historical sources of care, approximately 20% of primary care physicians in the United States treat approximately 80% of African American patients [15]. Many of these physicians and their healthcare organizations face barriers to providing optimal care, including larger burdens of uncompensated care, fewer technical resources such as electronic medical records, and less access to high-quality specialists for their patients.
Whereas expanded insurance coverage will provide financial access to a broader range of healthcare providers for many minority Americans who are currently uninsured, these individuals often will continue to seek care from local physicians, health centers, and hospitals that are most convenient and familiar to them. Ensuring that these clinicians and organizations have well-trained personnel and high-quality technical resources, including effective health-information systems, will be important components of systemic approaches to eliminate racial and ethnic disparities in health care. Because undocumented immigrants will not be eligible for expanded public or private coverage under healthcare reform, they will also continue to depend on safety-net organizations such as community health centers and public hospitals that play a substantial role in caring for minority patients.

Many of these organizations rely on federal, state, or local government funding to support health care for poor patients who are disproportionately from minority groups. Therefore, providing resources and training to promote quality improvement in these organizations will have particular benefits for minority patients who are at risk of experiencing health disparities. The Health Disparities Collaboratives sponsored by the federal Health Resources and Services Administration are a tangible example of ongoing efforts to improve quality of care for minority patients served by federally qualified health centers [16]. The Patient Protection and Affordable Care Act will provide $11 billion in additional funding to community health centers between 2010 and 2015. During 2013 and 2014, this Act also authorizes an increase in Medicaid payment rates to Medicare levels for primary care physicians, which will benefit community health centers and public hospitals that care for large numbers of Medicaid patients.

**Principle 2: Promote a Diverse Healthcare Workforce**

Promoting greater diversity in the healthcare workforce can provide a stronger foundation for efforts to eliminate healthcare disparities. African Americans, Latinos, and Native Americans remain substantially underrepresented among physicians and nurses relative to the corresponding proportions of these racial and ethnic groups in the United States. In the 2000 Census, African Americans (12.3%) and Latinos (12.5%) together comprised one-quarter of the US population, but they represented less than one-tenth of all physicians (4.4% and 5.1%, respectively) and only one-eighth of all registered nurses (8.8% and 3.3%, respectively). In 1980, 5.1% of all US medical school graduates were African Americans, and 3.1% of graduates were Latino. By 2007, these proportions have risen modestly to 6.8% and 6.7%, respectively [17], but they still represent only about half of the corresponding proportions of African Americans and Latinos in the US population. To address gaps in the diversity of the healthcare workforce, systems of primary, secondary, and university education must ensure that their minority students are well prepared and inspired to pursue healthcare careers.
A more diverse healthcare workforce could help to reduce disparities in several ways. First, minority physicians and nurses are more likely to have had personal experiences of healthcare disparities in their own lives or through the experiences of family members and friends. Such experiences can have a galvanizing effect on their professional careers, motivating them to lead efforts to address disparities in their healthcare organizations and communities. Second, by sharing their insights about how racial and ethnic disparities in care arise with colleagues who are white or international medical graduates (and thus less familiar with the experiences of minority Americans), minority health professionals can help to promote shared efforts to provide more equitable care. Third, a more diverse workforce can offer minority patients greater opportunities to be treated by a clinician of the same racial or ethnic group if they prefer this option for cultural or linguistic reasons.

Some evidence suggests that minority patients rate the quality of their communication with racially concordant physicians more highly [18, 19]. One study has found that African Americans and Latino patients who perceive discrimination in the healthcare system are more likely to prefer a physician of their racial or ethnic group, and patients who prefer racially or ethnically concordant physicians are more satisfied if they have one [20]. However, evidence is limited about whether minority patients experience more appropriate technical quality of care or better health outcomes when treated by racially or ethnically concordant physicians. In a study of white and African American patients hospitalized for acute myocardial infarction, comparably lower rates of cardiac catheterization were experienced by African American patients whether their attending physicians were white or African American [21, 22]. Further research will be needed to determine whether improved communication is consistently found when minority patients are treated by physicians of their own racial or ethnic group and whether this improved communication is associated with more appropriate treatment and better health outcomes.

Promoting greater opportunities for minority Americans to pursue professional careers in health care is an essential goal. It is also important to recognize, however, that most minority patients will continue to be treated by health professionals of a different racial or ethnic group, even if minority enrollment in health professional schools and training programs was immediately and substantially increased. Therefore, health professionals of all racial and ethnic groups must develop the skills to provide care effectively for the increasingly diverse US population.

Principle 3: Deliver Patient-Centered Care

Patient-centered care is a core aim of high-quality health care as defined by the Institute of Medicine in its Crossing the Quality Chasm report [23]. Moreover, a focus on patient-centered care may be one of the most important tools for achieving equitable care. Components of patient-centered care include treating all patients with respect, understanding their expectations and preferences, ensuring they are fully informed
and offered appropriate treatment options, responding promptly to symptoms, and providing well-coordinated care [24, 25]. Recent research on these patient-centered domains indicates that nonwhite patients and non-English-speaking patients face an increased risk of suboptimal care. Among patients with colorectal cancer in California, African American, Latino, and Asian/Pacific Islander patients reported significantly more problems with coordination of care, the strongest correlate of lower ratings of quality of care for all racial and ethnic groups [24, 26]. Patients in this study who did not speak English at home reported even more problems with their cancer care.

Implementing standards for culturally appropriate care in healthcare organizations and training healthcare professionals to interact effectively with patients of varied racial and ethnic backgrounds are key elements of patient-centered care. In 2001, the federal Office of Minority Health released national standards for cultural and linguistically appropriate services (CLAS) in health care [27]. These 14 standards were developed to guide healthcare professionals and organizations in caring for patients of varying cultural backgrounds, particularly those with limited English proficiency. The CLAS standards emphasize culturally competent care, language access services, and organizational supports for culturally competent care. The importance of professional translation services (as required by federal law) is underscored in the CLAS standards, recognizing that language barriers are an especially significant contributor to disparities in quality of care.

Cross-cultural education and cultural competency training have become more prominent over the past decade in medical schools, residency programs, and continuing education programs for health professionals [28], but evidence for the effectiveness of such programs to improve care for minority patients and reduce disparities is not well developed [29–32]. Three states (New Jersey, California, and Washington) have passed legislation mandating cultural competency training for healthcare professionals as a requirement for licensure renewal, and other states are contemplating similar legislation. Programs that provide a sustained focus and support for cultural competency are more likely to have lasting effects than brief programs that merely introduce the concepts of cultural competency without ongoing support for healthcare students and professionals.

**Principle 4: Maintain Accurate and Complete Race/Ethnicity Data to Monitor Disparities in Care**

Effective measurement is a cornerstone of efforts to monitor and improve the quality of care. Healthcare organizations must have data on their patients’ race and ethnicity to determine whether the quality of care is equivalent across racial and ethnic groups [33, 34]. Furthermore, data on patients’ race and ethnicity are essential to assess whether programs and incentives that are implemented to improve the quality of care are also effective in reducing disparities.

A number of data systems have been developed in recent years to monitor the quality of care in hospitals and health plans [35–37], but many of these systems do not require the collection of race, ethnicity, and language data that could be used to
monitor disparities in care. Healthcare organizations that are responsible for improving care often do not have the capacity to assess disparities in their own patient populations [34]. Many healthcare organizations have not consistently recorded patients’ race and ethnicity because of concerns that collecting these data may be legally unacceptable or that it could be offensive to some patients [38]. Among organizations that have collected patients’ race and ethnicity, these data have often been recorded by clerical or administrative staff based on patients’ physical appearance, rather than from patients’ own reports of their race and ethnicity. Similar inconsistencies have occurred in racial and ethnic data obtained for federal and state healthcare programs [39]. In the enrollment database of the Medicare program, for example, racial designations of white and African American beneficiaries are very accurate, with sensitivities of 97% and 95%, respectively, when compared with self-reported data in the Medicare Current Beneficiary Survey. However, the designations for Hispanic, Asian, and Native American beneficiaries are much less accurate [40].

Healthcare providers, hospitals, and health plans have a crucial role to play in consistently collecting self-reported race and ethnicity directly from patients [16, 34]. In 2007, Massachusetts began requiring hospitals to collect race, ethnicity, and preferred language from patients [41]. In 2009, the Institute of Medicine strongly endorsed collecting these standardized data in all healthcare organizations [42]. Most patients are willing to report their race and ethnicity to healthcare organizations if they understand that this information will be used to monitor and improve the quality of care [43]. Beginning in 2012, all federal health care and public health programs will be required to collect and report data on the race, ethnicity, and primary language (along with sex and disability status) of their applicants and participants as specified in the Patient Protection and Affordable Care Act.

Public and private agencies that accredit healthcare organizations, such as state health departments and the Joint Commission, have the potential to accelerate the collection of race, ethnicity, and language data from patients by making it a standard data element during accreditation reviews. For organizations that are not yet able to collect their patients’ race and ethnicity routinely, geocoding of residential addresses can be used to identify the predominant racial or ethnic groups in patients’ census tract or block group [44]. Such geocoding is most useful to identify African Americans who live in predominantly African American neighborhoods [45]. For Asian American and Latino patients, analyses of surnames are another method for determining race and ethnicity with reasonable accuracy [45, 46].

**Principle 5: Set Measurable Goals for Improving Quality and Ensure That Goals Are Achieved Equitably for All Racial and Ethnic Groups**

In its *Crossing the Quality Chasm* report, the Institute of Medicine identified equitable care as one of six core aims for high-quality healthcare systems [23]. Equitable care was defined as “care that does not vary in quality due to personal
characteristics, such as gender, ethnicity, geographic location, or socioeconomic status.” In this report, equity was emphasized as a crosscutting aim that should be applied to each of the other five core aims, including effectiveness, efficiency, patient-centeredness, timeliness, and safety. However, despite a steadily growing national emphasis on measuring, monitoring, and improving the quality of health care over the past decade, most quality monitoring and improvement programs have not included an explicit focus on disparities or equity. By focusing on inequalities in quality, the elimination of healthcare disparities will become a higher priority on the national health policy agenda [34, 47].

Several recent studies have demonstrated that broad efforts to improve quality – without tailoring for specific racial and ethnic groups – have been successful in enhancing quality for specific indicators related to processes of care. With improvements in overall quality, disparities in some of these process indicators have been substantially narrowed or eliminated for patients with reasonable access to care. Examples of these concomitant effects on quality and disparities have included hemodialysis dosing [48], diabetes testing [49, 50], use of β-blockers after acute myocardial infarction [50], assessments of ventricular function and use of angiotensin-converting-enzyme inhibitors or angiotensin receptor blockers for congestive heart failure [51], and adjuvant chemotherapy for colon cancer [52]. However, some studies have also demonstrated that measures of clinical outcomes have not improved as steadily, particularly for African American patients. Less effective control of glucose, blood pressure, and cholesterol has been observed for African American patients relative to white patients with diabetes mellitus, hypertension, or heart disease [14, 49, 50, 53]. Similarly, among patients with end-stage renal disease, hematocrit and serum albumin levels have remained significantly lower for African Americans than for whites [48]. These and other differences in clinical outcomes contribute to the substantial racial disparities in life expectancy for African Americans relative to white Americans [54, 55]. Racial disparities in mortality related to hypertension, diabetes, ischemic heart disease, and HIV infection – conditions that have highly effective treatments – together account for 40% of the disparity between African Americans and whites in life-years lost before age 75 [56].

Distinguishing differences in quality and outcomes by race and ethnicity between and within healthcare organizations is an important priority for disparities research [57]. If racial disparities arise primarily because minority patients are treated in lower quality hospitals or ambulatory practices, then efforts to eliminate disparities must focus on improving care at these sites or making other sites that provide better quality of care more accessible to minority patients. Alternately, if racial disparities exist within a wide range of healthcare organizations, then more systemic solutions will be required to help most healthcare organizations care for minority patients more effectively.

Over the past 15 years, well-validated systems for measuring the quality of health care have been widely disseminated. These systems include the Healthcare Effectiveness and Data Information Set (HEDIS) developed by the National Committee for Quality Assurance (http://www.ncqa.org) to measure the clinical quality of care and the Consumer Assessment of Healthcare Providers and Systems
(CAHPS) developed by the federal Agency for Healthcare Research and Quality (http://www.cahps.ahrq.gov) to assess the quality of patient-centered care and communication. These measures, as well as other measures of healthcare quality and outcomes for specific conditions and procedures, represent important tools for monitoring and addressing disparities in care, particularly if they can be stratified by patients’ self-reported race and ethnicity.

Recent studies have begun to distinguish the varied impact of racial disparities in care that occur between and within healthcare organizations for different types of services or outcomes. Differences between hospitals that serve larger and smaller proportions of African American patients are a major factor contributing to disparities in hospital-based services for cardiovascular disease or cancer [58–62]. In contrast, racial and ethnic differences in clinical outcomes of major chronic conditions in primary care, including control of glucose and cholesterol for patients with diabetes and control of blood pressure for patients with hypertension, are more pervasive in the general population [14] and across both higher and lower quality health plans and medical groups [49, 53].

An important focus for future research is to identify the strengths and limitations of quality improvement programs and their impact on racial and ethnic disparities in quality of care and clinical outcomes across a wide range of organizations, geographic areas, and medical conditions. Particular emphasis should be placed on developing, evaluating, and disseminating programs that are successful in improving the health outcomes of minority patients, thereby reducing or eliminating racial and ethnic disparities in these outcomes (Table 23.1). Numerous organizations in the United States have interrelated missions to develop evidence-based quality measures, monitor the quality of healthcare organizations and providers, and promote quality improvement in health care. Examples of these organizations include the National Committee for Quality Assurance, National Quality Forum (http://www.qualityforum.org), Joint Commission (http://www.jointcommission.org), and Quality Improvement Organizations funded by the Centers for Medicare and Medicaid Services to evaluate and promote the quality of health care for Medicare beneficiaries. The National Committee for Quality Assurance, for example, has recently launched a program to accredit health plans that excel in multicultural health care by providing culturally and linguistically appropriate services and reducing healthcare disparities. By embracing and explicitly linking their efforts to improve care with a focus on inequities in care, these organizations could play a substantial role in reducing healthcare disparities.

Table 23.1 Principles for eliminating racial and ethnic disparities in health care

<table>
<thead>
<tr>
<th>Principle</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Provide insurance coverage and access to high-quality care for all Americans</td>
</tr>
<tr>
<td>2. Promote a diverse healthcare workforce</td>
</tr>
<tr>
<td>3. Deliver patient-centered care</td>
</tr>
<tr>
<td>4. Maintain accurate and complete race/ethnicity data to monitor disparities in care</td>
</tr>
<tr>
<td>5. Set measurable goals for improving quality and ensure that goals are achieved equitably for all racial and ethnic groups</td>
</tr>
</tbody>
</table>
Conclusion

The five principles presented to eliminate racial and ethnic disparities in health care can be implemented at multiple levels of the US healthcare system by federal and state governments, health plans, hospitals, medical groups, and healthcare professionals. Disparities in health have deep social and economic origins related to discrimination, segregation, and socioeconomic deprivation across generations of American society and the life course of individuals. Healthcare professionals and leaders can begin to redress these disparities in health by ensuring that high-quality health care is provided equitably regardless of patients’ race or ethnicity.

References

Index

A

ABSMs. See Area-based socioeconomic measures
ACCME. See The Accreditation Council for Continuing Medical Education
The Accreditation Council for Continuing Medical Education (ACCME), 353
African Americans (AA)
CHD, 50–53
CVD
carotid endarterectomy, 57–58
hypertension, 57
stroke, 57
death gap, 49
diseases, 50
DM
features, 56–57
prevalence, 56
ESRD, 58
HF
A-HeFT, 55–56
black vs. white, 55
drug combination, 56
hypertension
age-adjusted percentage of persons, 53–54
prevalence, 53–54
treatment, 54
infant mortality rate, 48
life expectancy at birth and 65 years, 48
median age of blacks, 49
medical attention, 50
possesson, health insurance, 49
poverty, 49
premature death, 48–49
profile, 47

Agency for Healthcare Research and Quality (AHRQ)
creation, 340
customers, 341
NHDR, 343
NHQR findings, 342
reporting to the nation, 341–342
research priorities, 341
A-HeFT. See The African American Heart Failure Trial
AHRQ. See Agency for Healthcare Research and Quality
AIAN. See American Indians/Alaskan Natives
Aircraft fleet, RAM, 419–420
AMA. See American Medical Association
American Academy of Family Physicians (AAFP), 157
American Academy of Pediatrics (AAP), 157
American Indians/Alaskan Natives (AIAN)
health status, 62, 63
obesity and hypertension, 62–63
YPLL, 62
American Medical Association (AMA), 154–155
American Reinvestment and Recovery Act (ARRA), 131, 159
American Society of Clinical Oncology (ASCO), 13
An American Health Dilemma, 8
APIA. See Asian/Pacific Islander Americans
Area-based socioeconomic measures (ABSMs)
census-derived, 280
evaluation criteria, 277–278
interpretation, 276
Public Health Disparities Geocoding Project, 280
use, 273
ARRA. See American Reinvestment and Recovery Act
ASCO. See American society of clinical oncology
Asian/Pacific Islander Americans (APIA) health problems
  cancer, 59–60
  cardiovascular disease, 60–61
  diabetes mellitus (DM), 61
  Hepatitis B, 60
  mortality, 61
  stroke, 61
  tuberculosis, 60
  longevity, 58–59
  population in cities, 59
  in US population, 58
Association of Black Cardiologists (ABC)
  CIT Program, 353–354
  financial status, 353
  initiatives
    community education projects, 354–355
    participation in clinical trials, 355–356
  internal structure
    CCEPD, 353
    membership body, 352
    women’s center, 352
    member participation and volunteer involvement, 356
  non-profit organization, 352
Asthma disparities
  CHW home visits
    Seattle-King County Healthy Homes I Project, 362–367
    Seattle-King County Healthy Homes II Project, 367–368
  home-based education, 361
  housing
    BEH Program, 371–376
    Better Homes for Asthma Project, 369–371
  results
    healthy housing, 378–379
    home visits by CHW, 376–378
    Seattle healthy homes projects, 362
    substandard housing, 361

B
  Bayes theory, 102
  Better Homes for Asthma Project
    assessment, 369
    intervention, 369–370
  limitations, 370–371
  participants and selection of homes, 369
Breast cancer, African American women
  health-care reform impact, 395
  prevention, 386
  screening, 386–387
  solutions
    awareness, therapies, 393
    biological factors, 394–395
    health education, 393
    oncology, 394
    research, 395
  treatment
    National Cancer Institute SEER database, 389–390
    NSABP, 387–388
    SWOG, 387
    triple-negative, 388–389
Breathe Easy Homes (BEH) Program
  BuildGreen, 373
  design and construction elements, 373, 374
  features, 373
  high point community, 371–372
  home visits by CHWs, 375
  HOPE VI, 371
  intervention effects, 375–376
  participants, 372
  recovery ventilation system, 374

C
  CABG. See Coronary bypass surgery
  Cardiologists-in-training (CIT) program, 353–354
  Cardiovascular disease (CVD), 57–58
  CCEPD. See The Center for Continuing Medical Education and Professional Education
  CDC. See Centers for Disease Control and Prevention
  Census tract (CT)
    data, 278
      lung and cervical cancer, 302
      PAF and poverty, 302–303
      poverty measure use
        data sets, 281–282
        ecological fallacy, 282
        etiological period, 282–283
        omitted variables and selection bias, 283
  The Center for Continuing Medical Education and Professional Education (CCEPD), 353
Index

The Center for Linguistic and Cultural Competency in HealthCare (CLCCHC), 345
Centers for Disease Control and Prevention (CDC), 332, 336
Centers for Medicare and Medicaid Services (CMS), 155, 157, 216, 221
CER. See Comparative Effectiveness Research
CHAT. See Community Health Advocacy Training
CHC. See Community Health Centers
CHD. See Coronary heart disease
Children’s Health Insurance Program (CHIP), 151
CHIP. See Children’s Health Insurance Program
CHWs. See Community health workers
CI. See Confidence interval
CIT. See Cardiologists-in-training
CLCCHC. See The Center for Linguistic and Cultural Competency in HealthCare
Clinical decision-making, prescriptive theory emerging evidence, 103–104
heuristics/clinical gestalts, 102
prejudice and discrimination process, 103
race-based unconscious bias, 104
social cognitive theory, 102–103
Community Health Advocacy Training (CHAT), 355
Community Health Centers (CHC), 158–159
Community health workers (CHWs), 204, 362
Comparative effectiveness research (CER), 159
Confidence interval (CI), 301
Coronary bypass surgery (CABG), 88
Coronary heart disease (CHD) age-adjusted risk factors, 51
death rates, 51
morbidity and mortality, 51–52
non-Hispanic blacks, 50–51
obesity, 52–53
CT. See Census tract
Cultural diversity in, medicine American population AA, 47–58
AIAN, 62–63
APIA, 58–61
HA, 44–47
race and ethnicity categories, 42–43
defined, 42
CVD. See Cardiovascular disease

\(D\)
Daichi Sankyo Incorporated (DSI), 355
Department of Health and Human Services (DHHS), 317, 336–337
DHHS. See Department of Health and Human Services
Diabetes mellitus (DM), 56–57
Diabetes quality improvement project (DQIP), 343
Disparities health care, racial/ethnic awareness and education, 105–106
clinical practice, 100
evidence-based interventions, 107
and limited-English proficiency, 101
mistrusts, 103
physician care, 101
quality of care, 98
systematic examination, 109
track and monitor, 106
Diversity benefits, health professionals accountability, 188
bridge programs, 186
categories, 169
complex factors, 188–189
educational pipeline, 185
financial aid, 186
institutional policies and practices, 187
IOM, 168
leadership, 188
minorities baby boom generation ages, 179
diversity experiences, 182
healthcare providers, 180
medical conditions and treatments, 181
racial and ethnic
minority community, 179
research and health policy benefits, 180
training, 181
nation’s health workforce, 183–184
programs and funders, 184
racial and ethnic, minority patients African American and Hispanic physicians, 176
financial challenges, 178
logistic regression used, 177
nationwide survey, household, 176
primary care physicians, 177
research focused, 175
racial concordance medical encounter, 170–174
stereotypes and bias, medical care, 174–175
Diversity benefits, health professionals (cont.)
  stakeholder organizations, 189
strategy, 182–188
Sullivan Commission
  IOM compelling interest reports, 185
  report, 183
US Health Care Workforce, 183
US Health Profession, 182–183
US Secretary of Health and Human
  Services, 168
DM. See Diabetes mellitus
DQIP. See Diabetes quality improvement
  project
DSI. See Daichi Sankyo Incorporated

E
Ecosocial theory, 273
EDs. See Emergency departments
EHR. See Electronic health records
Electronic health records (EHR)
  adoption, 400
discretionary programs, 404, 405
HITRC, 410
physicians reports, 404
Electronic medical records (EMR), 356
Emergency departments (EDs), 30–31
EMR. See Electronic medical records
EMR/EHR functional system, 405
End-stage renal disease (ESRD), 58
EPC. See Evidence-based
  practice center
Epidemiologic profiles, racial and ethnic
  disparities
accessibility and care quality
  effectiveness, 34
  health insurance, 34
  minority groups, 34, 36
  NHQR and NHDR, 34, 35
chronic diseases, 28–30
Healthy People 2010
  definition, 25
  goals, 25
life expectancy and mortality
  U.S. population, 26–28
  YPLL, 26, 27
limitations and challenges
  AIAN, 36
genetics and gene-environment
  interaction, 36
  legion and complex, 36
  misclassification, 34, 36
morbidity and life quality
  EDs, 30–31
  “healthy days,” 31
  hospital admissions, 28
  hospitalization prevalence, 28, 30
risk factor differences
  cardiovascular, 31
  CRP men, 32
death causes, 29–31
  NHANES, 31
  “no physical activity,” 31
  obesity, US adults, 32
unique opportunities
  interventions effect, 37
  policy and environmental changes, 36–37
USA
  classification, 24
  projected population, 24, 25
Equality Health Care Council, 324
ESRD. See End-stage renal disease
Evidence-based medicine (EBM)
decision-making considerations
  capacity, 118–119
diagnostic tests, 118
evidence strength, 119
limitation, 119
drug reviews and health coverage policy,
  application
  clinical flexibility and judgment,
    PDLs, 125–126
drug reviews, 122–123
  individualized medicine goals, 124
external validity
  deficiencies, 119–120
  minority physicians
    and researchers, 122
  protocols, 119
  racial and ethnic health-care
    disparities, 120
  systemic lack of attention,
    121–122
healthcare disparities, application
  APHA, 129–130
  and fragmentation, 128
Healthy People 2010 program,
  128–131
policy tool, 127
minority health
  conceptual framework, 117–118
  growing utilization, 118
racial health disparities, national dilemma
key variables, 116
receive reperfusion therapy and
coronary angiography, 116–117
surgical procedures, 117
Evidence-based practice center (EPC),
122–123
External validity, EBM implications
deficiency, 119–120
durable theoretical frameworks, 122
minority groups
classes of drugs,
120–121
physicians and
medical researchers, 121
therapeutic trial evidence, 120

F
Federally Qualified Health Centers
(FQHCs), 158
FQHCs. See Federally Qualified Health
Centers

G
GRADE. See Grades of recommendations,
assessment, development and
evaluation
Grades of recommendations, assessment, development and evaluation
(GRADE)
decision-making process, 125–126
racial and ethnic
minority populations, 130
Great Chain of Being theory, 9

H
HBCUs. See Historically Black Colleges and
Universities
HBMSs. See Historically Black Medical
Schools
Healthcare and race politics
solutions
electoral alchemy, 83
healthcare insurance, 82
Kabuki quality, 83
Liberals role, 83
polarization, 84
universal medical coverage, 82
straw men
clinical circumstances variations, 75
discrimination and racism, 76
insurance coverage and
ability to pay, 73
minority physicians’ beliefs and
attitudes, 75–76
uncertainty and discretion, 73–75
subsidies and morals
AA, 79, 82
actuarial fairness, 80
antidiscrimination laws, 79–80
auto insurance, 80
cross-subsidies, 80
differentials cost, 78–79
healthcare disparities, 78
heuristics reasoning, 81
payers and providers, 79
physician reliance, 81
racial disparities and differences, 77,
80–81
social Subscriptport availability, 82
stresses and medical treatments, 81–82
Health Care Antidiscrimination Act
adequate fines and regulatory
enforcement, 327–328
authorization and fund, medical testers,
322–323
data collection and reporting, 325–326
Equality Health Care Council, 324
health report card, 326–327
prevailing party attorney fees, 324
private and organizational right, 323
punitive damage, 324–325
recognition, multiple forms, 322
United States Commission
on Civil Rights, 321
Health care disparities elimination
African Americans and blacks, 234
communities initiative
advantages, genuine partnerships, 201
asthma, 206
breast and cervical cancer, 206
collaboration, 201–202
community-based intervention, 200,
204–205
diabetes, 205
health issues, 201
key principles, community
development, 200–201
poverty and racism elimination, 200
tobacco control, 205–206
communities role, health status
determination
health care services, 198
natural and built environment, 198
neighborhood factors, 197
Health care disparities elimination (cont.)

- nutritious and reasonably priced food, 198
- Subscribermarkets, 198
- urban and rural areas, 197–198

community and societal factors

- lack of insurance, 237–238
- lower quality providers, 237

definition, 196–197

disparities, health

- African Americans vs. whites, 232–233
- minority groups and SES, 233
- racism and social exclusion, 233–234

engagement communities strategies

- action model, 203
- CHWs, 204
- faith-based initiatives, 204
- residents organization, 202
- stakeholders convention, 202–203

ethnicity and race data, 254

factors, 196, 200

Hispanics, Pacific Islanders and Alaska Natives, 234–235

identification, 254

intervention implementation, 254–255

organizational factors, 236–237

patient factors, 235, 238

provider factors, 236

QI

- initiatives, 253–254
- role, 238–240
- tools, 240–244

race, ethnicity and socioeconomic status, 234

reports, 232

socioeconomic factors

- health care services, 199
- income and poverty, 199
- social relationships, 200

successful models

- adult immunization, 250
- cancer screening, diagnosis and treatment, 246–247
- childhood immunizations, 245
- Chlamydia screening, 245–246
- condition-specific interventions, 244–245
- depression management, 247–248
- diabetes management, 250
- dialysis, 251
- hypertension control, 248–249
- interpreters use, 252
- liver transplantation, 251

pay-for-performance, 252

provider bias, 251–252

Will and resources, 252

Healthcare disparities, potential impact

- breast cancer mortality, 215

narrowing

- health care methods improvement, CMS, 216
- “‘minority’ maxim” approach, 216

neutral impact

- caring quality improved, 216
- patient-physician communication, 215–216

widening

- minority patients care, physician/health care organization, 217
- patients implementation, 216–217
- small/solo practices, organization, 217

Healthcare disparities spectrum

- discrimination, patients assessment, 90
- ethnic and racial differences
  - health insurance status, 87
  - medical management, 88–89
  - patient/provider interaction, 89–90
  - function, segregation, 91

IOM conceptual model, 86–87

socioeconomic status, 91

Health disparities

challenges

- cultural and linguistic competency, 345
- health reform, 345–346
- HIT, 344–345

measures and data collection, 343–344

core measures, 330

DHHS, 336–337

eliminating disparities

- emergence of quality, 340–343
- States’ roles, 337–339

governmental programs

- HBCUs, 339–340

minority education initiatives, 340

life expectancy, 330

minority health issues

- IHS, 331
- Tuskegee syphilis experiment, 331–333

NHDR, 330

OMH, 334–335

racial/ethnic

- consistency and equity of care, 117
- GRADE, considerations, 125–126

minority trial data, 120
morbidity and mortality, risk, 124
policy-setting capacity, 129–130
Secretary’s task force
advisory groups, 333
DHHS and NIH, 333
recommendations, 333–334
Health information technology (HIT) approaches
practice level information management, 401–402
provider decision-making, 402
efforts to minimize disparities
ONC goal, 410–411
risk, 408, 410
EHR adoption, 400
fragmentation, 402–403
HITECH Act Programs, 404–408
Meaningful Use stages, 408, 409
Subscriptport, patient engagement, 403–404
Health Information Technology Research Center (HITRC), 410
Health insurance status, 87
Health literacy assessment
REALM and S-TOFHLA test, 137
screening and preventive behaviors, 138
sociodemographic covariables, 137–138
governmental and organizational remedies
daily strategies, patients, 140
emphasis, 141
facilitate improvement, 141
potential intervention, 140
utilizes and assumes, numeracy level, 139
status and scope, 136–137
Health plan employer data and information set (HEDIS), 343
Health professions educational institution (HPEI)
IOM and Sullivan Commission reports, 187
leadership, 187
Health reform law and healthcare disparities
cost-effective, 148
eliminating disparities, 147–148
minority-related areas, identification
affordability and health insurance coverage, 151–152
AIAN, 153
cultural competency, 159
data collection and reporting, 150–151
empowerment community, 153–154
expansion and improvement, CHC, 158–159
health professions, diversity, 156–157
higher education, 154
HIV/AIDS combating, 159–161
itemized provisions combating, 149–150
literacy, health, 152–153
medical home model, 157–158
minority health, 155–156
patient-centered research, 159
racial and ethnic minorities, 148
wellness, health promotion and disease prevention, 161–162
workforce, improvement, 154–155
objectives, 147
racial and ethnic minorities, 146
vital signs, 162–164
Health Resources and Service Administration (HRSA), 336–337
Heart failure (HF), AA, 55–56
HEDIS. See Health plan employer data and information set
HHANES. See Hispanic Health and Nutrition Examination Survey
Hispanic Americans (HA)
age-adjusted heart disease death rates, 45
health insurance, 46–47
health status, 47
HHANES, 45
Hispanic/Latino profile, 44
Hispanic paradox, 45
NHANES II, 46
risk for diseases, 45–46
socioeconomic factors, 45
Hispanic Health and Nutrition Examination Survey (HHANES), 45
Historically Black Colleges and Universities (HBCUs), 339–340
Historically Black Medical Schools (HBMSs), 156
Historical perspectives
An American Health Dilemma, 8
black skin remedies, 10
Crania Americana, 10–11
fifty centuries of blacks, medicine
physicians, 14–15
slaves, 14
governmental involvement, blacks
insurance coverage, 16–17
municipal medical centers, 16
“separate but equal,” 15–16
stereotypes and attitudes, white physicians, 17–18
Historical perspectives (cont.)

Tuskegee syphilis study, 18
 twentieth century and sharecropping, 17
Hottentot Venus, 9
ideal physical features, 11
origin of species, 8–9
racial and ethnic differences, disease expression
blacks vs. whites, 18
pulmonary arterial hypertension study, 19
Textbook of Black-related Diseases, 18–19
reconstruction/deconstruction
emancipation proclamation, 12–13
Freedman’s Bureau and carpet-baggers, 13
“Negro sanitarians,” 13–14
shackles and chains
The Bell Curve, 12
Dred Scott case, 11–12
United States Census of 1840, 12
single-origin theory, 9–10
skin color and slavery, 8
skull specimens, 10–11
Systemae Naturae, 9

HIT. See Health information technology
HITECH Act Programs
EMR/EHR functional systems, 405
health IT adoption, 405
limitations, implementation and interventions, 406
NAMCS, 404
ONC Program, 407
stages, Meaningful Use, 406, 407
structure, 404, 405

HITPC. See HIT Policy Committee
HIT Policy Committee (HITPC), 411
HITRC. See Health Information Technology Research Center
HPEI. See Health professions educational institution
HRSA. See Health Resources and Service Administration
Hypertension Detection and Follow-up Program, 249

I
IAT. See Implicit association test
IHS. See Indian Health Service
Implicit association test (IAT), 103–104
Indian Health Service (IHS), 331

Institute of Medicine (IOM)
conceptual model
minorities and non-minorities
quality, 86
unequal treatment and access/utilization, healthcare, 86
leadership, 188
Sullivan Commission reports, 187
International society on hypertension in blacks (ISHIB), 54

IOM. See Institute of Medicine
IOM unequal treatment reports
cardiac diagnostic and therapeutic, utilization, 98
clinical practice aspects
decision-making, prescriptive theory, 102–104
mistrust, health-care providers, 104–105
provider-patient communication, 100–102
convention committee, 99
disparities health care recommendations
awareness and education, 105–106
cross-cultural education, 109
guidelines and quality improvement, 107
language interpretation services, use, 108
underrepresented minorities, proportion, 108
utilization data, 106–107
patient-based approach, interactions, 109
renal transplantation, treatment, 98
streams evidence, 99–100

ISHIB. See International society on hypertension in blacks

L
LEP. See Limited-English proficiency
Limited-English proficiency (LEP), 101

M
Meaningful Use
stages, 408, 409
structure, 407, 409
Minority health issues, health disparities
IHS, 331
Tuskegee syphilis experiment
CDC and DHHS, 332
treatment programs, 332
USPHS, 331–332
Monitoring socioeconomic determinants, healthcare disparities 
data, politics and health inequities, 307 
project implications, 305–307
Public Health Disparities Geocoding Project
ABSMs, 273
data availability, 272
ecosocial theory, 273
historical context, 274–276
study design and key results, 276–305
Motor/ground vehicles fleet RAM, 420
MyThedaCare, 404

N
The National Adult Literacy Survey (NALS), 152
National Center for Health and Health Disparities (NCMHD), 155
National Committee for Quality Assurance (NCQA), 253
National Health and Nutrition Examination Survey (NHANES), 31
National Healthcare Quality Report (NHQR), 34, 341
National Health Disparities Report (NHDR), 34, 341
National Heart, Lung and Blood Institute (NHLBI), 355
National Institutes of Health (NIH), 155, 337
National Surgical Adjuvant Breast and Bowel Project (NSABP), 394
The Nationwide Health Information Network (NHIN), 403
Native Hawaiian or Pacific Islanders (NHOP), 146
NHANES. See National Health and Nutrition Examination Survey
NHANES II. See Second National Health and Nutrition Examination Survey
NHDR. See National Health Disparities Report
NHIN. See The Nationwide Health Information Network
NHLBI. See National Heart, Lung and Blood Institute
NHQR. See National Healthcare Quality Report
NIH. See National Institutes of Health
NSABP. See National Surgical Adjuvant Breast and Bowel Project

O
OCR. See Office of Civil Rights
Office of Civil Rights (OCR), 317, 319
Office of Minority Health (OMH)
educational and resource activities, 334
funding activities, 335
programs and initiatives, 335
Office of the National Coordinator (ONC)
HIPTC, 411
HITRC, 410
incentive payments, 410
Regional Extension Centers, 410
ONC. See Office of the National Coordinator

P
PAF. See Population attributable fraction
PAOD. See Peripheral artery occlusive disease
Patient centered medical homes (PCMHs), 158
Patient Protection and Affordable Care Act (PPACA)
authorizations, 163
meritorious aspect, 164
Public Health Investment Fund, 154
Patient Protection and
Affordable Care Act of 2010 failure, 320–321
racial discrimination, 319–320
PCMHs. See Patient centered medical homes
PDLs. See Preferred drug lists
Percutaneous transluminal coronary angioplasty (PTCA), 88
Performance incentive programs, racial disparities
definition, 212–213
design and implementation, 223
designing and implementing performance, 223
equity
Children’s Health Insurance Program (CHIP), 212
healthcare quality components, 211–212
Patient Protection and Affordable Care Act, 212
ethnic and racial minorities, 223–224
evidence/literature review
CABG rates and HbA1c testing rates, 218
contemporary parlance, 217
Downs and Black tool, 218
Performance incentive programs, racial disparities (cont.)
  incentive program effectiveness, 218, 219
  healthcare disparities, potential impact
  breast cancer mortality, 215
  narrowing, 216
  neutral impact, 215–216
  widening, 216–217
  incentives flow
  payees, 214
  payers types, 213–214
  structure, 213
  umbrella provider organization, 214
  incentive types, triggers and measures
  “carrots”, and reputation-based incentives, 214
  clinical care processes, 214–215
  patient satisfaction, 215
  rewards and sanctions, 214
  intended effects effort, 223
  minorities vs. majority, targeted quality measurement, 222
  minority maxim approach, 224
  organization, patient populations, 223
  patient race and ethnicity
  explicitly/implicitly, 222
  payment system, health care, 222
  quality improvement,
  American health care, 221–222
  reduction
  CMS programs, 221
  health care quality improvement, 221
  monetary-based incentives, 220
  quality measurement, 220
  solo and small group practices, 220
  tactics, 220
  risk-adjustment techniques
  equivalent dimensions quality, 225
  medically/socially complicated patients care, 224
  role, quality improvement, 224
Peripheral artery occlusive disease (PAOD), 88
Population attributable fraction (PAF), 302–303
Preferred drug lists (PDLs)
  clinical flexibility and clinical judgment, 125–126
  decision-making processes, 117
Prostate cancer, African American men
  biological causes
  genetic polymorphisms, 392
  site-specific prostate, 391–392
  health-care reform impact, 395
  prevention, 390
  screening, 391
  solutions
  awareness, therapies, 393
  biological factors, 394–395
  health education, 393
  oncology, 394
  research, 395
  treatment, 391
PTCA. See Percutaneous transluminal coronary angioplasty
Public Health Disparities
  Geocoding Project
  ABSMs
  evaluation criteria, 277–278
  interpretation, 276
  use, 273
  CT poverty measure use
  data sets, 281–282
  ecological fallacy, 282
  etiological period, 282–283
  omitted variables and selection bias, 283
  data availability, 272
  ecosocial theory, 273
  health inequalities, race/ethnicity and gender outcomes
  age-standardized rate and CI, 301
  cancer incidence, 291–293
  childhood, 284–285
  CT poverty level, 283, 295
  incidence rates and CT poverty level, cancer, 302
  lead poisoning, children, 301
  mortality, 294–300
  PAF and CT poverty, 302–303
  premature mortality, black and white, 303, 305
  sexually transmitted infections, 286–288
  socioeconomic gradients, STD, 301–302
  tuberculosis, 289
  weapons-related injury, 290
historical context
   On Diet, 274
   health inequities, 274
   mortality rates, Parisian districts, 275–276
   social inequality, 275
implications
   hospital records improvement, 307
   question types, 305
   ZC-level socioeconomic data, 305–306
study base and ABSMs
   census-derived, 280
   levels and geocoding, 280
   population data, Massachusetts and Rhode Island, 278–279
   social class and SEP, 279–280
   US census building blocks, 278
study design, 276–277

Q
Quality Enhancement by Strategic Teaming (QuEST), 247–248
Quality improvement (QI), health care disparities elimination initiatives
   Aetna project, 253
   health centers and programs, 253–254
   report card development and NCQA, 253
role and strategies
   content and delivery, interventions, 240
   minorities vs. non-minorities, 239
   organizations and regions, 238
   patient-providers and risk-assessments, 239
   targeting, patients and minorities, 239
tools
   community-based interventions, 244
   education patient, 242–243
   intensive outreach, 242
   interventions targeting specific causes, 240, 241
   organizational change/practice re-design, 243–244
   patient activation and cultural competency training, 243
   practice guidelines, 242
   provider feedback, 240–241
   reminders, 240
QuEST. See Quality Enhancement by Strategic Teaming

R
Racial and Ethnic Approaches to Community Health (REACH) program, 206, 336
Racial and ethnic disparities elimination
   Consumer assessment of healthcare providers and systems (CAHPS), 428–429
   Crossing the Quality Chasm report, 427
   Cultural and linguistically appropriate services (CLAS), 426
data care
   agencies, 427
   hospitals and health plans, 427
   patients’ race and ethnicity, 426
   programs and incentives, 427
   systems, 426–427
goals
   care indicators, 428
   clinical outcomes, 428
   equitable care, 427–428
   health care organizations, 428
   HEDIS and CAHPS, 428–429
   hospital-based services, 429
   quality improvement programs, 429
Healthcare effectiveness and data information set (HEDIS), 428
health care workforce
   census, 424
   minority patients, 425
   minority physicians and nurses, 425
insurance coverage, Americans barriers, 423
   benefits, minority patients, 424
   financial access, 424
   health care reform, 423
   individuals, families and communities, 423
   Medicare program, 423
   minority, 423
   PPACA, 423
   uninsured probability, 422–423
patient-centered care
   CLAS, 426
   components, 425–426
   cross-cultural education and cultural competency training, 426
   definition, 425
   non-English-speaking, 426
   principles, health care, 429
Racial concordance, medical encounter care behaviors, 171–172
criticism
benefits, 173
excellent care and outcomes, 174
patient-centered care and cultural awareness, 174
effective communication, 171
ethnicity and language concordance, 171
race-concordant physician, 170
racial and ethnic minority patients, 170
training programs, 172
Racial stereotypes and bias, medical care clinical decisions, 174
transcranial magnetic stimulation used, 175
treatment recommendation, 175
Rapid estimate of adult literacy in medicine (REALM), 137
Reach Across AMerica, 416–417
REACH program. See Racial and Ethnic Approaches to Community Health program
REALM. See Rapid estimate of adult literacy in medicine
Red Dress program, 352
Remote area medical programs (RAM)
Cang wild horse, 414–415
counties, free clinics, 415
expeditions, 417
folks places, free care, 420
foundation, 419
free clinics, 415
hospitals and health practitioners, medical care, 415
mission and volunteer corps, 418
Reach Across AMerica, 416–417
resources
fleet, 419–420
volunteers, 419
Rural AMerica program
Appalachia, 415–416
development, 416
vision and dental care, 415
services
dental and vision care, 418
medical, 418
tropical cattle ranch, 414
volunteer medical professionals, efforts, 415
Rural AMerica program, 415–416
S
Seattle housing authority (SHA), 366
Seattle-King County Healthy Homes I Project action plan
reduce exposures, 364–365
SHA, 366
CHW, 362–363
home assessment, 363–364
intervention effects, 366–367
project participants, 363
Seattle-King County Healthy Homes II Project
care coordination, 368
CHW home visits, 367
clinic-based asthma education, 368
intervention effects, 368
Second National Health and Nutrition Examination Survey (NHANES II), 46
SEER. See Surveillance, epidemiology, and end results
SEP. See Socioeconomic position
SES. See Socioeconomic status
SHA. See Seattle housing authority
SHEP. See Systolic hypertension in the elderly program
Shortened test of functional health literacy in adults (S-TOFHLA)
health literacy, measurement, 138
patients/subjects read, list, 137
practical, screening tool, 140
Single-origin theory, 9–10
Socioeconomic factors, health disparities elimination
health care services, 199
income and poverty educational and employment status, 199
income level comparison, blacks vs. Latinos, 199
race and income segregation, 199
relationships, 200
Socioeconomic position (SEP), 279
Socioeconomic status (SES), 233
Southwest oncology group (SWOG), 387
S-TOFHLA. See Shortened test of functional health literacy in adults
Straw men, healthcare and race politics clinical circumstances variations
bioethics, 75
patient preferences, 75
discrimination and racism, 76
insurance coverage and ability to pay, 73
minority physicians’ beliefs and attitudes, 75–76
uncertainty and discretion
clinical judgment, 74
doctor–patient communication, 74
IOM committee’s report, 73–74
race-linked heuristics, 74
stereotypes, 74
Successful models, health care disparities
elimination
adult immunization, 250
cancer screening, diagnosis and treatment
mammography effect, 246
patient navigation program, 247
routine care vs. CHWs case-management, 246–247
childhood immunizations, 245
Chlamydia screening
complications and treatment, 245–246
team-oriented approach, 246
condition-specific interventions, 244–245
depression management
Matched Prim Care practices, 248
QuEST role, 247–248
whites and blacks, 247
diabetes management, 250
dialysis, 251
hypertension control
African Americans vs. white population, 248–249
cost-sharing groups, 249
Hypertension Detection and Follow-up Program, 249
liver transplantation, 251
pay-for-performance, 252
provider bias, 251–252
use, interpreters, 252
Surveillance, epidemiology, and end results (SEER), 389
SWOG. See Southwest oncology group
Systolic hypertension in the elderly program (SHEP), 57–58

T

Textbook of Black-related Diseases, 18–19
Title VI, Civil Rights Act of 1964
discrimination, 315–316
enforcement problem, 319
OCR and DHHS, 317
Patient Protection and Affordable Care Act of 2010, 319–321
recipient and regulations, 317–318
Sandoval case, 318
section 601, 315
Tuskegee syphilis study, 18

U

United States Commission on Civil Rights, 321
United States healthcare system and health disparities
culture of wellness, 5
distribution problem and manpower status, 4
infectious diseases and vaccination, 3
racial and ethnic makeup, professionals, 4–5
Reform Bill, 5
Sullivan Alliance, 5
surgical techniques, 3

W

Women’s center, ABC, 352

Y

Years of Potential Life Lost (YPLL), 26, 62
YPLL. See Years of Potential Life Lost
H. R. 3590

One Hundred Eleventh Congress of the
United States of America

AT THE SECOND SESSION
Begun and held at the City of Washington on Tuesday,
the fifth day of January, two thousand and ten

An Act

Entitled The Patient Protection and Affordable Care Act.

Be it enacted by the Senate and House of Representatives of
the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.
(a) SHORT TITLE.—This Act may be cited as the "Patient Protection
and Affordable Care Act".
(b) TABLE OF CONTENTS.—The table of contents of this Act
is as follows:

Sec. 1. Short title, table of contents.

Title I—Quality, Affordable Health Care for All Americans

Subtitle A—Immediate Improvements in Health Care Coverage for All Americans
Sec. 1001. Amendments to the Public Health Service Act.

PART A—Individual and Group Market Reforms

SUBPART I—Improving Coverage
*Sec. 2711. No lifetime or annual limits.
*Sec. 2712. Prohibition on rescissions.
*Sec. 2713. Coverage of preventive health services.
*Sec. 2714. Extension of dependent coverage.
*Sec. 2715. Development and utilization of uniform explanation of coverage
documents and standardized definitions.

Sec. 2716. Prohibition of discrimination based on salary.

Sec. 2717. Ensuring the quality of care.

Sec. 2718. Bringing down the cost of health care coverage.

Sec. 2719. Appeals process.

Sec. 1002. Health insurance consumer information.

Sec. 1003. Ensuring that consumers get value for their dollars.

Sec. 1004. Effective date.

Subtitle B—Immediate Actions to Preserve and Expand Coverage

Sec. 1101. Immediate access to insurance for uninsured individuals with a preexisting
condition.

Sec. 1102. Reinsurance for early retirees.

Sec. 1103. Immediate information that allows consumers to identify affordable coverage
options.

Sec. 1104. Administrative simplification.

Sec. 1105. Effective date.

Subtitle C—Quality Health Insurance Coverage for All Americans

PART I—Health Insurance Market Reforms
Sec. 1201. Amendment to the Public Health Service Act

SUBPART I—General Reform
*Sec. 2701. Prohibition of preexisting condition exclusions or other discrimination
based on health status.
*Sec. 2702. Fair health insurance premiums.