Eliminating Healthcare Disparities in America

Beyond the IOM Report

Edited by

Richard Allen Williams, MD

Humana Press

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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

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Dedication

To my children, Kelly, LaRae, Danielle, and Allen,
who have been a source of joy and inspiration
over the years. They are my real legacy.

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 celebrates its 50th reunion in 2007, was the first to have integrated dormitories and dining facilities on that campus. After graduating with honors, he went 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 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 multimillion 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.

Dr. Williams is the Founder of the Association of Black Cardiologists (ABC, 1974) and of the Minority Health Institute (MHI, 1985). He has 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.

Foreword

Those who dig the well…….

In their timely and important book, ELIMINATING HEALTHCARE DISPARITIES IN AMERICA: *BEYOND THE IOM REPORT*, Dr. Richard Allen Williams and colleagues provide a comprehensive analysis of the causes and potential solutions to eliminating health care disparities. Their work is timely, because little progress has been made in reducing disparities since they were first systematically documented in the 1985 Report on Minority Health; yet the 21st century will certainly bring a huge shift in the demographics of the country such that people of color will be the new majority. However, we must not forget that Williams' scholarly tone is about real people and how to improve the healthcare system so their health care and lives are better.

Allow me to share an interesting story about someone I recently met and who is counting on us to heed the sage words in ELIMINATING HEALTHCARE DISPARITIES IN AMERICA: *BEYOND THE IOM REPORT* if she is ever going to have the chance of surviving in our world. I will call her Mrs. Jones.

When my schedule permits, I supervise medical residents who train at a community health clinic about a half hour drive from our offices outside Princeton. The health clinic is where I encountered Mrs. Jones, a 56-year old African-American woman diagnosed with diabetes. While obtaining her family history, it was determined that diabetes runs in her family and caused the amputation of her mother's foot some time in the past.

When Mrs. Jones showed up at the clinic struggling to walk, a medical resident and I examined her and discovered her toe was badly infected. Her blood sugar was over 600 and her HgbA1c was 13– suggesting that her blood sugar had been high for some time. We told her she needed to go to the hospital immediately. She burst into tears– not because she did not have health insurance, which she did not– not because she had to take care of her family, which she did– and not because she knew she badly needed to be at work because she was paying off a six thousand dollar bill for a previous, preventable hospitalization. Mrs. Jones is employed in one of the most difficult occupations imaginable; she works as a full-time home health aide for elderly and disabled patients. She was upset because she had to care for a patient who would suffer if she did not show up, and Mrs. Jones always showed up.

The economics of managing her disease was also a problem. She could not afford the chem strips to test her blood glucose, pay the out-of-pocket costs to get her feet checked, or take time from work to wait in long lines for what little charity care might be available. Her choices were as basic as they come, a healthier life versus livelihood itself. Guess which one she picked?

The resident and I felt helpless. We knew what to do and did what we could. We performed the right tests, confirmed the diagnosis and recommended treatment on the spot. We pushed hard to give her excellent acute care, but Mrs. Jones' condition was chronic – and chronically unmanaged. Though the care we did provide was good, it was still too little care, delivered too late, with no way for Mrs. Jones to get more. I felt like I had struck out.

With all our training, all our technology – even with the full armamentarium of our profession – we still could not overcome the biggest problem Mrs. Jones presented to us: she needed a system that engaged her at its center, with the concern, compassion and competence to address her as a unique individual – culturally, clinically, and financially. She needed a system that would treat her like someone worthy of respect, support, and fair treatment.

But our system of care is not fair, it is not equitable, and it barely blinks when it forces patients like Mrs. Jones to get worse – without helping them to get well. Mrs. Jones needed a lifetime of chronic care management – and all we could give her was an acute care band-aid. The terrible irony was that here was a patient who is devoting her life to improving the quality of life for everyone around her but we could not improve hers. It is like the old African proverb: "Those who dig the well should not be denied a drink from the well."

My hope is that this book and the work it represents will ensure that those who dig the well will also drink from the well……..

Risa Lavizzo-Mourey, MD, MBA
President and Chief Executive Officer
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Preface

"Of all the forms of inequality, injustice in health care is the Most shocking and inhumane."
The Rev. Dr. Martin Luther King, Jr. at the Second National Convention of the Medical Committee for Human Rights, Chicago, Illinois, March 25, 1966.

In the sixteenth century, Paracelsus stated that the art of medicine is as important as its science. As we progress farther into the twenty-first century, it is apparent that we should revisit Paracelsus' dictum by emphasizing the need to practice medicine more artfully than has been the case. When we view medical practice across the spectrum of our diverse ethnic, racial, and cultural mix in the United States, it is very evident that the outcomes of our treatment are quite good in general but are woefully inadequate and disparate. In other words, treatment is applied unequally, and as a result we have disparities in healthcare. There is great speculation on the reasons for these disparities, with putative causes ranging from patient preferences to racism. Although it is difficult to get our arms around the causes, we do know what the disparities are.

The book by the Institute of Medicine (the IOM Report) that emerged from years of deliberations on healthcare disparities in fact carried the title *Unequal Treatment* and delivered a powerful indictment against our healthcare delivery system. Basically, the book was a compendium of more than 100 studies which were analyzed for the presence of bias in favor of one racial or ethnic group, or against that group. Racial bias was documented in many of the studies cited, and this was viewed as a problem in need of fixing.

One thing that should be clear from the IOM Report and from other books and papers which have appeared in recent years on healthcare disparities is that our focus needs to be on eliminating the disparities, no matter what their cause. It would be futile to concentrate only on racial bias, not just because that problem is often covert, but also because it will require so much time, energy, and resources to eradicate even when it is overt. Bias is largely a matter of attitudes which need to be changed, which will require time and education. This by no means pardons or accepts racial bias or racism; in fact, these things are taken for granted. They have been documented to be a part of the fabric of the practice of medicine and the delivery of healthcare in

America. What we must now do is move on to solving the problem of healthcare disparities rather than bemoaning racism. We must be smart and determined and not be stultified and paralyzed by prejudice; instead, we must devote our energies to defeating the forces which threaten the health and survival of a very large part of our population, while the efforts to change attitudes and to wipe out bias continue.

It is intriguing that in the eighteenth century, the demographer Hoffman surveyed the slave population of the United States, and based on the poor health characteristics of the group, predicted the extinction of the black race by the year 2000. That prediction should not be taken literally nor deemed to be incorrect because black people obviously still exist. What we should surmise from the prediction is a figurative meaning; there is no doubt that African Americans are losing ground in the survival race compared to whites, and that there is an ever-widening "death gap" typified by a chasm between longevity for blacks and whites. Thus, blacks are on a course towards demise, from a comparative standpoint.

This latter point was brought home to me very poignantly when I recently visited the new Freedom Center and Underground Railroad Museum in Cincinnati, Ohio. This unique institution is dedicated to exposing the public to the horrors that slavery imposed upon its victims. One was able to witness the origins of the disparities that are occurring today. I got a real sense of how the "slave health deficit" described by Byrd and Clayton evolved. I was struck by the harshness of the treatment the slaves received at the hands of their slavemasters, and could only imagine how that brutality must have been translated into illness and disease. Further, I was induced to reflect upon how much illness and how many deaths must have occurred because of neglect, delayed treatment of their illnesses, lack of access to care, slave reluctance to complain of illness, and slavemaster refusal to accept complaints if they were lodged. These are some of the things that are linked to healthcare disparities today, and it may be said that there is a direct relationship between the situation then and now.

Although we cannot turn back the clock and correct the crimes of slavery, we can correct the current situation. Elimination of disparities in healthcare must become a priority of this nation, and local, state, and federal governments, healthcare institutions, schools of medical education, medical societies and organizations, licensing and accrediting bodies, and most importantly practitioners of medicine must subscribe to this concept. That is where the art of medicine—with the implementation of culturally competent practices, for example—should interface with the awesome science of medicine which this country possesses in abundance. That is how we will extract ourselves from an embarrassing position in which the United States, the most technologically advanced country in the history of the world, ranks near the bottom (37th) among industrialized nations in terms of the quality of the health care we dispense. Recently, the state of New Jersey has taken firm steps to eliminate disparities by requiring physicians to pass a test of cultural competence as a condition of relicensure, and some other states including Florida and California are in the process of doing something similar. Every state needs to follow their lead. This is a very solid and significant first step in the right direction.

In this book, I have attempted to assemble a group of the very best scholars on healthcare disparities to provide the benefits of their experience and expertise as a resource for helping others to make judicious determinations about how to proceed in their efforts to improve the disparities situation. Toward this end, I have arranged the chapters in discrete categories which will allow a comprehensive coverage of the issues related to disparities. Very importantly, this book is not intended to be one in which all of the answers are supposedly given to the multitude of problems. Instead, it is intended to raise the reader's level of consciousness and concern and to increase the knowledge base about the issues. My hope is that it will be the next step beyond the ground-breaking IOM Report and will increase our resolve to reduce and eliminate healthcare disparities as we move toward the target year of 2010.

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Introduction

Eliminating Unequal Treatment

By Congressman Jesse L. Jackson, Jr.

Stamps, races, pink products ranging from ribbons to vacuum cleaners. There are countless efforts to combat this cancer, yet in the same month dedicated to raising awareness about it, a shocking headline: "Study finds race disparity in breast cancer mortality rates."

It was in the Tuesday, October 17, 2006 issue of the Chicago Tribune. The article cited a study by the Sinai Urban Health Institute. According to the study, breast cancer death rates were similar for Chicago's white and African American women in the 1980s. The rate then was about 38 breast cancer deaths per 100,000 women per year. By 2003, the rate for Chicago's African American women had risen to 40.5 breast cancer deaths per 100,000, but for white women the rate was 23.4 per 100,000. In New York City, the rate for African American women was 35.8, and 30.7 for whites. Nationally, the rate was 34.6 for African American women, and 25.2 for white women.(1) The bottom line is that a woman's chances of surviving breast cancer have significantly increased over the past twenty years, unless she is black.

The same day the Chicago Tribune reported on the disparity with regard to breast cancer survival rates, The Washington Post cited a "race gap" in health screenings for breast and other cancers as well as flu shots and cholesterol tests. The story, "Race Gap Persists in Health Screening", focused on research funded by the federal government's Agency for Healthcare Research Quality which was published online by BMC Health Services Research.(2) It was discovered that African American women said they were getting mammograms almost as often as white women, but mortality statistics like those mentioned in the Tribune article persisted. Experts cited in the article said that self-reporting about health screenings was not altogether accurate. Therefore, they suggested using a variety of methods to measure the true nature of health disparities, as well as more effective medical practices that do more than simply share information with patients about the need for health screenings.

Six days later, the Chicago Sun-Times ran an article about a study on the racial disparity in breast cancer mortality rates done at the University of

Texas' M.D. Anderson Cancer Center. The study's lead researcher said in the article on "Biology blamed for black breast cancer rates" that the biological factor "deserves more research so that we can develop better therapies for African-American women at higher risk."(3)

Reports of healthcare disparities have become commonplace. Much of the debate has moved away from the question of *if* the disparities exist to *why* and *what can be done* about them. That was not always the case. I am a member of the U.S. House of Representatives' Appropriations Committee. My subcommittee assignments include what is now called the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (Labor-HHS). In 1999, after hearing years of testimony by medical professionals, I was struck by the high incidence of health disparities. Was I more likely to receive poor healthcare, be sicker and die sooner just because I was an African-American? Where was the definitive report proving to those who held the federal purse strings that this was a real problem that required real federal involvement? What would that involvement look like? As the only African-American on the subcommittee, it was my responsibility to get answers to those questions. So, I secured funding in the Fiscal Year 2000 federal budget to gather scientific evidence of what many patients and healthcare providers had been saying – and fearing – for years: that the quality of a person's healthcare was too closely tied to the color of his or her skin. That evidence was released in March of 2001 by the Institute of Medicine (IOM). Its report was entitled "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care." It presented indisputable evidence that disparities in healthcare are real, and offered prescriptions for treating them.

Progress filling those prescriptions, however, has been slow. Debates were almost immediately launched about the lack of capital to implement the IOM report's suggested programs; yet human capital was in abundance. Scholars, scientists, healthcare providers and other stakeholders have been developing practices that will transform the recommendations of "Unequal Treatment" into the reality of American healthcare. Those recommendations included increasing the number of represented minorities in the health professions, promoting cultural competency training in all health professions education, expanding biomedical research on health status disparities, and strengthening patient protections for all Americans enrolled in managed care plans. We *can* eliminate health disparities. We just need the will, and the road map. This book provides the road map. It is incumbent upon each of us to maintain the will. The stakes are too high to do anything less. It is the 21st Century and minorities in the wealthiest, most powerful nation on the planet continue to suffer disproportionately from almost every disease.

Good healthcare should not depend upon a patient's ethnicity, salary or geography. I believe that *every* American has the right to healthcare of equal high quality. To get there, we must end unequal treatment, heal hearts that continue to see patients as colors and not fellow human beings in need, and expand our vision of healthcare – a vision that leaves no American behind. This may be the most challenging part. Generations of dependence upon an employer-based healthcare system designed within government parameters can be a hard habit to kick. Many Americans share my belief that every one of us has a human right to healthcare of equal high quality, at least as an ideal. However, they cannot imagine that it is practical, that the money for it exists and that a large enough group of politicians could be coerced into passing the legislation to make it happen.

I believe that it can be done. The American economy has the financial resources and technological skills to provide a comprehensive, universal healthcare system. We have a strong government complemented by the most efficient financial and industrial sectors in the world. As a result, we have the world's most powerful and productive economy. Many of us know and even brag about these facts, but they're enough to make you feel ill when you take a close look at how we spend our healthcare dollars.

In 2005, federal spending for health care was more than $600 billion. That's about one quarter of the federal budget.(4) Overall, the United States spends more than $2 trillion annually on health care, about 16% of our Gross Domestic Product (GDP) – more than any other nation in the world. In ten years, that figure is expected to rise to 20%.(5) Yet, of 23 industrialized nations, the United States had the highest infant mortality rates (6), and we ranked among the bottom of industrialized nations on healthy life expectancy at 60 years of age(7). Almost 47 million people were uninsured in 2005, about 16% of Americans. That's about twice the population of the state of Texas! (8) How is it that we can have an employer-based healthcare system, but more than two-thirds of our nation's uninsured adults were working in 2005?(9) Not to mention those who are under-insured, and let's not forget the millions of additional, hard-working Americans who are unhappy about the fact that they are paying more money but receiving less health care. And they're doing it under 50 different state health care systems, 3,141 county systems, 20,000 municipal systems, and nearly 1000 private insurance companies – all separate and unequal.

We can't have it both ways. It defies reason to have the resources of the United States, spend the most money on health care, and then argue that we can't figure out how to organize, implement and pay for a healthcare system that is available to everyone. We should not be satisfied with the world's best doctors, hospitals, clinics, researchers and pharmaceuticals if they are not available to every American who needs them. They are not, so I believe we must develop the political will to make sure they are. Yes, the *political* will, while losing the fear of a visionary transformation of our current healthcare system. Transformation is long overdue. The best healthcare should not be available only for the wealthy. It should not be difficult for an increasing number of middle-class Americans to afford healthcare, while they worry that raising healthcare standards for the poor will further erode their healthcare and economic options.

"The only thing we have to fear is fear itself." That's the most famous line from President Franklin Delano Roosevelt's first inaugural speech in 1933. Fearless political will has shaped the nation as a whole. FDR was one of many presidents who took the challenges at hand, then fearlessly used his power and influence to transform them for the greater good, especially with regard to healthcare. As a Democrat, I am proud of the party's support for national health insurance from FDR through the middle of the 1980's. Presidents Harry Truman, John Kennedy, Lyndon Johnson and Jimmy Carter were all elected with it in the party platform. Even the Bill Clinton Administration's idea of universal healthcare was popular, but as the old saying goes, "the devil is in the details." As the Clinton plan's details became known, the flaws condemned it – and significant national discussion about health care – to the devil. Democrats ran from the issue, and Republicans continued to ignore it. Years passed, healthcare policy stalled and healthcare for *all* moved farther from becoming a reality.

I still believe that certain aspects of healthcare policy can move from vision to reality. Eradicating health disparities is one of them. I propose a three-pronged approach: Become aware of the reality and impact of health disparities, put forth and support public policy designed to eradicate them, and commit to a personal health care policy. Awareness comes through books like this. Read it, share it and quote it whenever necessary. Public policy, and public servants, can come from any political party or organization. Critically assess them. Immediate legislative remedies are welcome, but as mentioned earlier, keep an eye on those devilish details. I also propose raising the national health care standard via public policy. I have proposed an amendment to the U.S. Constitution guaranteeing every American the right to healthcare of equal high quality. One of our nation's most sacred documents, the one that lends the weight of law to our ideals, should do the same for our ideal with regard to one of our most sacred personal assets – our health. As for that precious personal asset, we all know we have nothing if we don't have our health. Committing to a personal health care policy can be as simple as quitting smoking, cutting down on drinking and losing a few pounds.

We need every body we can get to do what is needed to rid the nation of the scourge of healthcare disparities, and that work is a heck of a lot easier if the body is healthy.

Ernest Hemingway expressed it best when he wrote: “My health is the main capital I have and I want to administer it intelligently.” As individuals, we must place a high value on our health. As a nation, we must marshal all of our resources to address the inadequacies of our healthcare system such as health disparities based upon race. Anything less is definitely not intelligent.

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Richard Allen Williams, MD

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I

UNDERLYING CAUSES OF HEALTHCARE DISPARITIES

1

Historical Perspectives of Healthcare Disparities

Is the Past Prologue?

Richard Allen Williams, MD

> "It must be Canaan, your first-born, whom they enslave…Canaan's children shall be born ugly and black!...Your grandchildren's hair shall be twisted into kinks…[their lips] shall swell" *(1)*.

INTRODUCTION

What is the historical background of disparities in healthcare delivery and how did these disparities evolve? The history goes back to slavery, wherein 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.

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

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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.

Regarding 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 those who 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 15th 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 Gliddon. 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 espouse the separate-origin theory was Paracelsus (1493–1541), a Swiss who did not believe that nonwhites 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 freedom 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 nonwhites, 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 yr, and was the basis of racist dogma relating to physical differences between the races. It was bolstered in the 18th century when S. T. von Sommering, 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 18th and 19th century 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 as a result of 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 on 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 17th through the 19th 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 antislavery, liberal activist of the time who wrote, "The history of the creation 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 celebrated case of exslave 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 unity of the human species" in his groundbreaking book, "Essay on the Causes of 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 owing 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 mirrored Greek mythology cited previously.

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 physician Franz Joseph Gall (1758–1828) *(12)* was perpetuated in the United States, with measurements of the human skull with calipers replacing aesthetic 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-yr-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 on 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 it be found "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 vermillion?" 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, because 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 that was one of the heaviest blows suffered by antislavery and proequality 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 yr in a free state where he had been taken by his master. The case was argued before the United States 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 healthcare. 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 with enslaved Negroes in the South. The incidence of insanity among free Negroes in the North was one in 162.4, whereas it was only one in 1558 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 proslavery 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 coconspirators were Gliddon and Morton, who provided scientific consultation to him. This fraud perpetrated by a federal official on a US 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 toward 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 postwar 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 healthcare for the liberated blacks, who were experiencing their worst health conditions in the immediate postwar period. This dire health situation was partially ameliorated by the Freedman's Bureau programs cited earlier, but most of them were not to last, and the Freedman's Bureau was totally eliminated in 1872. This left freed men 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, nine of the 11 medical schools dedicated to producing black doctors opened since 1868 were thriving *(18)* and had produced more than 1000 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, CA were added.

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 approx 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 Sakkara, 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 4500 yr 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 2500 yr before Aesculapius laid claim to the same title in Greece.

In the 18th 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 Glascow, 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 yr 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 HEALTHCARE 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" where 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, where 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.

The author had the opportunity to speak with Dr. W. Montague Cobb, the 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-yr period where 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 nonexistent and penalties for noncompliance 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; DC. General Hospital in Washington DC; Cook County in Chicago; Charity Hospital in New Orleans, Louisiana; Boston Medical Center in Roxbury, MA; and Kings County Hospital in Brooklyn, NY. 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 that 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 the system what might be called "wealthcare" rather than healthcare.

The end of the 19th and the beginning of the 20th 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 resubjugation 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. Therefore, they 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 owing 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 because of 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, the author 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 with whites in America. It was intended to fill a void, because only a small literature was available on the principal diseases affecting blacks. This was due in part to the fact that 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. Before 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 healthcare 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 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. Therefore, clinicians must 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 United States. In 2000, *An American Health Dilemma* was a breakthrough book, which revisited the problem of black healthcare in a major way for the first time in 15 yr. The Institute of Medicine 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 the people 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 the latter will not be achieved 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 are being witnessed today, and to realize how much the medical practitioners are the cause of those disparities. The principle focus has been on how racist attitudes developed over the centuries and how they have impacted the delivery of healthcare 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 healthcare, and also because the nation is still very much affected by these influences. Hopefully, this brief review of the past will help 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 the ability to interrupt such a negative impetus.

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2

Epidemiology of Racial and Ethnic Disparities in Health and Healthcare

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INTRODUCTION

Disparities in health status and healthcare delivery have been documented in the United States throughout most of the past two centuries *(1–3)*. More recently, the Institute of Medicine (IOM) *(4)* and the Agency for Healthcare Research and Quality *(5)* have confirmed that such disparities are pervasive but improvements are possible. Eliminating these disparities is one of the two overarching goals of the Healthy People 2010 national public health agenda *(6)*. 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 in which additional research is needed.

In this chapter, published data from national health statistics and surveillance reports is used to present epidemiological profiles of established disparities in health status and healthcare delivery for population subgroups defined by race and ethnicity. First the categories of race and ethnicity are introduced and the concept of disparities in healthcare is defined. 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 for elimination of disparities are discussed. Current data and trends related to life expectancy, prevalence of risk factors and chronic diseases, 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

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caveats on the challenges and limitations in the interpretation of racial and ethnic comparisons in the healthcare setting, and describes future opportunities for the development and implementation of programs and strategies to eliminate these disparities in health and healthcare.

RACE AND ETHNICITY IN THE UNITED STATES

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 *(7)*. This revision identified 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 defined. Persons of any race with Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin were designated Hispanic/Latino and all others were designated non-Hispanic. Herein, this classification of race and ethnicity is followed whenever complete data on all racial/ethnic groups are available. Often, complete stable estimates are not available for all racial/ethnic groups. In these instances, data are presented typically for blacks and whites; non-Hispanic blacks, non-Hispanic whites, and Hispanics; or for blacks, whites, and Mexican Americans, depending on the data source.

As shown in Table 1, whites constituted 81% of the total US 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 the ethnic minority population, which often has poorer health and access to healthcare could have significant adverse implications for national health indicators, unless disparities in health and healthcare are addressed and eliminated.

CONCEPT OF DISPARITIES AND THE HEALTHY PEOPLE 2010 GOALS

The term *disparities*, as defined by the National Institutes of Health, first working group on health disparities, refers to “differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions” *(8)*. In a broader sense, *health disparities* refers to preventable differences

Table 1
Projected Population of the United States, by Race and Hispanic Origin: 2000, 2020, and 2050

	Projected population[a] (%)		
Population group	2000	2020	2050
Total	282,125	335,805	419,854
Whites alone	228,548 (81)	260,629 (77.6)	302,626 (72.1)
Blacks alone	35,818 (12.7)	45,365 (13.5)	61,361 (14.6)
Asians alone	10,684 (3.8)	17,988 (5.4)	33,430 (8)
All other races	7075 (2.5)	11,822 (3.5)	22,437 (5.3)
Hispanics (of any race)	35,622 (12.6)	59,756 (17.8)	102,283 (24.4)

Source: From ref. *38*.

Whites: Origins in any of the people of Europe, the Middle East, or North Africa.

Blacks: Origins in any of the black racial groups of Africa.

Hispanics: Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race.

Asians: Origins in any of the original peoples of the Far East, Southeast Asian, or the Indian subcontinent.

NHOPI: Origins in any of the original people of Hawaii, Guam, Samoa, or the Pacific Islands (included in "all other races").

AIs/ANs: Origins in any of the original people of North and South America, including Central America, and who maintain tribal affiliation or community attachment (included in "all other races").

[a] In thousands.

in the health indicators of different population groups, often defined by race/ethnicity, sex, educational level, income, socioeconomic status, and geographic location of residence. In this chapter, epidemiological profiles are discussed of those disparities identified on the basis of race and ethnicity alone, although the importance of eliminating all forms of health disparities in accordance with the Healthy People 2010 goals is recognized *(6)*. The overarching goals of Healthy People 2010 are: (1) to increase the quality and years of healthy life and (2) to eliminate health disparities *(6)*. The overall Healthy People 2010 goals and objectives are divided into 28 focus areas, each of which contains a concise goal statement. Some target areas 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 Healthy People 2010, a small set of measures identified as the "leading health indicators" were selected to address individual behaviors, physical and social environmental factors, and health system issues *(9)*. These health indicators include physical activity, overweight/obesity, tobacco use, substance abuse, responsible sexual behavior, mental health, injury and violence, environmental quality, immunization, and access to healthcare. In the subsequent sections, several of these indicators are used in characterizing the epidemiological profile of health disparities.

THE BURDEN OF HEALTH 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, hospitalizations 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 healthcare delivered significantly supplement these epidemiological profiles.

Life Expectancy and Mortality

Life expectancy at birth in the United States increased dramatically from 47.3 yr in 1900 to 77.3 yr in 2002, and reached a record high of 77.5 yr in 2003 *(10,11)*. However, marked racial disparities have persisted. As shown in Fig. 1, life expectancy is highest in white women (80.5 yr), followed in decreasing order by black women (76.1 yr), white men (75.3 yr), and black men (69 yr) *(11)*. Blacks have higher death rates at all ages and more premature mortality than whites, as measured by years of potential life lost from diseases of the heart and stroke (Fig. 2). Data are presented only for 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 *(10)*.

The enormous excess of deaths in blacks resulting from disparities in life expectancy was also revealed in the analysis by Satcher et al. *(12)* showing an estimated 83,570 excess deaths in blacks could be prevented each year in the United States if this black–white mortality gap could be eliminated. In their *Eight Americas Study*, Murray et al. *(13)* divided the US population into eight distinct groups with different epidemiological patterns and mortality experience. The eight are: 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 (America 6), poor blacks living in the rural south (America 7), and blacks living in high-risk urban environments (America 8). *(13)* The authors estimated that the disparity between the life expectancy for males in

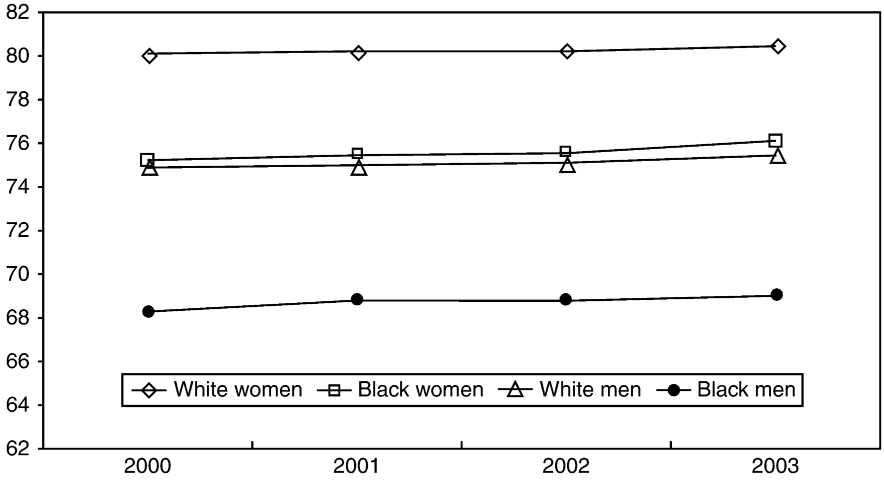

Fig. 1. Life expectancy at birth, by race and sex: United States, 2003 *(11)*.

America 8 and females in America 1 was 21 yr *(13,14)*. They identified an "enormous excess" of mortality in young and middle-aged persons that was largely attributable to chronic diseases *(13)*.

Chronic Diseases as Leading Causes of Death and Disparities

The leading causes of death vary by race and ethnicity. However, for all racial/ethnic groups, most of the leading causes of death are chronic diseases (Table 2). Heart disease and cancer rank first and second in all racial groups except for Asians and Pacific Islanders among whom cancer ranks first and heart disease ranks second. Stroke is the third leading cause of death in all racial/ethnic groups except for Hispanics (among whom it ranks fourth) and AIs/ANs (among whom it ranks seventh) *(11)*.

These chronic diseases contribute substantially to overall racial/ethnic disparities in life expectancy and overall mortality. In a 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. *(15)* demonstrated that cardiovascular diseases and cancer alone accounted for 35.3 and 26.5%, respectively, of the differences between blacks and whites with the same education level. The contribution of cardiovascular diseases to the black–white disparities was in large part because of difference in prevalence of hypertension. When examined across all racial/ethnic groups, the mortality from all diseases of the heart, ischemic heart disease,

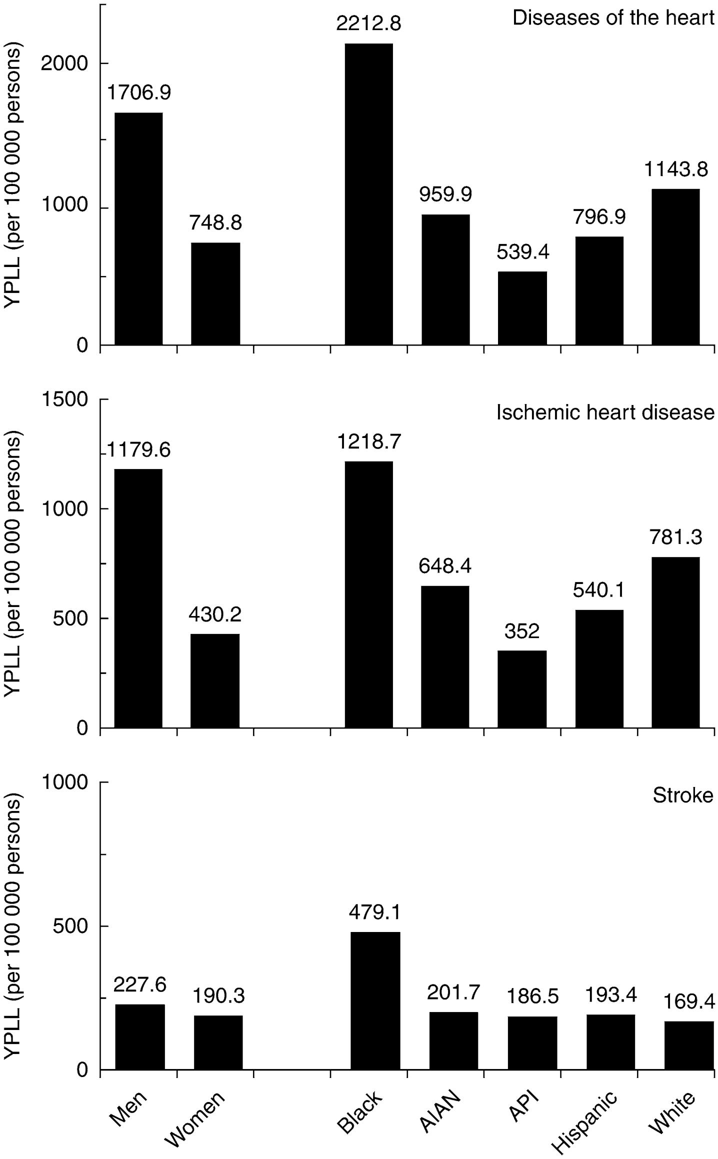

Fig. 2. Years of potential life lost before 75 yr of age resulting from diseases of the heart, ischemic heart disease, and stroke, according to sex, race, and Hispanic origin, United States, 2002 *(10)*.

or stroke remains highest among blacks (Fig. 3). One important reason for this high risk, as recently emphasized by Williams et al. *(16)*, is the high prevalence of multiple cardiovascular and chronic disease risk factors in African Americans compared with white Americans.

Table 2
Deaths and Percentage of Total Deaths for the 15 Leading Causes of Death, by Race and Hispanic Origin, United States, 2002

Cause of death (based on the *International Classification of Diseases, Tenth Revision*)	White		Black		AI		Asian/Pacific Islander		Hispanic	
	Rank	Total deaths (%)	Rank	Total deaths (%)	Rank	Total deaths (%)	Rank	Total deaths (%)	Rank	Total deaths (%)
Diseases of the heart	1	28.9	1	26.8	1	19.9	2	26	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	8	2.6
Accidents (unintentional injuries)	5	4.3	5	4.3	3	12	4	4.9	3	8.6
Diabetes mellitus	6	2.8	4	4.4	4	6	5	3.5	5	5
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	–	–

(Continued)

Table 2 (Continued)

Cause of death (based on the *International Classification of Diseases, Tenth Revision*)	White		Black		AI		Asian/Pacific Islander		Hispanic	
	Rank	Total deaths (%)	Rank	Total deaths (%)	Rank	Total deaths (%)	Rank	Total deaths (%)	Rank	Total deaths (%)
Chronic liver disease and cirrhosis	–	–	–		6	4.4	–	–	6	2.9
Assault	–	–	6	2.9	10	2.2	–	–	7	2.7
Human immunodeficiency virus disease	–	–	7	2.7	–	–	–	–	–	–
Certain conditions originating in the perinatal period	–	–	–	–	–	–	–	–	10	2.1

Source: From ref. *39*.
AI, American Indian.
Causes of death not ranked in top 10 for respective race/ethnic group.

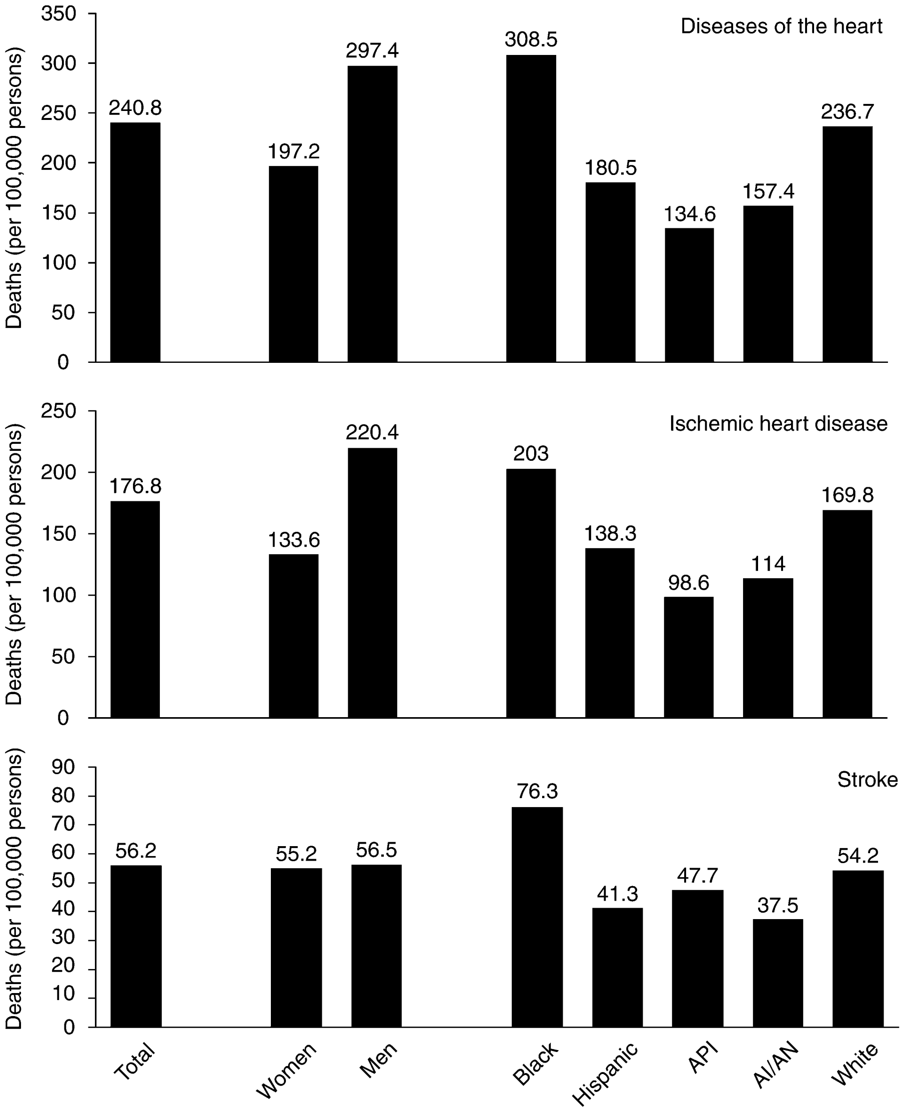

Fig. 3. Age-adjusted death rates for selected causes of death, according to sex, race, and Hispanic origin: United States, 2002 *(10)*.

Morbidity and Quality of Life

Hospital admissions serve as a useful measure of the burden of morbidity, and they are an important contributor to overall quality of life. Although hospital admissions per 1000 population have declined for both blacks and whites since the early 1990s, admission rates continue to be significantly higher for blacks *(17)*. Among American adults over the age of 65 yr, data from the Medicare program show that hospitalization rates are significantly higher for black, Hispanic, and Native American than for white beneficiaries and are lowest for Asian American beneficiaries *(17,18)*. Whites have the highest prevalence of hospitalization for acute myocardial infarction *(19)*. However, hospitalization for chronic heart failure is higher among blacks, Hispanics, and AIs/ANs than among whites *(19)*. In the Medicare population, blacks have the highest prevalence of hospitalization for stroke *(19)*. Many such hospitalizations are preventable through increased adherence to and uniform application of established clinical prevention guidelines.

There are significant disparities in the utilization of hospital emergency departments (EDs) by race and age group *(17)*. Bernstein et al. *(17)* have shown that among persons aged 45–64 yr, the ED visit rate for blacks in 2000 was almost twice that for whites. Among persons aged 65 yr and older, the ED utilization in 2000 was also higher in blacks than whites, and compared with the 1992–1993 period, had increased significantly more for blacks (51%) than for whites (19%) *(17)*. 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 *(20)*. The greatest burden of unhealthy days or impaired health-related quality of life is reported by AIs/ANs, African Americans, and Hispanics, and the lowest reported burden is in Asians and whites *(20)*. This disparity may even be underestimated for AIs because of survey-related underreporting, as demonstrated by Gilliland et al. *(21)* in their analysis of health-related quality of life for rural AIs in New Mexico.

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 *(22,23)*. An important contributor to and effect of many of these risk factors is obesity, which not only is highly prevalent in the United States but also is increasing and has marked racial, ethnic, and geographic disparities (Fig. 4). Although all of these risk factors are common in the United States, 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 "no physical activity" is prevalent in all racial/ethnic groups, and especially so in women with less than a high school education. Similarly, the

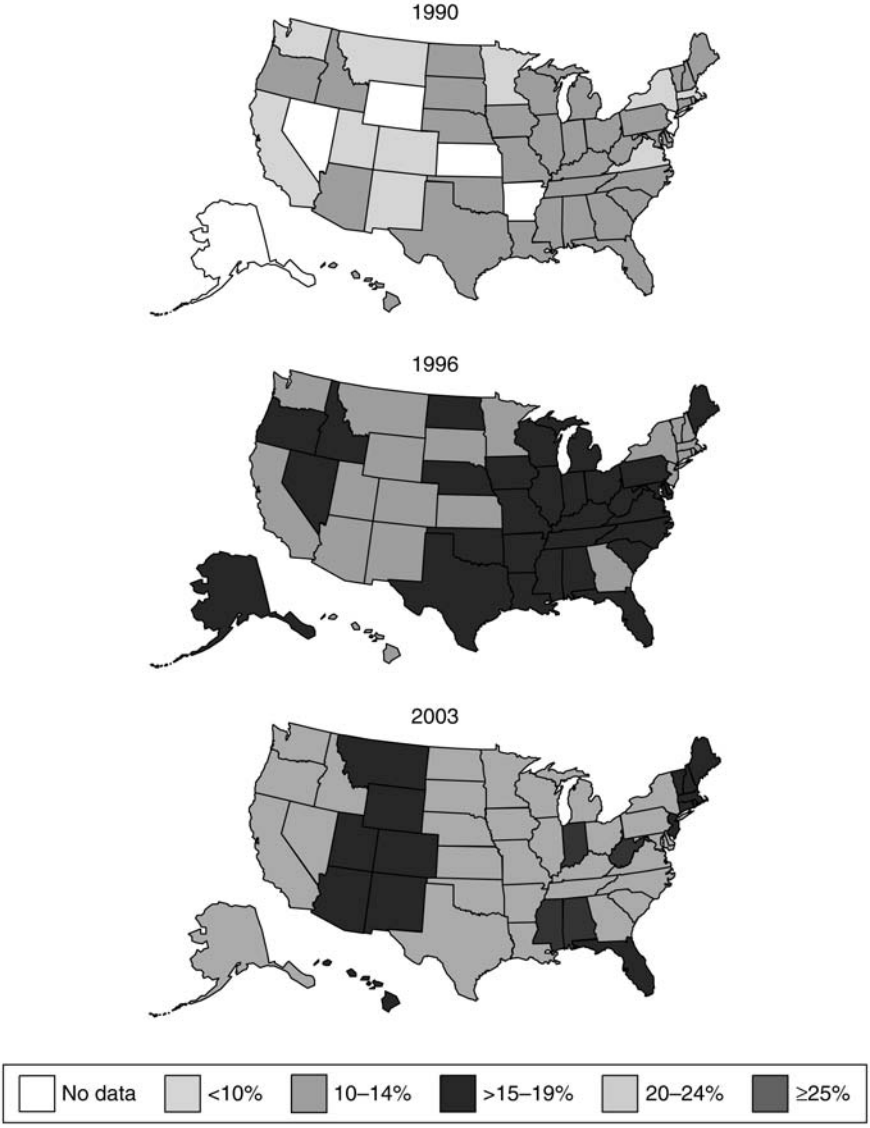

Fig. 4. Trends in obesity (defined as Body Mass Index [BMI] ≥ 30 kg/m^2) among US adults, Behavioral Risk Factor Surveillance System (BRFSS) 1990, 1996, and 2003 *(19)*.

daily consumption of five servings of fruits and vegetables is low in all groups, but lowest in black and white men with less than a high school education *(19)*. Blacks have the highest prevalence of diagnosed diabetes and high blood pressure (Table 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 *(19)*.

Measured risk factor data from the National Health and Nutrition Examination Survey (1999–2002) also show that, in general, blacks have a high prevalence of hypertension, compared with the other racial/ethnic groups, 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 with the other racial groups; measured levels of glycosylated hemoglobin (≥7%) is highest in black men *(19)*. Compared with blacks, the prevalence of hypercholesterolemia is generally high among white and Mexican American men and white women regardless of their educational status. Measured surveillance data for the emerging cardiovascular risk factors also show significant racial/ethnic disparities within educational and socioeconomic strata. For example, among men who have not completed a high school education, the prevalence of elevated concentrations of C-reactive protein (CRP) is highest among whites. However, among men who have completed high school, CRP prevalence is highest among blacks *(19)*. Among women who completed high school, the prevalence of elevated CRP concentrations is highest in black and Mexican Americans. In both men and women of all racial/ethnic groups examined, the prevalence of elevated homocysteine (≥10 μmol/L) is higher in those with less than a high school education *(19)*.

DISPARITIES IN ACCESS TO AND QUALITY OF CARE

The provision and accessibility of "healthcare of equal quality based solely on need and clinical factors" is the essence of health equity envisioned by the IOM *(24)*. In issuing the guidance for preparing the national annual healthcare disparities report, the IOM stated that disparities in access to care and quality of care "are among this nation's most serious healthcare problems"*(24)*. The National Healthcare Quality Report (NHQR) and the National Healthcare Disparities Report (NHDR) provide a comprehensive overview of the quality of healthcare in America and the spectrum of disparities that exist in the healthcare of the US population. 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 healthcare. Still, disparities have persisted or widened in many areas *(5,25)*.

Areas of significant disparities in the effectiveness of care documented in NHDR and NHQR include the prevention of female cancer deaths (poorest in

Table 3
Unadjusted Prevalence of Risk Factors for Cardiovascular Disease Among US Adults ≥18 yr of Age, Behavioral Risk Factor Surveillance System, 2003

	White				African American				Mexican American			
	<High school		≥High school		<High school		≥High school		<High school		≥High school	
	Percentage	Standard Error (SE)	Percentage	SE	Percentage	SE	Percentage	SE	Percentage	SE	Percentage	SE
Current smoker												
Men	40.6	1.1	22.9	0.3	41.8	2.7	27.4	1	27.3	1.7	22.6	1.1
Women	34.6	0.9	19.9	0.2	25.6	1.6	17.8	0.7	10.6	1	12.9	0.7
Total	37.5	0.7	21.4	0.2	33	1.5	22	0.6	18.6	1	17.7	0.7
No physical activity												
Men	40.1	1	17.7	0.2	42.1	2.7	24.7	1	46.5	1.9	24.9	1.1
Women	45.3	0.9	21.5	0.2	50.7	1.9	32.2	0.8	52.2	1.7	33.3	1
Total	42.8	0.7	19.7	0.2	46.8	1.6	28.9	0.6	49.4	1.3	29.1	0.8
Five servings or more of fruits and vegetables												
Men	13.3	0.7	18.6	0.3	14.6	2	18.9	0.9	18.2	1.6	17.4	1.1
Women	20.6	0.7	29.5	0.2	22.5	1.8	25.8	0.8	24.1	1.5	25.3	1
Total	17.1	0.5	24.3	0.2	18.9	1.3	22.8	0.6	21.3	1.1	21.4	0.7
Told have diabetes												
Men	11.9	0.7	7	0.2	14.6	1.7	10.1	0.7	9	1	5.6	0.6
Women	13.3	0.5	5.9	0.1	19.2	1.3	10.6	0.5	11.5	1	6.4	0.5
Total	12.6	0.4	6.4	0.1	17.1	1.1	10.4	0.4	10.3	0.7	6	0.4

Source: From ref. *19*.

blacks); mammography for breast cancer screening within the previous 2 yr (fewest screenings in Asians and Hispanics compared with white and non-Hispanic white women); prevalence of limb amputations in diabetes (highest prevalence in blacks); prevalence of glycated hemoglobin testing and eye and foot examinations in monitoring diabetes control (lower in Hispanics compared with non-Hispanic whites); suboptimal care for heart attack patients (poorer care for blacks, AIs and ANs, and Hispanics compared with whites); prevalence of physician advice to quit smoking (lowest in Hispanics); suboptimal prenatal care in first trimester (poorer care for in blacks, NHOPIs, and Hispanics); high infant mortality (highest in blacks); low prevalence of childhood vaccinations (lowest rates are in blacks and Hispanics); and preventable asthma hospitalizations (highest in blacks). As shown in Tables 4 and 5, the major disparities in healthcare 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 (lack of timeliness). Asian, AI and AN, and Hispanic adults reported that providers never listen carefully to them, explain things, respect them, or spend enough time with them or their children.

The 2005 Healthcare Disparities Report provided data on disparities in healthcare access that encompassed facilitators and barriers to care and healthcare utilization *(5)*. It addressed healthcare access including gaining entry into the healthcare system, getting access to sites of care, and finding providers who meet a individual patient's needs in an environment of mutual communication and trust. The data show that health insurance is a key barrier to healthcare among blacks and Hispanics, resulting in difficulties and or delays in obtaining care because of the patient's socioeconomic status and insurance coverage. Blacks, Hispanics, and Asians indicated that they do not have a usual source of care and more often use the ED for that purpose. Hispanics in particular reported difficulty with patient–provider communication, a problem for both adults and children *(5)*. Several racial and ethnic minority groups still have significant disparities regarding dental visits (fewer among blacks, Asians, AIs/ANs, and Hispanics), potentially avoidable hospital admissions (greater number among blacks and Hispanics), and suboptimal mental healthcare (worse among blacks, Asians, AIs/ANs, and Hispanics) *(5)*. Tables 4 and 5 show the largest disparities in quality healthcare for selected racial and ethnic groups, as compared with whites, and areas where disparities are increasing.

LIMITATIONS AND CHALLENGES IN RACIAL AND ETHNIC COMPARISONS OF HEALTHCARE DATA

The limitations and challenges related to comparisons based on race and ethnicity are well recognized *(26,27)* and include misclassification of race and

Table 4
Persistent Disparities in Healthcare, by Race or Ethnicity Relative to Reference Group

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

Source: From ref. *5*.
AI, American Indian; AN: Alaska native.

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 AIs and ANs *(28–30)*, can lead to incorrect data that skews comparisons. For example, Rhoades *(28)* recently showed that vital event data unadjusted for racial misclassification showed AIs and ANs as having the lowest mortality rates from major cardiovascular diseases. However, after appropriate adjustment, AIs and ANs had the highest mortality rates. That study highlighted the rapidly growing disparity between cardiovascular mortality rates in AIs and ANs as compared with rates in the US all-races and white populations *(28)*. Often data on specific racial and ethnic groups either are not collected or are collected in formats that differ from federal

Table 5
Three Largest Disparities in Quality of Healthcare for Selected Groups: Measure and Rate Relative to Reference Group

Group	Measure	Relative rate[a]
Black vs White	New AIDS cases	10.4
	Children with hospital admission for asthma	3.7
	Left ED without being seen	1.9
Asian vs White	Mental health treatment for serious mental illness	1.6
	Illness/injury care as soon as wanted	1.6
	Elderly with pneumococcal vaccine	1.5
AI/AN vs White	New AIDS cases	2.1
	Illness/injury care as soon as wanted	1.8
	Children with patient–provider communication problems	1.3
Hispanic vs non-Hispanic White	New AIDS cases	3.7
	Illness/injury care as soon as wanted	2
	Children with patient–provider communication problems	1.8

Source: From ref. *5*.

AI, American Indian; AN: Alaska native; ED, emergency department.

[a] The relative rate is the rate for the stated group divided by the rate for the comparison group.

standards *(28)*. When appropriately collected, the data may be insufficient to generate reliable estimates for specific racial and ethnic groups *(26)*.

The causes of the disparities profiles presented herein are legion and complex *(31)*. Whereas genetics and the gene–environment interaction are important, the disparities described in this chapter should not be assumed to be caused by genetic differences. Race and ethnicity in these settings should be viewed as social, not biological constructs (*32,33)*. 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 their causation. Finally, the availability and quality of data on race and ethnicity may also vary according to the type of data collected, the source of the information, and the definitions and methods used for measurements. The lack of consensus regarding "conceptual and operational definitions of disparities" and the "complexity of measuring health and health determinants" remain major programmatic and research challenges, as recently emphasized by the IOM *(34).*

UNIQUE OPPORTUNITIES FOR THE FUTURE

The epidemiological profiles presented in this chapter can be useful for informing policy and environmental changes that may 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 no readily accessible, well-documented, "credible and comprehensive database" *(35)* or registry of interventions effective in eliminating disparities. Development, implementation, and formal evaluation of such interventions are crucial and are far more important in the effort to eliminate disparities than the continued documentation of their existence *(36).* 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 represents an important opportunity for building a database of effective interventions for reducing and eliminating disparities *(35).* Similarly, the proposal to apply clinical epidemiological methods in the "equity effectiveness loop" *(37),* 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 an important and multifaceted opportunity. The recent IOM recommendations *(34)* on the health disparities research plan of the National Institutes of Health, outlines additional opportunities for improving the strong science base for research to understand and help eliminate health disparities.

CONCLUSIONS

The epidemiological profiles presented herein demonstrate that racial and ethnic disparities in health status and healthcare delivery are pervasive in the United States. Incomplete data and often unstable estimates in some racial/ethnic groups preclude conclusive comparisons. Although modest progress has been made, significant differences still persist in life expectancy and in 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, and disability and their major determinants. The extensive documentation on and vast knowledge about these disparities are unmatched by availability and effectively delivered interventions for their elimination. Thus, the primary challenge that remains is the development and implementation of programs, interventions, and strategies to overcome these disparities in health status and healthcare delivery.

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3

Cultural Diversity in Medicine and in Healthcare Delivery

Richard Allen Williams, MD

INTRODUCTION

The past century has borne witness to a most unique development in the annals of American medicine. The patients who 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 yr, 100 yr 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 yr. 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

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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.

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-yr 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.

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

According to the 2000 US census, minority groups include approximately one-third of the population, with Hispanics replacing 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 AA.
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 20th century, and because there is still a deficiency of record-keeping with the use of race/ethnicity identifiers, this is 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, which 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, 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 12.5% to the present time. 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 *(3)*. 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 11,000 USD. 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 *(4)*. However, it has only been recently that attention has been focused on the health status of the HA community. The Hispanic health and nutrition examination survey, or the so-called "Hispanic HANES" or HHANES *(5)* 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. 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 *(6)*. Coronary atherosclerosis, a major 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 *(7)*.

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 *(8)* 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 *(9)*. Two studies, the Stanford five-city project *(10)* and the San Antonio heart study *(11)* both showed that HA have a higher body-mass index (the ratio of weight to height in kg/m^2) 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 *(10)*.

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 *(12)*. 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 *(13)*.

Regarding health insurance, HA as a group has a higher rate of noncoverage 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 *(14)*. 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 *(15)* revealed that 24 and 34% of HA men and women, respectively, earned less than 10,000 USD/yr, 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 and increasing to 12.3% by the census of 2000. 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, i.e., death, incidence, prevalence, and complication rates are higher for AA and recovery rates tend to be lower. Overall life expectancy, which has improved for all sectors of the population in the 20th century, remains lowest for AA *(16)*. For example, if one compares life expectancy figures for whites and blacks, the following statistics were observed in 1992: white males, 73.2 yr; black males, 65 yr; white females, 79.8 yr; and black females, 73.9 yr. 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 most major categories *(17)*.

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 21st century, and it is predicted that by the year 2015, AA will increase to almost 23% of the total population *(18)*. 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 yr, which is 7 yr younger and 3 yr 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) *(19)*.

AA consist 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 *(20)* 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, USA, 1995*, only 28% of AA had private health insurance, compared with 71% of whites *(21)*. 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 (22)*, 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 *(23)*. A study by University of Michigan researchers *(24)* 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-yr span from the National Survey of Black Americans. A report from Harvard *(24)* 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 *(25)* 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 which 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; 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 *(26)*.

CORONARY HEART DISEASE IN AFRICAN AMERICANS

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. Overall, CHD death rates in 1995 for black males were 133.1/1000 compared with 124.4/1000 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 60.3/1000, 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 *(27)*.

In addition, Gillum *(27)* 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.

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 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 yr, 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" *(28)*. 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 was very large, and African American study of kidney disease as well as A-HeFT were uniformly black.

HYPERTENSION IN AA

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.
- 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.
- 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.
- Response to some pharmacological agents is blunted in many AA patients when these drugs are administered as monotherapy for hypertension. The drugs include β-blockers (with the exception of bisoprolol) and angiotensin-converting enzyme inhibitors. The antihypertensive effects of these classes of drugs is linked to the renin-angiotensin-aldosterone system (RAAS), which does not seem to be as responsive in AA. However, there is greater responsiveness to them at higher dosage levels, but at a cost of more side effects.

Blacks tend to respond better to calcium channel blockers, diuretics, and α1 blockers. In addition, the angiotensin-receptor blockers might also have a salutory effect on black hypertensives; candesartin celexitil, an angiotensin-receptor blocker, was shown to have unusual effectiveness in this group. This was determined in the ABC Study of Hypertension, which was carried out in conjunction with the Association of Black Cardiologists (ABC). The ABC study, which concluded in 1998, was the first to be performed to determine the effectiveness of a single antihypertensive agent in a single racial group.

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 10 billion USD. 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 *(29)* 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 *(30)*. Medicare data have also demonstrated higher rates of admission *(31)* and discharge diagnoses of HF *(32)* for blacks.

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 *(33)*. In addition, Mathew *(34)* 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 *(35)*.

A new treatment paradigm for AA with HF has been proposed based on the African American Heart Failure Trial (A-HeFT) *(36)*. This study, which was carried out in conjunction with the Association of Black Cardiologists, involved 1050 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 suggest that blacks have less natural bioavailability of nitric oxide, and they cite 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 is expected to slow the progression of HF, decrease hospitalizations for exacerbations of HF, and increase survival in AA.

DIABETES MELLITUS (DM) IN AA

DM is the fourth leading cause of death in AA. 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 yr 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 because of 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 USD/yr 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 which 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 *(36)* 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 *(37)*. 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, for example, from the Hypertension Optimal Treatment (HOT) study, 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 advocates a more conservative, nonpharmacological initiation of therapy for lower levels of hypertension whereby there are no other risk factors *(38)*. 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 endarterectomy to detect stenosis. This is an area which 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 *(39)*.

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 *(40)*.
- 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/d, and in AA with renal insufficiency, a goal of 125/75 mmHg should be sought *(41)*.
- 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 *(42)*.

Asian/Pacific Islander Americans

Although it is not the largest minority group in America, APIA represents the fastest-growing group in this country, with an increase in population from 3.5 to 10 million people in just 17 yr, from 1980 to 1997. Currently, APIA represents about 4% of the total US population. Most of the group has emigrated to the US 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 19th 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; and the yonsei (fourth), born here after 1965. 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 *(43)*.

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 which 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 *(44)*. 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 *(45)*. 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 *(46)*. 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 *(47)*. About 32% of all cancer in the city of Canton (Guangzhou) in China are of this type *(48)*.

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) *(49)*.

Tuberculosis

The incidence of tuberculosis is five times higher in APIA than in the rest of the population. 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 *(50)*.

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 *(51)*.

Cardiovascular Disease

As stated earlier, CVD is the leading cause of death for most APIA. 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 *(52)*.

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 *(53)*. In addition, Kagan et al. *(54)* 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 *(55)* 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, 21.8/1000 for total cases and 15.5/1000 for new cases of diabetes; Chinese have the lowest prevalence rates *(56)*. 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, 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 *(57)*. 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 20th 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 yr in 1940 to 71.1 yr 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 *(58)*.

AIAN are 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 one year has lost 74 yr of potential life. For the years 1990–1992, the age-adjusted YPLL for the nation as a whole was 8384/100,000; for AA the comparative figure was 15,468 and for it was 11,875. These figures highlight the disparities, which 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 *(59)*. 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 *(60)*. Regarding hypertension, the Strong Heart Study *(61)*, which was a longitudinal investigation of CVD and attendant risk factors in over 1500 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 yr 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 *(62)*.

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 *(63)*. 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 which 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 attention, 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 OF KEY TERMS

1. *Culture:* the shared values, norms, traditions, customs, arts, history, folklore, and institutions of a group of people.
2. *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.
3. *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.
4. *Cultural sensitivity:* an awareness of the nuances of one's own and other cultures.
5. *Culturally appropriate:* demonstrating both sensitivity to cultural differences and similarities and effectiveness in using cultural symbols to communicate a message.
6. *Ethnic:* belonging to a common group—often linked by race, nationality, and language—with a common cultural heritage and/or derivation.

7. *Language:* the form or pattern of speech—spoken or written—used by residents or descendents 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.
8. *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.
9. *Multicultural:* designed for or pertaining to two or more distinctive cultures.
10. *Nationality:* the country where a person lives and/or one that he or she identifies as a homeland.
11. *Race:* a socially defined population that is derived from distinguishable physical characteristics that are genetically transmitted.
12. *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 *(64).*

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II

CURRENT PROBLEMS

4

Healthcare and the Politics of Race

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INTRODUCTION

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 bottom, I contend, 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 healthcare 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 healthcare.

The Institute of Medicine's (IOM) report on racial disparity in healthcare *(1)* 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 healthcare 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" *(2)*. Some on the left, meanwhile, have criticized the IOM for papering over pervasive racism in American medicine. Since the politics of race are hardly genteel (and since I was a

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coconspirator in the IOM report*), 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 have 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" *(3)*. 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 will devote some effort in this chapter to flushing them out. But my larger aim is to understand the ire. To this end, I will search for the competing moral premises that inspire conflict over whether racial disparities in healthcare are a problem and what the state should do about them. At bottom, I contend, 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 group differences in healthcare 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

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*I 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.

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.

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 *(4)* 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 *(1)*. 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 by comparison with differences between the care that insured and uninsured Americans receive. The panel also noted that health *status*—as opposed to healthcare—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 *(5)*. 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 *(6)*. 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 *(7)*. 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 doesn't 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 and 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 *(8)*. 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, and 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 *(9)*, was a matter of choice, not just Jim Crow law. Sellers of myriad goods and services, including healthcare, 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 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 hasn't 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 doesn't acknowledge the need to draw such lines; instead, he merely ignores the psychic costs suffered by disappointed bigots whom markets (or law) won't let discriminate. But surely

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*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.

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.* Likewise, nearly all would 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?

*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.

†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.

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 *(10)*. 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 don't like, but he doesn't 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 wouldn't. For example, applying a disparate impact standard to health plans would press them to ignore the 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 givens—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 socio-economic 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 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

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*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 by comparison with lifestyle, socio-economic 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 *(11)*.

†More precisely, these costs are spread, but within separate groups, without cross-subsidies between groups.

the mechanisms that contribute to disparity and making political and moral judgements 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 *(12)*. Medical practice surely qualifies *(11)*. 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) don't like to think about.* 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.† 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

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*A 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).

†In criticizing "political correctness" in medicine, Satel and Klick have made this point, albeit in more polarizing fashion than I thinks is helpful, given this topic's sensitivity.

highlights the importance of paying attention to black patients' support systems.* 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 *(13).*

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 *(14).* 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

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*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.

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 *(15)*.

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 healthcare and ridiculing proposed solutions are consistent with this approach. Dispensing with caricatures in order to search for common ground would depart sharply from it.*

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

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*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.

initiatives that target core inequalities of opportunity in American life.* 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, 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.

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*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.

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Barriers to Eliminating Disparities in Clinical Practice

Lessons From the IOM Report "Unequal Treatment"

Joseph R. Betancourt, MD, MPH **and Angela Maina,** BS

INTRODUCTION

Over the last 200 yr, the United States has experienced dramatic improvements in overall health and life expectancy largely owing 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 with whites) from preventable and treatable conditions such as cardiovascular disease, diabetes, asthma, cancer, and HIV/AIDS, among others *(1)*. 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 close proximity to environmental hazards disproportionately impact minority populations and thus contribute to their poorer health outcomes *(2–6)*. 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 *(7)*. 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 delay in seeking care, and are more likely to report that they have not received needed care—all resulting in experiencing avoidable hospitalizations, emergency hospital care, and adverse health outcomes *(8–10)*. Minorities are more

From: *Eliminating Healthcare Disparities in America: Beyond the IOM Report*
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likely to be uninsured than their white counterparts, with data from the US Census Bureau demonstrating that in 2002, 32% of Hispanics and 20% of African Americans were uninsured, compared with only 11% uninsured whites *(11)*.

However, in the last 20 yr 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 *healthcare*. These racial and ethnic disparities in *quality of care* for those with access to the healthcare 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 healthcare 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) *(12–16)*, prescription of analgesia for pain control (African Americans and Latinos receiving less pain medication than whites for long bone fractures and cancer) *(17–19)*, and surgical treatment of lung cancer (African Americans receiving less curative surgery than whites for nonsmall-cell lung cancer) *(20)*. Disparities have also been seen in referral to renal transplantation (African Americans with end-stage renal disease being referred less to the transplant list than whites) *(21)*, treatment of pneumonia and congestive heart failure (African Americans receiving less optimal care than whites when hospitalized for these conditions) *(22)*, and the utilization of general services covered by Medicare (i.e., immunizations and mammograms) *(23)*. 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 United States today (which include minorities on the whole, having lower levels of education and less annual income than whites) *(24)*, research highlighting racial/ethnic disparities in healthcare sheds light on a so far less visible crisis that has up until been given little national attention. As a result of this work, the United States Congress commissioned the Institute of Medicine (IOM) in 1999 to further study the issue of racial/ethnic disparities in the healthcare 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 do the following: assess the extent of racial/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); evaluate 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 systems level; and provide recommendations regarding interventions to eliminate healthcare 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 healthcare 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 *healthcare* (against 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, and so on), provider factors (communication in the medical encounter, the effect of race/ethnicity on clinical decision making, and so on), and consumer factors (patient preferences). To carry out its responsibilities over the 18 mo 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" *(25)* was released on March 20th, 2002. The major findings stated the following:

1. Racial and ethnic disparities in healthcare exist, and because they are associated with worse health outcomes, are unacceptable.
2. Racial and ethnic disparities in healthcare 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.
3. Many sources—including health systems, healthcare providers, patients, and utilization managers—may contribute to racial and ethnic disparities in healthcare.
4. Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare.
5. 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 healthcare 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, all aspects of clinical practice that might lead to racial/ethnic disparities in healthcare were explored. Three in particular—provider–patient communication, clinical decision making, and mistrust stood out. Herein, their clinical relevance, and how they contribute to racial/ethnic disparities in healthcare is explained.

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 *(26)*. Healthcare 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 *(27,28)*. 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 might result *(29)*.

A recent telephone survey of 6722 Americans, 18 and over, commissioned by the Commonwealth Fund *(30)* shed additional light on this issue, and was particularly relevant given the important link between provider and patient communication and health outcomes. White, African American, Hispanic, and Asian Americans who had had a medical visit in the last 2 yr 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 with 23% of the time for African Americans, 33% for Hispanics, and 27% for Asian Americans.

In addition, provider–patient communication without an interpreter, in the setting of even a minimal language barrier, is recognized as a major challenge to effective healthcare delivery *(31–33)*. 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 *(34)*; 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 *(35)*; and less satisfied with the patient–provider relationship *(35)*. In addition, physicians who have access to trained interpreters report a significantly higher quality of patient–physician communication than physicians who used other methods *(36,37)*. Hispanic patients with language discordant physicians are more likely to omit medication, miss office appointments, and visit the emergency room for care *(38)*. 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 healthcare.

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) *(39)*. 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 short-cuts for clinical decision making (e.g., cough and fever likely equals bronchitis or pneumonia). Although this runs counter to what is taught about generating a detailed review of symptoms and a broad differential diagnosis, as is practiced under greater stress and time pressure one becomes more susceptible to using these "shortcuts" in the 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.

However, the explorations revealed that many nonmedical factors, ranging from the patient's physical appearance to the organizational setting in which medical care is delivered, might have as much influence on clinical decisions as the actual signs and symptoms of disease *(39,40)*. The 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) *(41–51).*

The literature on social cognitive theory has also brought to attention the ways in which natural tendencies to stereotype might influence clinical decision making. Everyday the researchers are faced with enormous amounts of information that must sift through in order to make decisions. As a result, they share the subconscious strategy of attempting to simplify the decision making process and lessen the cognitive effort by using "categories" or "stereotypes" in which they apply beliefs and expectations about groups of people to individuals from that group *(52–54).* Interestingly, one might not be aware of ones 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,* and *cognitive* process that is oftentimes automatic, and most likely centered on (in rank order) *race, gender,* and *age*—characteristics that manifest visually *(53).* Most importantly, one tends to activate stereotypes most when *stressed, multitasking,* and under the *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 might lead to disparate treatment; discrimination is conscious and intentional disparate treatment *(53).* All stereotype naturally and oftentimes subconsciously, despite the 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 *(55,56).*

Several processes may contribute to the development of stereotypes, even among those who consider themselves well intentioned and egalitarian. Based on the training or practice location, one might develop certain perceptions about race/ethnicity, culture, and class that might evolve into stereotypes *(57).* 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 and so on) than patient's racial/ethnic background or cultural traditions. This "conditioning" phenomena 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 healthcare system than any other racial or ethnic group (with Latinos not far behind) *(58)*. This mistrust might 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. Again, this stereotyping is natural and expected—but no less dangerous—phenomena that might affect the way doctors make decisions and offer specific interventions to different patients based on their race or ethnicity.

Mistrust

Mistrust has become a major concern for many institutions today. Frequent scandals in social groups, financial, political, and healthcare institutions have led to deteriorating levels of trust among members of the general public. The IOM Reports, "To Err is Human: Building a Safer Health System," which documented alarming rates of medical errors *(59)*, and "Unequal Treatment" made patients feel vulnerable and the public less trusting of the US healthcare system. The increased publication of medical errors and poor quality care has also clearly diminished trust in doctors and nurses *(60)*. The media has played a significant role in the public's mistrust of healthcare providers with headlines such as "Nursing Mistakes Kill, Injure Thousands" *(61)* and "How Hospitals are Gambling with your Life" *(62)* perpetuating mistrust among patients and prompting second thoughts about seeking medical attention.

Trust is a crucial element in the therapeutic alliance between patient and healthcare provider. It facilitates open communication and is directly correlated with adherence to physician recommendations and patient satisfaction *(63)*. Patients who mistrust their healthcare providers are less satisfied with the care they receive *(64)* and mistrust of the healthcare system greatly affects patient's 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 *(65)*.

Based on historical factors of discrimination, segregation, and medical experimentation, African Americans in particular may be especially mistrustful of providers *(66)*. The exploitation by the US Public Health Service during the Tuskegee study left a legacy of mistrust that persists even today among this population *(67,68)*. A recent national telephone survey conducted by the Kaiser Family Foundation in 2000, found that there is significant mistrust for the healthcare system among minority populations. Of the 3884 individuals surveyed, 36% of Hispanics and 35% of African Americans (compared with 15% of whites) felt they were treated unfairly in the healthcare system in the past based on their race and ethnicity. Perhaps even more alarming—65% of African Americans and 58% of Hispanics (compared with 22% of whites) were afraid of being treated unfairly in the future based on their race/ethnicity *(69)*. In contrast, a similar national mail survey of 2608 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 healthcare system "never," (14%), or "rarely" (55%) treats people unfairly based on race/ethnicity *(70)*. 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 *(71)*.

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.

WHERE DO WE GO FROM HERE?

The IOM Report "Unequal Treatment" provided a series of recommendations to address racial and ethnic disparities in healthcare 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. They are as follows:

1. Increase awareness of racial/ethnic disparities in healthcare: as described above, recent surveys have shown that both physicians and patients are not aware of the extent, or the severity, of racial and ethnic disparities in healthcare in the United States. Increasing awareness of racial and ethnic disparities among healthcare professionals is an important first step in addressing disparities in healthcare. Strategies to increase awareness and education regarding health disparities can occur through several venues—including through Grand Rounds, public relations campaigns, newsletters, as part of ongoing curricula, and so on *(70)*.
2. Collect and report healthcare access and utilization data by patient's race/ethnicity: one of the foremost challenges in the effort to eliminate racial/ethnic disparities in healthcare 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 healthcare disparities based on race and ethnicity. As a result, the report is unable to give a local "snapshot" of the issues facing a particular healthcare 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" *(72)*. Consequently, not only does one lack the appropriate systems to track and monitor racial and ethnic disparities in healthcare, but also knows little about the disparities that other minority groups (Hispanics, Asian Americans, Pacific Islanders, Native Americans, and Alaska Natives) might 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 healthcare systems, hospitals, and health plans, with a few notable exceptions, do not collect data on patients' or enrollees' race, ethnicity, or primary language. It is clear that the ability to track and eliminate racial and ethnic disparities centers on the ability to collect race and ethnicity data in a systematic and standardized fashion. Only then can one effectively identify disparities locally, and then implement strategies to monitor and eliminate them as part of quality improvement and performance measurement efforts. This leads directly into the next recommendation.

3. 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 healthcare by describing how clinicians may offer different diagnostic and treatment options to different patients (consciously and unconsciously) based on their race or ethnicity, even in the presence of well-delineated practice guidelines. As such, the adoption and implementation of evidence-based guidelines broadly 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 wherein 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. The goal of the use of evidence-based guidelines is to ensure that all patients are getting the highest quality of care, regardless of their race, ethnicity, culture, or class. Healthcare providers can play a major role in advancing this agenda.
4. Support the use of language interpretation services in the clinical setting: as described previously, healthcare systems that lack interpreter services can lead to patient dissatisfaction, poor comprehension and compliance, and ineffective lower quality care for patients with limited English proficiency *(31–38,73)*. Doctor–patient communication without an interpreter, in the setting of even a minimal language barrier, is recognized as a major challenge to effective

healthcare delivery *(31–33)*. The report's recommendation to support the use of interpretation services has clear implications for healthcare delivery.

5. Increase the proportion of underrepresented minorities in the healthcare workforce: recent data available from the American Medical Association is indicative of the 70.5% of US physicians whose race and ethnicity is known, Hispanics make up 3.5%, African Americans 2.6%, and American Indian and Alaska Natives less than 0.5% percent, respectively. Minority physicians are also poorly represented in specialties such as cardiology, surgery, and radiation oncology *(74)*. Data regarding the racial/ethnic composition of medical school faculty is no different, with minorities making only 4.2% nationally. It should further be noted that approx 20% of this group are located at three historically black medical schools (Howard University School of Medicine, Meharry Medical College, Morehouse School of Medicine), and three Puerto Rican medical schools (Universidad Central del Caribe School of Medicine, Ponce School of Medicine, and the University of Puerto Rico School of Medicine) *(75)*. As it relates to the future healthcare workforce, despite making 30% of the population, minority students accounted for approx 10% of medical school graduates in 2001. The majority of these students (65%) were African American, with smaller percentages of Mexican American students (22.6%), mainland Puerto Ricans (6.4%), and Native Americans (5.9%) *(76)*. Among medical school graduates in 2001, nearly half of minority graduates indicated plans to practice in underserved areas, compared with less than one-fifth of nonminority students. In sum, given the important role academic health centers play in training the future healthcare 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 healthcare 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.
6. Integrate cross-cultural education into the training of all healthcare 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 healthcare providers might lead to disparate treatment based on a patient's race or ethnicity, it is now felt that cross-cultural curricula should be expanded to explore the role of race, ethnicity, and culture on clinical decision making. In summary, cross-cultural curricula should provide an overview of healthcare 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.

CONCLUSION

The IOM Report "Unequal Treatment" provides the first detailed, systematic examination of racial/ethnic disparities in healthcare. 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—race/ethnicity data collection, quality improvement through the use of evidence-based guidelines, and interpreter services—as well as those related to healthcare professionals—increasing awareness, providing cross-cultural education, and minority recruitment—should help address disparities that arise from the clinical encounter. Ultimately, the strategies presented herein 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 healthcare providers. Ultimately, we can ill afford to have patients sustain complications of long term, treatable chronic conditions because we were not able to provide the highest quality of care to all patients we see, regardless of their race, ethnicity, culture, class, or language proficiency.

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6

Second-Class Medicine

Implications of Evidence-Based Medicine for Improving Minority Access to the Correct Pharmaceutical Therapy

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INTRODUCTION

The Promise of Evidence-Based Medicine

The spectacular ascent of medical science at the dawn of the 21st century trumpets a new era in US healthcare 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 life-saving technologies to low-income and minority patient populations, whereas simultaneously controlling ever-rising healthcare 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 healthcare 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

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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 *(1–4)*."

The National Dilemma of Racial Health Disparities

This latter promise—the assurance of greater fairness, and, by logical extension, a reduction in healthcare disparities—should not be accepted without critique. Health inequality represents one of the most persistent, ubiquitous, and troubling phenomena in the United States health system. Evidence of racial disparities in health status long predates the Civil Rights era *(5)*, with systematic studies that document these disparities appearing in the literature at least as early as 1899 *(6)*. Clayton and Byrd have richly documented a continuous pattern of systemic racial inequality in healthcare dating back to at least the 17th century and persisting, significantly unabated, into the present millennium *(7,8)*.

Over the past two decades, at least 600 journal articles and eight 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 healthcare *(9,10)*. 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 healthcare 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 healthcare *(11–13)*. Accounting for key variables such as age, sex, socioeconomic status, and health plan, the studies analyzed healthcare 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 *(11)*.

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 *(12)*. 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 *(13)*." 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 EBM to promote "greater fairness" in healthcare 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 *(9)*. 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 overrepresented. The mechanism by which—or evidence of how—restrictive formularies/PDLs will reduce healthcare costs whereas 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 healthcare, 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 dormant but crucial concerns, a discussion intended to generate greater dialog about the actual potential of EBM to improve minority access to medical technologies, specifically life-saving 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 healthcare coverage decision making, and the implications of this trend for minority access to life-saving medications are discussed. Third, to explore the capacity (and potential) of EBM to reduce (or exacerbate) healthcare disparities, health system fragmentation is discussed in brief—a key system-level factor identified by IOM that contributes to healthcare 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 healthcare 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 *(14)*. 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 *(15,16)*.

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 *(14)*. Steinberg and Luce *(14)* 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 life-saving 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 *(15)*.

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 *(14)*." 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 *(14)*.

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 *(17–19)*. 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 *(20)*. 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 *[21]*), 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 United States is that scientists have copiously reported racial and ethnic healthcare disparities across an impressive array of diseases, whereas 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 *(20)*.

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 homogenous 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 *(22)*, 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 *(23)*. 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 healthcare 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 *[24]*) are at risk for regulatory profiling, despite the lack of evidence to counter these clinical experiences. This leads to "cherrypicking"—"high-risk" patients are excluded from care to improve healthcare report cards—thereby exacerbating disparities *(25)*.

The lack of therapeutic trial data for minority populations arises, at least in part, from the lack of diversity among researchers *(9,10)*. 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 *(26)*." 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 *(10)*.

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 *(27)*. 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 *(10)*. 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 healthcare 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 *(28–32)*. 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 sociohistoric dimensions of health, including their historic exclusion from the nation's healthcare workforce, African American physicians may bring different viewpoints to the prioritization of research projects; 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 *(33)* 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 healthcare system *(10)*. 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 *(34)*." A largely unchecked use of EBM is its application to drug review processes that control access to life-saving 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 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 *(35)*.

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 healthcare 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

Table 1
Classes of Drugs Reviewed By the Oregon EPC as of September 2004

Angiotensin-converting enzyme inhibitors
Angiotensin-II receptor antagonists
Antidepressants (second generation)
β-adrenergic blockers
Calcium-channel blockers
Estrogens
Inhaled corticosteroids
Opioids (long acting)
Nonsteroidal anti-inflammatory drugs
Oral hypoglycemics
Proton pump inhibitors
Skeletal muscle relaxants
Statins
Triptans
Urinary incontinence drugs

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 three newly selected drug classes (Table 1).

There is increasing evidence that systematic drug reviews can change the economic dynamics of healthcare delivery by controlling product selection, influencing market share, and increasing supplemental rebates to the states from the drug manufacturers *(35)*. However, a significant decisional gamble arises, in that, healthcare policymakers who use EBM frameworks to set distributional policy must presuppose that the evidence required to make their decisions is present in the EBM framework and relevant to the target population *(36)*. Stated another way, policymakers must assume that any *unavailable* evidence is insignificant and that the *available* evidence is "one-size-fits-all" in terms of external validity. Consequently, current EBM-based drug coverage decisions are potentially problematic because: (1) they disregard the clinical implications of different responses to drugs of racial and ethnic minority groups and (2) they discount the variables of patient preference and physician experience, which integrate the clinical and sociocultural conditions often excluded from the trials forming the EBM evidence base.

Regression From the Optimal Goal of Individualized Medicine

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 *(26)*." 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 healthcare 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 *(37)*." 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 *(37)*."

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 *(38)*. 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 healthcare 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 *(9)*." 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 healthcare. 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 *(39)*. 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 *(40)*.

Helfand and others *(16)* 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 d.
- 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 HEALTHCARE 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 *(41)*. 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 healthcare delivery. Indeed, the paramount objective of cost-focused EBM is the reduction and/or containment of healthcare costs, achieved through direct or indirect political control of the clinical environment.

Over the past half-century, legitimate concerns about healthcare spending have given rise to a cost-management industry, which now seeks increasingly greater control of the healthcare 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 *(42)*.” 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 healthcare 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" healthcare 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 *(4)*."

Healthcare 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 healthcare 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 healthcare 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 *(4)*."

According to the IOM, the conscious or subconscious decision by healthcare 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 healthcare 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) *(9)*." 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 *(9)*." For example, in 2003, 49% of Medicaid beneficiaries were racial and ethnic minorities *(43)*.

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* healthcare disparities. To the contrary, EBM's greater fragmentation of healthcare delivery will almost certainly worsen racial inequities in healthcare delivery, increase morbidity and mortality among minority groups, and increase healthcare 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 *(44)*.

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 healthcare 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 *(45)*. 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 healthcare delivery. These antidisparity 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 healthcare access for racial and ethnic minorities and other populations facing systemic access barriers to life-saving 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 *(46)*. 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 *(9)*." 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, antidisparity policies must promote proactive efforts to identify, understand, and eliminate racism in EBM. Semmes *(47)* 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 healthcare today is, which exists institutionally through polices 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 *(22)*. These agendas have resulted in the persistence of well-marked patterns of racial inequality in healthcare delivery.

Previous calls have been made to investigate and challenge the influence of racism in the health sciences and in health disparity interventions *(48)*. In the absence of policies that identify and eradicate this debilitating health system phenomenon, EBM reviews will likely advance along the well-trod path of "scientific racism" in the health sciences *(7,8,49)*. Antidisparity policies can serve as an important vehicle for countering this trend and ensuring a more equitable and responsive healthcare 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 healthcare system. Last, antidisparity provisions in EBM must be driven by an explicit policy commitment to support federal and state mandates to eliminate racial and ethnic disparities in healthcare. This overarching commitment should ensure that EBM projects take account of equity and justice in project design, data analysis, and health policy decision making.

CONCLUSION

As policymakers struggle with rising healthcare costs, there is an urgent need to revisit the use of EBM and to assess its impact on delivering equitable healthcare 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 healthcare. First, states have increasingly adopted EBM as a cost containment device, subjugating health outcomes to cost control, further fragmenting the healthcare 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 healthcare 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 healthcare delivery—it is likely that "EBM" will *worsen* minority access to therapeutic interventions, *exacerbate* health status disparities, and *increase* associated spending.

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7

The Diversity Benefit

How Does Diversity Among Health Professionals Address Public Needs?

Brian D. Smedley, PhD

INTRODUCTION

Recent US Census data confirm what many Americans have casually observed: racial and ethnic minorities are the fastest-growing segments of the US population. By mid century, nearly 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 3.5 million or over one-half of the population increase of 6.9 million individuals in the United States. The number of Asian Americans grew at a larger proportion (9%) than any other racial or ethnic group during this same time period. And in at least three states (California, Hawaii, and New Mexico) and the District of Columbia, racial and ethnic "minorities" constitute a majority of the population *(1)*.

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 Islander health professionals has grown only modestly at best over the past 25 yr. 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, make up over 12% of the US population, but only 2% of the registered nurse population, 3.4% of psychologists, and 3.5% of physicians. Similarly, one in eight individuals in the United States is African American, yet less than one in twenty dentists or physicians are African American.

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In 2004, two major reports on racial and ethnic diversity among healthcare professionals—one released by the Institute of Medicine (IOM) *(2)* and another released by a commission chaired by the former US Secretary of Health and Human Services, Dr. Louis Sullivan (The Sullivan Commission) *(3)*—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 healthcare for racial and ethnic minority populations. 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)".

How should the health professions respond to these demographic shifts? 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 owing to diseases such as diabetes, HIV/AIDS, cardiovascular diseases, and other chronic and infectious illnesses? And if so, how can greater diversity among health professionals be achieved? This chapter will briefly summarize research relevant to these questions.

DOES DIVERSITY MAKE A DIFFERENCE?

Researchers, policymakers, healthcare administrators, and public health officials are increasingly focused on reducing and eliminating racial and ethnic disparities in healthcare. Often, their discussions focus on 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? 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?

Definitive answers to these questions are not yet apparent, as few studies have adequately assessed the role of patient-provider racial/ethnic concordance in patient outcomes. One study, by Chen and colleagues *(4)* 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 d of hospitalization—regardless of whether the patients' physicians were black or white. But this study has been criticized on the grounds that it is unclear whether the patients' admitting physician made the decision to recommend catheterization, or whether this decision rested with a cardiologist or other specialist, who tend to be overwhelmingly white *(5)*. More recently, a study by Bach and colleagues *(6)* found that physicians who serve predominantly racial and ethnic minority patients are less likely to possess board certification, and have greater difficulties accessing high-quality specialists, diagnostic imaging, and nonemergency admission of their patients to the hospital than physicians who serve predominantly nonminority patients. This suggests that comparisons of minority patient outcomes among those in concordant and nonconcordant relationships must carefully control for the range of potential differences in their physicians' training and access to clinical resources. On the other hand, Rosenheck *(7)* found that, compared with 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 improve ment in 1 of 15 health outcomes. More research must be conducted to fully understand the relationship between provider-patient race concordance and patient outcomes.

Perhaps more significantly, although it's logical to pose questions regarding racial/ethnic patient-provider concordance and patient outcomes, they are often not the most important questions to ask regarding the importance of diversity among health professionals. 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, whereas in other instances they are less so.

However, this chapter 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, and how diversity affects minority patient choice, satisfaction, and access to care. Viewed in this context, greater diversity among health professionals confers at least three broad benefits. First, it is now well established that racial and ethnic minority health professionals are more likely to work in minority and medically underserved communities, and have a higher caseload of patients who might not otherwise have access to a healthcare provider. Greater diversity among health professionals would therefore tend to increase the availability of providers who understand the needs of and are committed to working in communities with some of the most significant health needs. Second, a growing body of research demonstrates that a number of healthcare process variables—including the quality of communication, the degree of patient understanding and of satisfaction with care, and the likelihood of appropriate follow-up and referral—are improved when patients who desire providers of their own racial and ethnic background are able to select them. Third, a new line of research suggests that greater diversity among health professions students and faculty in training settings, as well as in in-service settings, is important to assist efforts to improve the cultural competency of health systems, and to improve the clinical training of *all* students. The implication of this research is that diversity in training settings yield benefits for all patients, minority and nonminority alike. Fourth, greater diversity among healthcare scientists and professionals can be expected to help improve health research on and involving racial and ethnic minority populations, as minority investigators and their clinical colleagues are likely to have greater success in building trust and recruiting minority clinical research participants. These issues are explored in greater detail in the following sections.

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

Racial and ethnic minority healthcare professionals are 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 is true across a range of health professions, although the bulk of this research has focused on the practice patterns of physicians.

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 *(8)*, for example, in a nationwide survey of households, found that minority patients were more than four times more likely than white patients to receive healthcare 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. *(9)* 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. Similarly, Komaromy et al. *(10)* in a survey of over 1000 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 are also more likely than their white peers to practice in racial and ethnic minority communities. Solomon, et al. *(11)*, 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 *(12)*, 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.

Diversity and Minority Patient Choice and Satisfaction

Racial and ethnic minority patients who have a choice are more likely to select healthcare providers of their own racial or ethnic background. They are also generally more satisfied with the care that they receive from minority physicians. Saha, et al. *(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 healthcare, 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 healthcare, 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 *(14)* 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 had a choice in physician, African American patients in race-concordant relationshipxs 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 colleagues *(15)* also found that minority patients' ratings of the quality of their healthcare 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. However, patients in race- and ethnic-concordant relationships rated their visits as significantly more participatory than patients in race- and ethnic-discordant relationships.

Diversity and Quality of Healthcare Process and Communication for Minority Patients

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, et al. *(16)*, 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, whereas 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.

In addition, as aforementioned, research indicates that minority physicians display better process-of-care behaviors with minority patients than nonminority clinicians. Cooper-Patrick and colleagues, in a study of over 1800 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. *(17)* 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 effect in these visits than did patients in nonconcordant dyads. Patient in race-concordant relationships also reported higher levels of satisfaction with care, and rated their physicians as more participatory than patients in nonconcordant dyads. However, measures of physicians' communication styles 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.

These studies suggest that cross-cultural education and communication strategies may help to improve healthcare process measures and communication among racial and ethnic minority patients. Should training programs improve physicians' participatory decision-making and communication skills, 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 *(18)*.

Diversity and Quality of Training for All Health Professionals

As aforementioned, 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. *(19)* 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 previous educational experiences, as the percentage of students reporting contact with other groups increased from 50% before 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. Students from diverse backgrounds interacting with each other in training settings may therefore help to challenge assumptions 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 *(20,21)*. Diversity among students in training settings, these studies find, may enrich classroom discussions and spur changes in curricula to address students' cross-cultural educational 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, standardized test scores, high school grade-point average, parents' educational level, racial composition of high school and neighborhood when growing up), institutional characteristics, and initial (pretest) 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' previous academic and socioeconomic background and precollege racial exposure, as well as measures of democracy orientation on 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.

Diversity Among Health Professionals: Benefits for Research and Health Policy

In addition to these benefits for healthcare delivery, greater diversity among health professionals may also yield benefits in other important areas. Greater participation of minority scientists in health research can 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 *(22)*. 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 historical 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 patients' mistrust and improve communication between the scientific and lay communities *(23)*.

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. However, diversity in health systems leadership should not be assumed to (in and of itself) 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 *(24)*.

STRATEGIES TO INCREASE DIVERSITY IN THE HEALTH PROFESSIONS

Over the past 35 yr, federal and state governments, many leading health philanthropies, and many educational institutions have developed initiatives to increase diversity among health professionals. To date, such efforts have met with limited success. The Association of American Medical Colleges' Project 3000 × 2000, for example, sought to achieve the goal of admitting and graduating 3000 new underrepresented minority medical students by 2000. The Association of American Medical Colleges 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 3000 × 2000 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 declines (in some cases, temporarily) in the recruitment and admission of minority students in health professions schools *(25)*.

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 the 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 nonminority 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 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 and more experienced teachers, and the resources to address students' learning and counseling needs. And studies demonstrate conclusively that teacher quality and preparation are correlated with student performance *(26)*.

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 mathematic skills to college entrance exams (e.g., the SAT) and graduate health professions education admissions tests (e.g., the Medical College Admission Test, the Dental Admission Test) *(27)*. And even when minorities who attended poor quality schools succeed despite the odds and gain admission to higher education institutions or HPEIs, their poor previous education leaves many unprepared to handle the demanding curriculum of a prehealth professions or health professions course of study *(28)*.

The Sullivan Commission and IOM *Compelling Interest* reports acknowledge this reality, and call for wholesale changes in the 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 *(29)*.

Priming the Educational Pipeline

The Sullivan Commission report calls for efforts to provide support for 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 US Public Health Service, state health departments, HPEIs, and others support a public awareness campaign to encourage minority students to pursue careers in health professions.
- HPEIs 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 *(30)*.

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 prehealth professions programs, from 2–4-yr 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-yr colleges—particularly graduates of 2-yr 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, whereas at the same time sources of grant aid have decreased (Advisory Committee on Student Financial Assistance, 2002). The trends toward increased tuition costs and decreased 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 US 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. However, federal financial aid is unlikely to be sufficient 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 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 member 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 *(31)*. The IOM and Sullivan Commission reports encourage HPEIs to:

- Encourage admissions procedures to closely follow the institutions' stated mission concering 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' previous 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 healthcare, 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 underrepresented minority 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." 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, and judicial and policy decisions that have hampered efforts to consider the importance of diversity in the admissions process. Many of these barriers can be reduced, if not eliminated, if the individuals and organizations that stand to benefit from greater diversity among health professionals—including health professionals, the HPEI community, health policymakers, grassroots and community leaders, educators, corporate and business leaders, organized labor, and the general public—can commit to work in coalitions to create the necessary "push" to support strategies to increase diversity among health professionals. As a start, health professions organizations should assess and disseminate information about HPEI applicants, matriculants, and graduates from underrepresented 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 dissemination 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. 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. History has demonstrated that absent such a multifaceted, collective approach, diversity efforts will fail to fully achieve their goals. More significantly, the ability of the American healthcare workforce to meet the needs of the nation will continue to erode.

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III

APPROACHES TO CORRECTING THE PROBLEMS

8

Eliminating Disparities in Healthcare Through Quality Improvement

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INTRODUCTION

This chapter discusses the role of quality improvement (QI) as a vehicle for eliminating racial and ethnic disparities in healthcare. Disparities in health and disparities *healthcare* 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 healthcare requires addressing the predominant cause of a particular healthcare disparity. This can be done through well-designed QI 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 QI activities to all patients in the expectation that the intervention disproportionately benefits minorities. A range of QI tools exist to improve care to minorities. Review of available evidence shows that it is possible to reduce, if not eliminate, disparities in healthcare using these tools. However, doing so requires a concerted commitment on the part of health plans and insurance payers to adequately finance such efforts.

The release of "Healthy People 2010 Goals for the Nation" and the Institute of Medicine report, "Unequal Treatment," *(1)* has shifted focus from merely documenting disparities in healthcare to implementing interventions designed to address them. In another report, the Institute of Medicine acknowledges equity as a core dimension of quality *(2)*. This acknowledgment effectively institutionalizes the elimination of disparities in healthcare as an essential function of QI. A key point of this chapter is the critical role

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that QI can play in the elimination of racial/ethnic disparities in healthcare. The chapter reviews the potential causes of these disparities and discusses QI tools potentially relevant to addressing disparities in healthcare. The chapter concludes with a discussion of current QI efforts specifically designed to address disparities in healthcare.

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 *(3)*. Racial/ethnic disparities in health refer to instances in which 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 healthcare. Moreover, because disparities in *healthcare* represent inequities in the process of healthcare, they are potentially addressable through interventions designed to impact health delivery. Eliminating healthcare disparities will facilitate progress toward the 2010 goal of eliminating disparities in health. However, achievement of the national goal of eliminating racial and ethnic disparities in health will likely require fundamental societal reform.

DISPARITIES IN HEALTH

Racial and ethnic minorities, particularly African Americans, have historically experienced inferior health outcomes as compared with whites *(4)*. African Americans have higher adult and infant mortality than whites and other minority groups *(5–7)*. They also have considerably higher mortality rates than whites from cardiovascular disease, cerebrovascular disease, cancer (lung, colorectal, breast, prostate, and cervical), pneumonia/influenza, diabetes, human immuno deficiency virus (HIV), unintentional injuries, pregnancy, sudden infant death syndrome, and homicide *(8)*. 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 *(8)*. Rates of stomach, liver, and cervical cancer among Asian Americans and Pacific islanders also exceeds those of whites *(9)*.

Additionally, rates of disease and death for American Indians/Alaska natives are higher than whites for pneumonia/influenza, liver disease, obesity, pediatric tuberculosis, bronchiolitis, diabetes, sudden infant death syndrome, and diabetic kidney disease *(10,11)*. 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 *(12,13)*. In fact, most of the 5.5-yr gap in adult life expectancy between black and white males is explained by racial disparity in SES *(14)*. Moreover, contrary to popular portrayal, there is currently little evidence that genetics make an appreciable contribution to disparities in health *(15,16)*.

Racism also strongly affects the health of African Americans (and other minorities to varying extent) at three distinct levels: (1) institutionalized policies and practices, (2) individual discrimination and biased treatment, and (3) internalization of racial stereotypes *(17)*. Each of these levels reinforces the other. Institutionalized racism, manifested by historic inequities in employment opportunities, income, wealth, education, healthcare, and criminal justice *(18)*, 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 *(19)*. 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 dropout and/or emulation of gangster subculture portrayed through the popular media *(20)*.

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 *(21)*. African Americans experience the greatest residential segregation of any minority group *(22)*, resulting in a veritable *American Apartheid (23)*. 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 of institutions, including healthcare *(18,19,24)*. Contrary to popular perception, lifestyle factors contribute only moderately to disparities in health *(6,25)*. 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.

DISPARITIES IN HEALTHCARE

Although racial/ethnic disparities have been highlighted in recent years, they can be traced back to the enslavement of African Americans *(26)*. The National Healthcare Disparities report, produced annually by the Agency for Healthcare Research and Quality documents persistent disparities in healthcare quality by race, ethnicity, and SES *(27)*. Nonetheless, disparities are at times subtle and by no means ubiquitous. For example, no racial disparities were observed in directly observed primary care encounters *(28)*. In their study, Escarce and Kapur *(29)* found no racial or ethnic disparities in expenditures among Medicare beneficiaries. Additionally, Asch et al. *(30)* observed no racial disparities in the quality of healthcare in a national sample. 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 disparity 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 a sense of optimism that focused QI efforts might yield success in eliminating healthcare disparities when they are identified.

Racial disparities in healthcare have been noted across most of the key dimensions in the healthcare process (effectiveness, safety, timelines, 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)*. In addition, this minority group experiences lower quality prenatal care *(42)*;

fewer root canals compared with 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)*. However, among Medicare Health Maintenance Organization (HMO) enrollees African Americans show the largest disparities in quality followed by Hispanics and American Indians/Alaska natives, whereas Asians/Pacific islanders receive higher quality care than whites for some measures *(54)*.

In the end, the variation in disparities in healthcare across region, type of healthcare, 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 healthcare. Examples include patient knowledge *(56,57)*, mistrust *(58)*, affordability *(59–61)*, limited English proficiency *(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 healthcare *(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 clearly affected by presence of 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)*, previous experience, social networks *(80)*, racism *(81)*, previous experience among friends and family *(82)*, and most importantly, information provided by physicians. 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 healthcare include patient stereotyping *(83)*, expectation of benefits *(43)*, clinical uncertainty stemming from lack of cultural/linguistic competency *(84–86)*, physician participatory decision making style *(87)*, and competing demands during visits and cognitive overload *(88,89)*. That being said, provider factors strongly affect patient factors *(85)*, as patient "preferences" are shaped not only by previous experience, but also by provider–patient trust, clear communication, and the ability to provide culturally competent care. It is interesting to note that a survey of nephrologists showed that most nephrologists discounted providers' factors as contributors to disparities in access to transplantation *(90)*. 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 *(90)*.

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 *(91)*. Provider-level factors are likely to be paramount when guidelines for performing a particular procedure are unclear and medical uncertainty is high *(92)*. Examples include hospital admission for chest pain *(41)*, as well as the performance of certain diagnostic or therapeutic procedures such as angiography *(93)*, coronary artery bypass surgery *(94)*, total hip replacement *(95)*, and renal transplantation *(96)*. Physicians may be more susceptible to unconscious stereotyping and/or patient demand when confronted by medical or surgical uncertainty *(89)*. The result is often a combination of under utilization of the service by minorities and excessive use by whites *(96,97)*.

Organizational Factors

Organizational factors can also contribute to disparities in healthcare. Healthcare systems and healthcare plans influence the location of physician offices, the diversity of the work-force *(98)*, provider continuity, availability of interpreters *(78)*, reading level and cultural appropriateness of written materials *(98)*, size of copayments and deductibles, location of facilities *(99)*, implementation of practice guidelines, and culturally appropriate health promotions *(1)*. Most importantly, organizations are responsible for implementing effective QI 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 *(100)*, 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 healthcare. These factors include community rates of insurance *(101)*, availability of safety net providers *(102)*, proximity and availability of providers *(103)*, community trust in healthcare providers *(104)*, availability of regular sources of care *(74,105)*, continuity of care *(106,107)*, community medical knowledge *(108)*, and variation in community practice *(109)*. Most of the disparity in knee arthroplasty for elderly Hispanics is explained by geographic differences whereas only one-third of the disparity for elderly black women and little for elderly black men is explained by geography and practice variation *(109)*. Inequality in other procedures also varies considerably by region of the country *(110)*.

In some instances, minorities receive care from lower quality providers. African Americans are more likely to be seen by primary-care physicians who report they lack the necessary resources to provide high-quality care *(111)*. At least in New York state, African Americans are more likely to undergo cardiac surgery from a surgeons with higher mortality rates *(82)*, are more likely to be re-admitted for complications following coronary artery bypass surgery *(112)*. In Maryland, blacks have been reported to undergo carotid endarterectomy more often than whites by less experienced surgeons *(113)*. African American very low birthweight infants are more likely to be treated in hospitals with higher neonatal intensive care mortality rates *(114)*. Elderly African Americans are more likely to be enrolled in HMOs with lower quality ratings *(115)* and admitted to nursing homes of lower quality *(116)*. 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 ensure 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 healthcare. Lack of insurance has been linked to suboptimal healthcare (and higher mortality) *(117)*. Among the 46 million uninsured Americans, there are striking racial/ethnic disparities. Rates of uninsured whites, blacks, Hispanics, Asians, and American Indians are 8, 15, 23, 13, and 20%, respectively *(118)*. Among those with insurance, minorities are more likely to lack supplemental or prescription coverage *(119)*. African Americans are more likely to be insured through Medicaid *(120)*, and many providers do not participate in this program *(103,120)*. Because insurance is so strongly linked to access to care *(117)*, lack of universal health insurance and difference in quality of insurance imposes a critical limit on reductions in racial/ethnic disparities in healthcare quality.

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 *(121–124)*. Provider factors play a smaller role in disparities for commonly recommended preventive services such as Pap smears, mammography, and immunizations *(28,125)*, 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 *(91)*. In addition, providers are likely to be most susceptible to bias when indications for a particular procedure are unclear and medical uncertainty is high *(126)*. Organizational and community factors impact healthcare disparities primarily by affecting patient and provider behavior.

ROLE OF QI

Despite the complexity of disparities, available evidence suggests that disparities in healthcare are not intractable. The finding that disparities differ between organizations and regions suggest 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 healthcare, 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 healthcare 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 can reduce health disparities in several basic ways.

1. 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, use of culturally tailored messages delivered in minority communities by minority community health workers.
2. QI can target practices that serve large numbers of minorities. African American patients often receive care from providers with fewer resources *(111)*. QI, particularly when accompanied by the infusion of additional resources, can be used to boost the overall quality of care of practices that serve large numbers of minorities. This is the approach adopted by the United States Department of Health and Human Services (HHS) Bureau of Primary Care's Health Disparities Collaboratives, which aims to improve the overall quality of care among Federally Qualified Community Health Centers *(127)*.
3. Certain types of universally applied QI sometimes benefit minorities more than nonminorities. For example, if minorities in a community are less aware of the benefits of mammography screening than majority members, a mammography educational campaign will disproportionately benefit those with less knowledge. Furthermore, a community-wide media campaign that focuses on African American males at risk for prostate cancer might help reduce any racial disparities in knowledge about prostate cancer. 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 *(128,129)*, and in some cases, may paradoxically increase disparities if nonminorities prove more responsive to the intervention. In these instances, targeted approaches may be needed *(130)*.
4. QI efforts can also focus directly on patient-provider behavior and communication skills. Conceivably, improved training in cultural competence *(84)* 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 *(131)*.
5. Efforts designed to reduce unnecessary utilization such as overuse of tympanostomy tubes or cardiovascular procedures among whites will tend to reduce disparities because whites tend to overutilize these procedures *(97,132,133)*.

At any rate, the content and delivery of interventions should be specifically tailored to the culture of the community. 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.

QI TOOLS

The taxonomy of causes of disparities presented earlier is consistent with a conceptual framework for QI tools for preventive care *(134)*. 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 10 types of interventions that offer potential for improving healthcare quality and reducing disparities. Some have been rigorously evaluated. Table 1 provides a summary of interventions that specifically target a cause of disparities. Each is briefly discussed as follows.

Reminders

Available data suggest that provider prompts improves delivery of preventive care *(135)*. Definitive data are limited, but provider prompts may also help reduce disparities in care *(128,136)*. Providers often fail to initiate appropriate preventive care because of competing demands *(88)*. Owing 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 *(137)*. 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 *(138)*. However, use of letter reminders as a sole intervention may be less effective in low-income populations because of lower literacy rates and more frequent change of address *(139)*.

Provider Feedback

Many health plans provide participating physicians with individualized feedback regarding their performance. When used alone, it has weak effects on quality measures *(140,141)*. However, coupling feedback with financial incentives or achievable benchmarks may improve performance *(142)*. Conceivably, providing detailed, but meaningful feedback to providers regarding disparities in their own practice may reduce inequalities in healthcare. Such feedback may motivate providers to be more attentive to the

Table 1
Examples of Interventions Targeting Specific Causes of Disparities

Factor targeted	Group targeted	Intervention
Patient knowledge	Patient	Culturally appropriate educational materials Culturally diverse medical and ancillary staff
	Community	Community educational campaign
Patient attitudes and beliefs	Patient	Community health workers
	Community	Community opinion leaders Social marketing
Self-care skills	Patient	Demonstration of skills followed by direct observation
	Community	Mailings, TV, and community training
Patient self-efficacy	Patient	Coaching and role play
	Community	Community training sessions
Patient adherence	Patient	Mailed or telephone reminders Adherence programs Open access appointments
Low literacy	Patient	Audio-visual materials and in-person coaching Low literacy reading materials Intensive patient education
	Community	TV and community health workers
Limited English proficiency	Patient	Patient educational materials available in different languages Onsite or remote interpretation
	Community	Mailings, TV, and bill board advertising
Affordability	Patient	Social work availability Copayments for visits, testing, and prescriptions based on income Assistance in applying to pharmaceutical indigent prescription programs
	Community	Support for charitable care
Provider stereotyping	Provider	Practice guidelines to reduce clinical uncertainty Performance feedback to providers Race/ethnicity blinded decision making Training patients to assert their needs
Provider adherence	Provider	Prompts and reminders
Patient–provider communication	Provider	Provider and patient communication skills training
	Patient	Patient coaching Patient training manuals Patient navigators/advocates
Provision of care based on need	Delivery system	Redesign of delivery systems to systematically address patients needs, barriers to care, and tailor care based on those needs

needs of their minority or low-income patients and help reduce bias. However, empirical data regarding this approach are currently lacking.

Provider Education

Clinical uncertainty promotes practice variation and probably increases disparities through unconscious bias *(1,85)*. Disparities are most apparent for new technologies and when indications for a procedure are marginal *(143)*. The development and effective implementation of guidelines may help to offset underutilization for minorities and low-income groups while minimizing overutilization for majority groups. Although guidelines alone have limited effectiveness *(140)*, 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 was satisfied.

Increasingly Intensive Outreach

A graduated approach to influencing and educating patients means that increasingly intensive outreach is used 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 *(144)*. In selected instances, assistance with transportation, child care, or language might be provided *(145–147)*.

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 in which guidelines are unclear and practice variation is high. Examples include invasive cardiovascular interventions *(148)*, organ transplantation *(96)*, and joint replacement surgery *(149)*. 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 *(150)*. Furthermore, confirmation of patient understanding by providers improves diabetic control among low-literacy patients *(151)*. 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 *(152)*. 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 *(153–160)*. Furthermore, patient assertiveness may attenuate disparities in breast cancer evaluation *(161)*. 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. Although there is evidence that physicians can be trained to communicate more effectively with patients *(162,163,164–169)*, only a few studies show that such training affects patient outcomes *(168)*, much less reduce disparities. 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 healthcare.

Organizational Change/Practice Redesign

Organizational change presents a potent but relatively unstudied lever for addressing disparities. As discussed under "Successful Models-Depression," 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, although there are limited empirical data.

The chronic care model includes components likely to impact disparities *(170)*. 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 owing to the continuing digital divide. 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. Available evidence suggest that these providers report that they often lack the necessary resources essential to provide optimal care *(111)*. The federal government currently supports care to underserved patients through partial funding to federally qualified community health centers. It could provide these sites with critical health information technology necessary to support ongoing QI efforts *(171)*.

Community-Based Interventions

Last, community-based interventions that promote changes in community norms, knowledge, attitudes, and behavior related to healthcare 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.

SUCCESSFUL MODELS

Although a comprehensive review of the literature conducted by the General Accounting Office found no model intervention specifically designed to address disparities *(172)*, 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 2 and discussed in detail as follows.

Childhood Immunizations

Hispanic, American Indian/Alaskan Native, and in some instances, Asian/Pacific islander children aged 19–35 mo have lower immunization rates than white children *(173)*. 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 *(174)*. The RRO relied on lay community-based

Table 2
Condition-Specific Interventions for Addressing Disparities

Disparity condition	QI intervention
Childhood immunizations	Registry, reminders, and outreach
Screening and treatment of Chlamydia	Multidisciplinary QI teams, new technology, guidelines, and performance tracking
Mammography	Protocols, tracking, and outreach
Cancer diagnosis and treatment	Patient navigation
Depression management	Practice redesign, case management
Hypertension management	Use of protocols, intensive patient education
Diabetes management	Intensive patient education
Influenza and pneumococcal vaccination	Registry, reminders, and outreach
Dialysis	Educational materials, global performance, and training sessions
Angiography	Race-blinded decision making

outreach workers assigned to city practices to track immunization rates of all 0- to 2-yr-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 postcomparison 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. 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 *(175–177)*, and complications of Chlamydia including PID, ectopic pregnancy, and infertility are several times higher among black women *(178)*.

A team-oriented approach to testing for Chlamydia increased the screening rate of sexually active 14- to 18-yr-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.

Mammography

The incidence of breast cancer is lower among black women compared with white, yet death rates from breast cancer are higher among black women *(9)*. Medicare claims and Medicare HMO Health Employer Data and Information Set (HEDIS) data show that black women continue to have significantly lower mammography rates than whites *(115,179)*.

The Health Insurance Plan of Greater New York conducted randomized trial of the effect of mammography screening on mortality *(180)*. Roughly 62,000 women aged 40–64 yr from the Health Insurance Plan of Greater New York were randomized to control or study groups of equal size. Study subjects were offered an initial screening mammogram and breast examination at their medical group center and three annual follow-up examinations. Study 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 with 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 no 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 community health workers (CHWs) *(181)*. The case management involved use of increasing outreach intensity (mailed cards, telephone calls, and home visits).

The CHWs also facilitated appointment scheduling, transportation, and child 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. *(182)* using telephone case management for low income, largely minority patients. These findings highlight the benefits of more intensive follow-up for harder-to-reach populations.

Cancer Diagnosis and Treatment

African Americans, and in some instances other minorities, experience higher rates of death from most major cancers *(9)*. Lower rates of cancer screening, delays in follow-up on abnormal screening results, and differences in treatment may contribute to these disparities *(33,183)*. In response to these disparities, the Harlem cancer education and demonstration project implemented a patient navigation program. Patient navigators were paraprofessional 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 *(184)*. Although these findings are limited by use of a nonrandomized study design, they suggest that patient navigation represents a promising means of eliminating disparities in cancer diagnosis and possibly treatment.

Depression Management

Depression affects all ages, races, and ethnic groups, although rates are higher among women *(185)*. Rates of depression do not appear to differ significantly between whites and blacks, but are higher among persons with low income *(185)*. Nonetheless, Caucasions are more likely to receive antidepressants than nonwhites *(37,186)*. Additionally, among patients receiving antidepressants, whites are more likely than minorities to receive selective serotonin reupdate inhibiters *(186)*, and to receive guideline concordant treatment for depression *(187)*.

The Quality Enhancement by Strategic Teaming Intervention *(188)* eliminated disparities in depression management between insured and uninsured patients. Twelve community primary care practices from three practice-based research networks participated in the study. Before the intervention, none of the practices had on-site mental health specialists to provide counseling. First, 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 whereas 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 wk 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 wk. Nurse care managers were then specifically trained to help depressed patients overcome insurance-related barriers. In the usual care group, insured patients compared with uninsured patients 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 mo. In contrast, in the enhanced care group there was no difference in improvement scores between the group. These effects were sustained at 24 mo *(189)*.

A similar project reduced racial and ethnic disparities in depression *(190)*. Matched primary 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 mo, racial and ethnic disparities in reported depression cases were reduced in both treatment groups as compared with 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 *(191)*. Hypertension sequela, including premature death from cardiovascular, cerebrovascular and renal disease, have enormous impact on the health of minorities, particularly

African Americans. Only 30% of all whites and 26% of all blacks with hypertension have their blood pressure adequately controlled *(191)*. 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 *(54,191,192)*. 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 2000 families were randomly assigned to one of 14 experimental insurance plans *(193)*. 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 (whereby the family paid 95% of its health bills up to a maximum of $1000 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 with 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 during the year, more likely to have potassium checked in the presence of a diuretic, and more likely to have their blood pressure controlled *(193)*. 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 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, antihypertensive treatment program (stepped care) *(194)*. 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 antihypertensive 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 was greater for blacks than for whites *(195)*. 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 *(196)*.

Diabetes Management

The prevalence of type II diabetes is higher among blacks, Hispanics, and American Indians and persons living in poverty *(197,198)*. Age-adjusted mortality rates from diabetes for blacks and American Indians are twice those of whites *(199)*. Blacks are at higher risk for complications from diabetes including amputation and renal failure *(200)*. 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 *(201)*.

Another study termed the Diabetes Control and Complications Trial was a randomized control trial designed to assess the impact of intensive control of diabetes type I on the development of diabetic complications *(202)*. Subjects randomized to conventional therapy were seen every 3 mo. 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 *(203)*.

Adult Immunization

National data show that fewer blacks (39%) than whites (60%) receive the influenza vaccine *(204)*. Hispanics and lower income persons also have significantly lower rates of influenza vaccination than whites *(205)*. Additionally, age-adjusted rates of death from pneumonia/influenza are higher among African Americans than whites and among persons with low vs high income *(8)*. The veterans' administration (VA) 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 *(206,207)*. 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 *(208)*. 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 *(209)*. Centers for Medicare and Medicaid Services (CMS) sponsored a QI project that markedly reduced both racial and gender disparities in adequacy of hemodialyis dose *(210)*. Regional quality oversight organizations monitored hemodialysis indicators every October, November, and December for the national, randomly selected 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% *(210)*. 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.

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 *(211)*. 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. Nonetheless, this approach warrants rigorous study particularly for interventions that involve either use of expensive technology or in which resources are particularly scare such as organ transplantation. 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 *(212)* and receive less optimal care *(62)*. Use of interpreters appears to improve outcomes *(213)* and there might be some difference in visit satisfaction between onsite professional interpreters and telephone interpreters *(214)*.

CURRENT QI DISPARITY INITIATIVES

There are a number of ongoing initiatives that explicitly link disparities in healthcare to QI. The Commonwealth Fund and the Health Resources and Services Administration 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 thirteen health plans *(215)*. Preliminary data appear promising. For example, members of one collaborative health plan and a provider group team designed a multi-faceted intervention, using patient focus groups and telephone surveys, to successfully address disparities in breast cancer screening and medication adherence among adults with asthma (David Nerenz, personal communication 4.9.07).

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

Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has recently proposed new 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 healthcare, home care, hospitals, long-term care, and assisted living.

Aetna has initiated ground-breaking work in this area with the assistance of a national advisory committee. They have begun collecting race and ethnicity data and have begun analyzing the association of race/ethnicity with healthcare. The next step is to develop a carefully crafted plan to address these disparities. Jack Rowe, the CEO of Aetna, forcefully argues for a business case for this work. He reports support from many of his corporate customers. The Aetna disparity project has the potential to demonstrate that it is feasible (and profitable) for health plans to collect race/ethnicity data, assess disparities in healthcare, and implement successful interventions when the corporate leadership is adequately committed.

Several national collaborative initiatives use QI to address disparities. These include the Health Disparity Collaboratives being conducted with federally qualified community health centers by the Bureau of Primary Health Care *(216)*, the QI organizations funded by CMS *(217)*, the Health Plan Collaborative funded by the Agency for Health Care Quality and Research and the Robert Wood Johnson Foundation *(218)*, and "Expecting Success" designed to address disparities in cardiovascular care in participating hospitals nationally, also funded by the Robert Wood Johnson Foundation. Beginning in 2003, CMS has required health plans that provide care to Medicare enrollees to undertake at least one project addressing racial/ethnic disparities, or cultural or linguistic competences under its Culturally and Linguistically Appropriate Services standards. Measures designed to assess these projects are still under development.

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 persons' race and ethnicity *(219)*.

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 QI teams that include different disciplines and are racially and ethically 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 to obtain feedback about these pilots from patient and providers using focus groups. These findings can be used to inform the design of larger scale interventions. Standard QI strategies such as plan-do-study-act *(220)*, or rapid cycle change *(221)*, 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 resources by government, health plans, hospitals, communities, and practices, and most importantly, on the full and active participation of minority patients.

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9

Eliminating Racial Discrimination in Healthcare

A Call for State Healthcare Anti-Discrimination Law

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> "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 *(1)*

INTRODUCTION

Equal access to quality healthcare is a crucial issue facing the United States *(2)*. For too long, too many Americans have been equal access to quality healthcare based on race, ethnicity, and gender *(3)*. Many factors contribute to disparities: cultural incompetence of healthcare providers, socioeconomic inequities, disparate impact of facially neutral practices and policies, inadequacy of civil rights laws and enforcement, and multiple forms of discrimination. These disparities exist in health status, access to healthcare services, participation in health research and receipt of healthcare financing *(4)*. This disparity in healthcare is doubly significant given the devastating racial disparity in health status that exists. The combination of racial disparity in health status, institutional racism in healthcare and inadequate legal protection points to a *need for a major civil rights law for healthcare*.

Several federal laws address access to healthcare: Title XVIII (Medicare) *(5)*, Title XIX (Medicaid) *(6)* of the Social Security Act, Title IX *(7)*, and the Hill Burton Act *(8)*. The only federal law related to eliminating racial discrimination in healthcare delivery is Title VI of the Civil Rights Act *(9)*.

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Racial inequality in healthcare persists in the United States despite laws against racial discrimination, in significant part because of the inadequacy of Title VI *(10)*. 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 healthcare *(11)*. Specifically, section 601 of Title VI provide:

> "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" *(12)*.

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. Unfortunately, the Supreme Court has held in Alexander V. Choate *(13)* that Title VI itself directly reached only instances of intentional discrimination; included in the definition is subtle discrimination. Subtle discrimination *(14)* is generally considered intentional based in large part on microaggressions *(15)*, with the primary difference being the reliance on circumstantial evidence to improve intent *(16)*. However, the reliance on intent, subtle or direct, is particularly problematic for healthcare where most discrimination is either disparate impact discrimination or "unthinking or unconscious" discrimination *(17)*.

[T]he course of treatment physicians recommend to their patients might 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 might affect—perhaps 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 *(18)*.

Although legal standards for discrimination have not always centered on intent, they do so now *(19)*. To prove a disparate treatment claim an individual must show that the defendant is intentionally discriminated *(20)*. Such a standard means that few of the discriminatory acts that occur in the healthcare system can be successfully litigated as most occur from "unthinking" or "unconscious" biases.

Psychiatric, psychological, and legal literature generally supports the idea that, in the society, most contemporary discrimination is based more on unconscious bias and stereotyping rather than on conscious bigotry *(21)*. 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 decisionmaker's beliefs, desires, and wishes" *(22)*.

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 *(23)*. This stereotype-linked bias is both an automatic process and an unconscious one *(24)*. Furthermore, it occurs even among persons who are not prejudiced *(25)*. According to Professor David Williams, several factors contribute to the unbias discrimination in healthcare:

> "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 viewed Black patients (compared with 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 change *(27)*: 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 Department of Health and Human Services issued interpretive regulations, which provided for disparate impact discrimination:*(29).* A recipient may not utilize criteria or methods of administration that have the *effect* of subjecting individuals to discrimination of their race, color, or national origin, or have the *effect* of defeating 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 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" *(33).* The regulations went further and prohibited:

- Criteria or methods of administration, which have the *effect* of subjecting individuals to discrimination *(34)*; criteria or methods of administration, which have the *effect* of defeating or substantially impairing accomplishment of the objectives of the progam *(35).*
- Difference in quality of services *(36).*
- Differences in quantity or the manner in which the benefit is provided *(37).*
- Locating services with the purpose or effect of excluding individuals from the benefits of the program *(38).*

In theory, then, Title VI regulations should improve access to and quality of healthcare 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 healthcare practitioners and institutions to evaluate their policies and practices that have a disparate impact (discriminatory effect) on racial minorities *(39).* Unfortunately, because of Alexander vs Sandoval and unique problems of healthcare discrimination, Title VI and its regulations are virtually useless.

In Sandoval, 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 sets a precedents, the disparate impact regulation (discriminatory effect) issued under section 602 could only be enforced through a private right of action *(40).* As the law requires a conscious discriminatory purpose or intent, individual discrimination claims cannot address the issue of unconscious discrimination, and healthcare providers will not be "appropriately motivated" to make the hard choice *(41).*

Even without the problem with Sandoval, Title VI enforcement has been problematic *(42)*. First, although required by regulation to produce data *(43)*, the OCR Title VI enforcement effort has produced little consistent data for evaluating Title VI compliance *(44)*. 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" *(45)*. Third, Title VI lacks specific definitions of prohibited discrimination and acceptable remedial action *(46)*. Fourth, OCR has relied on individual complaints to enforce Title VI *(47)*. Finally, Title VI would have limited application to healthcare treatment discrimination because HEW interpreted Title VI to not to apply to private physicians who received money for treating patients covered under Medicare Part B *(48)*. Thus, under Title VI physicians would not be recipients of federal financial assistance and consequently would not be covered by Title VI *(49)*.

Taking the "even if" a step further, even if the problems with Title VI enforcement did not exist and Title VI functioned perfectly, the healthcare industry presents unique problems that would still make Title VI ineffective. Furthermore, the healthcare 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 healthcare system, through managed care, has actually built in incentives that encourage "unconscious" discrimination. Because of these issues, an appropriate legal structure is essential to eliminat discrimination in healthcare.

State HealthCare Antidiscrimination Act

In an effective public health policy, appropriate state and federal laws must be available to eliminate discriminatory practices in healthcare. Thus, the crux of the problem given managed care, the historical disparity in healthcare, and "unthinking" discrimination is, the laws do not address the current barriers faced by minorities. The executive branch, the legislatures and the courts are singularly reluctant to hold healthcare institutions and providers responsible for institutional racism. As the United States Commission on Civil Rights found:

> "There is substantial evidence that discrimination in healthcare delivery, financing and research continues to exist. Such evidence suggests that Federal laws designed to address inequality in healthcare have not been adequately enforced by federal agencies [Such failure has], resulted in a failure

> to remove the historical barriers to access to quality healthcare for women and minorities, which, in turn has perpetuated these barriers" *(50).*

A HealthCare 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 agency, provider, or facility, 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 race discrimination that occurs in healthcare is probably the result of subconscious bias, disproportionate impact of policies and practices, and disparate impact. A state law on healthcare discrimination would at a minimum define discrimination in a way that included: intentional discrimination, subtle discrimination *(51)*, unthinking discrimination *(52)* and disparate impact *(53).* The law should define intentional discrimination to include knowledge of disparate impact and failure to take effect 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 healthcare 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 healthcare facilities or providers to prove that patients of a particular race receive different treatment *(54).* This is important because much of healthcare 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 patient. "Testing" could provide both evidence in the individual case and some accurate empirical data on the overall rate at which discrimination occurs in healthcare *(55).* Testing has been widely used to enforce Title VIII *(56)*, which prohibits discrimination in the sale, advertising, and rental of housing *(57).* However, although use of testes under Title VIII is wellsettled, it is an issue of great debates in other areas such as, employment discrimination under Title VII *(58)* and section 1981 of the Civil Rights Act of 1866 *(59).* 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" *(60).*
3. *Provide a private and organizational right of action:* an antidiscrimination healthcare 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 *(61)*.

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 *(62)*. Without a private right of action, racial discrimination in healthcare will be impossible to eliminate *(63)*. 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 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.

4. *Establish an Equality Healthcare 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 healthcare providers, institutions, and managers, providing counseling and healthcare-finding services to individuals, investigating discrimination complaints—mostly through testing and pursuing legal remedies *(64)*. Such council would provide a focal point to antidiscrimination work in healthcare *(65)*. It could easily be an extension of existing state minority health efforts. Thus, when someone believes she has been discriminated against in healthcare, she would have somewhere to turn for help.
5. *Prevailing party attorney fees:* the healthcare antidiscrimination statute would provide for attorneys' fees for a prevailing party *(66)*. Many federal statutes authorize attorneys' fees for a prevailing party *(67)*. 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 *(68)*.
6. *Punitive Damage, in part or in whole, to fund monitoring and assessment programs:* compensatory damages make discrimination victims whole for injuries to their injuries *(69)*. Punitive damages, on the other hand, punish past conduct, teach defendants not to commit these acts again and deter others from similar behavior *(70)*. Similar to split-recovery statutes *(71)*, all or part of the punitive damages should be placed into a fund that would ultimately be used to promote equality healthcare including discrimination testing *(72)*.
7. *Require data collection and reporting:* current data collection efforts fail to capture the diversity of racial and ethnic communities in the United States *(73)*. Data is aggregated information on subgroups within the five racial and ethnic categories, which are not collected systematically *(74)*. 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 *(75)*. To fully understand the health status of all individuals, as well as to recognize the barriers they face in obtaining quality healthcare, it is important to collect the most complete data on underrepresented groups and subpopulations *(76)*. The lack of data makes it difficult to conduct research studies and comparative analyses *(77)*. Furthermore, the lack of a uniform data collection method makes obtaining an accurate and specific description of race discrimination in healthcare difficult. The existing data collection does not allow for regular collection race data on provider and institutional behavior *(78)*. Given the array of potential issues, some researchers have argued that health data should not be disaggregated by race *(79)*. 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 see potential for harm from the use of race.

However, there are a number of important and compelling reasons for disaggregating health status and healthcare 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 (that is, 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 continues to exist as a worldwide problem. Here in the United States, even when one controls for socioeconomic status, health status and healthcare differentials continue to exist.

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 *(80)*. 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 *(81)*. Fifth, to fully understand the health status of all individuals as well as to recognize the barriers they face in obtaining quality healthcare, it is important to collect the most complete data on "racially disadvantaged" groups," and "sub-groups" *(82)*. The lack of a uniform data collection method makes obtaining an accurate and specific description of racial discrimination in healthcare 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 the 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" *(83)*. Race matters because racism and racial discrimination matter *(84)*. Disaggregating data based on race is important because it helps to make the impact of racism and racial discrimination visible and thus allows to address the root problem.

8. *Require a health report card for health agency, provider or facility (85):* if one is serious about eliminating racial discrimination, the systematic collection and reporting of data from each healthcare provider on racial disparities in the use of services and the choices of diagnostic and therapeutic alternatives would provide an additional tool in civil rights monitoring *(86)*. The "report card" approach is not new and is being down to "assure accountability, consumer choice, and goal-directed action" *(87)*. Existing and proposed healthcare "report cards" could be used and only need to be stratified by race *(88)*. As Sidney Watson discussed:

> "Reporting race-based data on healthcare 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" *(89)*.

   Report cards that reflect racial disparities will provide a strong evidence that racism—"intentional or unintentional, institutional or individual—is affecting patient care" *(90)*.

9. *Assure adequate fines and regulatory enforcement:* the importance of rigorous enforcement of regulation as a primary vehicle for policing the health services cannot be overemphasized. The collection of data and the development of a report care 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 violating of antidiscrimination law, such fines could be collected and deposited directly into a restricted account that could be used to eliminate racial disparities.

CONCLUSION

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. My 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. Regarding the question of whether we should create a new federal law, the answer depends on political feasibility. From a political perspective, the federal antagonism to civil rights makes it highly unlikely that such an approach will work. Furthermore, the states are major players in the civil rights arena, and have an infrastructure on which a new civil rights law could be based.

The discussion of discrimination in healthcare has been limited. That discussion has centered almost entirely around Title VI of the Civil Rights Act *(91)* and on assuring access to facilities and providers *(92)*. For an effective public health policy to be established, appropriate state and federal laws must be available to eliminate discriminatory practices in healthcare. This is the crux of the problem for the legal system: given managed care, the historical disparity in healthcare, and unthinking discrimination, what is the best way for the legal system to remedy racial disparity in the healthcare system? It should be clear from the discussion in this chapter that this will not be accomplished through using the Civil Rights Act as it now exists. 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.

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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.

7. 20 U.S.C. §§ 1681-88 (2002) (limited to sex discrimination in educational programs).
8. 42 U.S.C. §§ 291-291o (2002) (requires uncompensated care and community service by facilities that receive funding under Hill-Burton Acts).
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10

Quality of Care and Health Disparities

The Evolving Role of the Government

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INTRODUCTION

Over the past 20 yr 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 concentrated on.

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 20th century, dying "young" was relatively common. In 1900, the average life expectancy at birth for all Americans was 47.3 yr. However, blacks died younger on average, with a life expectancy at birth of only 33 yr. 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 yr, but only 69.6 yr for blacks. In 1981, the infant mortality rate for blacks was twice that for whites.

From: *Eliminating Healthcare Disparities in America: Beyond the IOM Report*
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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 yr 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 2004 National Healthcare Disparities Report (NHDR), "… disparities related to race, ethnicity, and socioeconomic status pervade the American healthcare system" *(7)*. For the up to 38 measures of care that the NHDR tracked from 2000 and 2001, blacks, Asians, and American Indians/Alaska Natives, received a lower quality of care than whites for about 66%, 10%, and 33% of measures, respectively; and had worse access to care than did whites for about 40%, 33%, and 50% of measures, respectively. Similarly, Hispanics received lower quality of care than non-Hispanic whites for about 50% of measures, and worse access to care for about 90% of measures. And, 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) for about 60% of measures, and worse access to care for about 80% of measures. In 2002, the gap in life expectancy at birth for whites compared with blacks (77.7 vs 72.3 yr) narrowed but still existed *(2)*. In 2000–2002, there were significant differences in infant mortality rates for Asians, Hispanics, whites, Native Americans, and blacks (4.8, 5.5, 5.7, 8.9, 13.6 deaths/1000 live births, respectively) *(2)*. Today, just as in 1985, a 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 19th 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. In a 2005 commemoration of the 50th anniversary of IHS, Michael Leavitt, Secretary of DHHS, called the formation of IHS "the beginning of recovery from many years of physical and spiritual wounds, the building of a health infrastructure to address the health disparities facing American Indian and Alaskan Native people, and the launching of a new era in healthcare" *(14)*.

Today, as an agency within DHHS, the IHS provides a comprehensive health delivery service to close to 2 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 yr—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-yr 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 then 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 yr time, 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 OMH

In December 1985, OMH was established as an entity within the office of the Secretary of DHHS. The office advises 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 without 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 website *(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, for Tribal Colleges and Universities, 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 HealthCare (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 Service Administration, and most recently, the National Center 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 yr 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 Service Administration

Health Resources and Service 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 HealthCare, HRSA has administered and expanded a community health centers program in response to a congressional mandate in 1996, and a 2002 Presidential initiative. 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 Center on Minority and Health Disparities at NIH is a recent addition in the fight to eliminate health disparities. NIH had an Office of Research on Minority Health (ORMH) beginning in 1990. NCHMD was established 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 *(33)*. Through NCHMD, NIH continues the work of the former ORMH to improve the visibility of health disparities research, and promotes research that examines why some populations have disproportionately high rates of disease. NCHMD awards grants and contracts independently, and supports research that focuses on basic and clinical research and training related to decreasing health disparities *(33)*.

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 yr 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 *(34)*. By 2004 that number had increased to 39 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 lead to national programs such as drug coverage for seniors and health insurance for low-income children *(35)*.

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 *(34,36)*. 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 *(34)*.

In 1998, OMH also decided to assess minority health infrastructure in eight states and one territory *(36)*. 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 four "crosscutting issues." Crosscutting issues, which relate to health disparities at all levels *(34)*, were identified as: data collection, analysis and reporting, cultural competence, access to healthcare, and health professional development.

The study methods *(36)* 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. Quality improvements in state healthcare are promoted in the 2004 National HealthCare Quality Report (NHQR) *(37)*, which includes state-level statistics for about 100 quality measures, and state rankings on 14 selected measures. A recent study by Trivedi et al. *(35)* notes 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), and 2002 (George W. Bush) 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 2005 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 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, addressing the needs of specific populations that experience health disparities, and 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 2004, AHRQ also established the AHRQ National Resource Center for Health Information Technology to continue its vital presence in this important field *(52)*.

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 *(53)*. Clearly, there is a great deal of overlap and interplay between the quality of care in the Nation as 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 NHQR *(3,4)* and the 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 up to 179 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" *(54)*. 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. From the 600 measures initially considered, the 2003 NHQR reported on 140 measures, and the 2004 NHQR on 179 measures *(3,4)*. Apart from the challenge of identifying appropriate measures, an initial and continuing challenge is to find reliable data (or to encourage the gathering of such data) across all measures, for all populations of interest. Another challenge is to devise transparent and convenient means for all of AHQR's customers to access that data. One key mechanism in meeting these challenges is the AHRQ program to develop "Quality Tools"—websites, databases, reports, fact sheets, and other mechanisms that can help AHRQ's customers access and use the collected health information *(55)*.

NHQR Findings

The 2003 NHQR defined quality of care as "doing the right thing at the right time in the right way for the right person and having the best results possible." Its key findings were summarized succinctly as: "High quality healthcare is not yet a universal reality. Opportunities for preventive care are frequently missed. Management of chronic diseases presents unique quality challenges. There is more to learn. Greater improvement is possible" *(3)*. Backing those conclusions was an appendix of 326 pertinent tables. The 2004

NHQR extended the findings of the previous year's report, reiterating again the similar themes that quality is improving, that gaps in health remain large, and that improvement is possible. The report based its analysis on 179 measures in four areas of quality, and examined nine clinical conditions for effectiveness of care: cancer, diabetes, end-stage renal disease, heart disease, HIV/AIDS, maternal and child health, mental health, respiratory diseases, and nursing home and home healthcare.

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 *(56)*. 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 *(56)*, "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 2003 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 2004 NHDR *(7)* enlarged on the same themes, concluding that: "Disparities are pervasive. Improvement is possible. Gaps in information exist, especially for specific conditions and populations."

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, has 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 *(57)* measures and the Diabetes Quality Improvement Project (DQIP) *(58)* 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. More than 20 yr 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 2004 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. The 2004 NHDR noted that "future NHDRs will benefit from ever improving data for examining and tracking disparities" *(7)*. 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 *(5,9,50,59)*. 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 *(50,59)*. Legitimate concerns regarding legality, privacy/confidentiality, potential misuse of data, financial costs, accountability, and reporting consistently arise in relation to the collection of specific data on minority populations *(59)*. 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. As noted in the 2004 NHDR, "the revolution in health information technologies will allow data needed to assess disparities to be collected and processed more quickly, efficiently, securely, and economically" *(7)*. 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 for Health Information Technology (ONCHIT) within DHHS *(60)*. ONCHIT 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 *(61)* 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 *(62–64)*.

"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 *(64)*. Low health literacy, including the ability 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 *(63,64)*. 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 patients needs. Cultural competency has emerged as a crucial element in efforts to eliminate health disparities *(65)*. 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.

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 cooperation between Federal and state agencies, and private and academic institutions, to use resources and expertise in common cause, holds the greatest hope for achieving health equity for all.

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11

The Role of Communities in Eliminating Healthcare Disparities

Getting Down to the Grass Roots

JudyAnn Bigby, MD

INTRODUCTION

Racial disparities in health status and healthcare 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 healthcare system influence health status. Efforts to eliminate health disparities will not succeed unless they include multiprong approaches focusing on the multiple levels of causation. Much attention has been paid to causes of healthcare disparities that operate primarily at the level of the individual and emphasize personal behaviors and individuals' access to and experience in the healthcare system. In addition, the role of individual healthcare providers' biased attitudes, stereotyping, and discrimination toward people of color, is often offered as an explanation of healthcare disparities. Barriers to accessing care and poorer quality of healthcare 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, and genes) contribute to health, but health status is largely determined by other factors including those that exist outside the healthcare system. The health of individuals is determined by multiple factors including the extent and quality of healthcare, individual characteristics, family factors, exposure in communities, and by social and political factors. These factors influence access to healthcare, risk, and personal health behaviors (Fig. 1). The decision to engage in specific personal health behaviors

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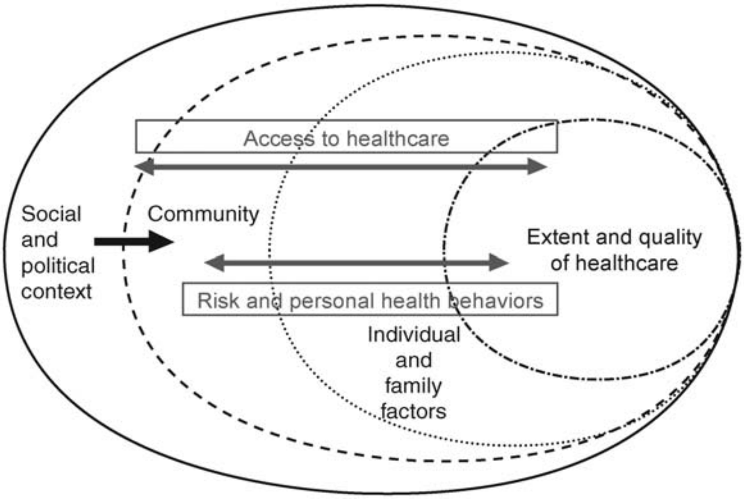

Fig. 1. Factors contributing to health and health disparities. Extent and quality of healthcare—includes the types of services that are available to individuals (e.g., primary care, specialty care, mental health, and oral health), the structure of the healthcare system (e.g., location and hours of operation), the competence and technical ability of staff and professionals, availability of support services (e.g., transportation, interpreters, out reach workers, and health educators), and quality of care (e.g., patient-centeredness, efficiency, equity, safety, and appropriateness). Individual and family factors—includes genetic predispositions, gender roles, social consequences of race, family attitudes toward wellness, and healthcare. Community–includes quality of services, built and natural environment, location of healthcare facilities, and violence. Social and political context—includes policies that determine healthcare 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 healthcare (e.g., time spent with providers and language and literacy appropriate health education). Access to healthcare is determined by all the factors in the model including the structure of the healthcare system (e.g., hours of operation and diversity of healthcare 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).

(e.g., smoking or regular exercise) are not made in isolation but are influenced by community characteristics, environmental conditions, and social and economic factors *(1,2)*. Access to affordable food, tobacco products, and illicit drugs vary significantly in communities across United States and have been demonstrated to influence personal health behaviors. Asthma, heart disease, diabetes, HIV and AIDS, and poor birth outcomes such as low birthweight 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.

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 consist 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 might 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 wherein people work, go to school, conduct business, participate in spiritual activities, and/or socialize. Communities can be part of larger cities or municipalities in both urban and rural areas. Often communities are dynamic entities owing 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. Violence and pollution, for example, 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 healthcare services affect access to care. Having access to resources related to employment and recreation also affect health (Table 1) *(3,4)*. In urban areas, especially those with large populations of persons from racial and ethnic minority groups,

Table 1
Factors Contributing to the Health of Communities

Socioeconomic factors

- Income
- Job opportunities
- Segregation resulting in concentrated poverty
- Cultural norms and behaviors
- Civic engagement (community mobilization, political power, and 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 healthcare services including mental and oral healthcare
- 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, and pharmacies)

Adapted from Policy link.

serious health problems are concentrated in distressed neighborhoods. In rural areas, health problems might 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 healthcare services, jobs, quality education, decent housing, and nutritious food.

Epidemiological 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 *(5)*. 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 *(3)*. The housing in communities of color is often substandard, lead contaminated, or dangerous owing 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 healthcare, 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 healthcare. These facilities are severely underfunded and in many communities have closed or been converted to private institutions over the last decade. One study reports that the best predictor to determine which hospitals closed in Philadelphia, during the movement to decrease beds and downsize, was the percent of black patients a hospital served *(6)*. 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 *(7)*. Communities with higher home values and that are homogeneous have more supermarkets. Communities of color have higher concentrations of liquor stores, bars, fast food restaurants, and advertisements for tobacco and alcohol *(8)*. 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 with 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 because of 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 *(9)*. The birthweight 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 *(10)*. Communities with pockets of concentrated poverty have higher rates of unemployed males, high rates of single female-headed households, and high rate of violence. In one study of West Oakland, California researchers found that living in this largely African American neighborhood was an independent risk factor for poor health *(11)*.

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 *(8)*. 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 *(12)*.

Access to Healthcare 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 that they have little or no choice in seeking care *(13)*. 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 in 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 *(14)*. Persons of color have less access to specialists and are more likely to visit physicians who are not board certified *(15)*.

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 10 times higher than neighborhoods of similar socioeconomic status but with high levels of social connectedness, as measured by residents' willingness to intervene when children participate in delinquent behavior or when community resources are threatened *(16)*. 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 healthcare and individual health behavior 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, healthcare leaders, and others. Therefore, it is important for individuals, healthcare leaders, communities, governments, and others to develop a framework for eliminating healthcare disparities that recognizes the specific intersecting contributing factors and identifies specific interventions (Fig. 1). Healthcare interventions should be connected to efforts to address resources and conditions in neighborhoods. Historically, healthcare 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 *(17–20)*.

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 healthcare institutions and providers, duplication of efforts, and squandering of resources. The challenges include

1. Different governance structures of healthcare systems and community organizations.
2. Different leadership styles including an emphasis on hierarchy in healthcare institutions.
3. Disproportionately more resources in healthcare.
4. Racial, ethnic, socioeconomic, and educational differences between leaders and other involved parties representing communities and healthcare.
5. Different and often conflicting priorities.

Working in partnership with communities has many advantages, which 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 healthcare 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, some times 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 fund-givers 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 might require a new not-for-profit organization, which 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 as 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 might 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, nonprofit, and the business community. In Boston, Massachusetts, the mayor convened hospital CEOs, community health center leaders, public health officials, 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). The recommendations focus on healthcare, 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 on 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 *(21,22)*. The Community Action Model (Fig. 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 *(23)*.

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, promoters, doulas, and others. CHWs generally reflect the demographics of the community they serve and often act as a bridge between the healthcare system and the community. They are strong advocates for individuals and for high-quality and culturally competent services. They might 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 *(24)*.

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 has increased

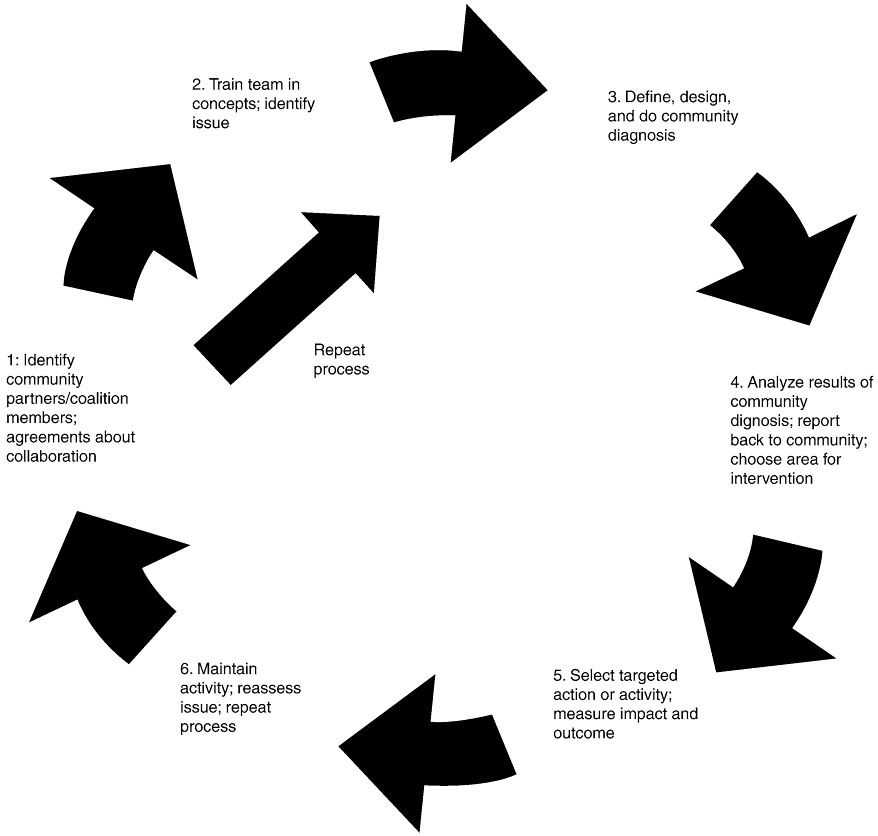

Fig. 2. Strategy for collaborative public health action by communities. Adapted from Lavery *(23)*.

healthcare 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 *(25)*. 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 birthweight and infant mortality have the potential of influencing health outcomes for several generations because of the increasing evidence that low birthweight infants are at higher risk for obesity and heart disease in later life *(26,27)* and of having low birthweight infants themselves *(28)*. Thus, although many community-based interventions are disease specific, they have the potential of influencing a diversity of health disparities. Table 2 summarizes a selected group of community interventions that are described in more detail as follows.

Diabetes

Community interventions might 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 *(7)*.

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 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 *(23)*.

Asthma

Asthma has increased in prevalence among urban and minority children for more than two decades. In some urban school systems more than 25% of

Table 2
Sample Community Interventions Addressing Healthcare Disparities

Health issue	Method	Level of intervention	References
Diabetes	Community coalition, community-based participatory research, and advocacy	Neighborhood bodegas, restaurants, and community education	*7*
Smoking	Community mobilization related to tobacco control	School board, regulation of smoking products by city and public universities, and housing complexes	*23*
Asthma	Community health workers	Homes of asthmatic children	*29*
Breast and cervical cancer	Community activation, and coalition	Health care system policies and procedures, community awareness of disparities, and neighborhood resources	*31*

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 healthcare services *(29)*.

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 *(30)*. 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 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 healthcare systems changes to decrease barriers to care *(31)*. 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 healthcare 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 healthcare 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.

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12

The Potential Impact of Performance Incentive Programs on Racial Disparities in Healthcare

Alyna T. Chien, MD, MS

INTRODUCTION

Performance incentive programs—in the form of pay-for-performance and public reporting—are receiving national and international attention. This chapter defines these programs and describes their basic features. It then outlines potential mechanisms by which these programs may impact racial and ethnic disparities in healthcare in a neutral, narrowing, or widening manner. It goes on to review the small body of literature evaluating whether performance incentive programs work, and the even smaller literature regarding how they impact disparities. It finds that performance incentive programs do not necessarily work, and that they can negatively impact disparities. The chapter then considers how particular aspects of program design should be approached with disparity-reducing goals in mind and provides a list of recommendations. It advocates that programs and research evaluate incentive programs for their intended effect, as well as for their unintended effect on disparities. Performance incentive programs are in their infancy—testing whether and how they impact racial and ethnic minorities will promote the design and implementation of programs that eliminate disparities as a part of raising quality.

EQUITY IS A PART OF QUALITY

Equity is one of the six dimensions of quality defined by the Institute of Medicine in *Crossing the Quality Chasm*; the other five dimensions are: safety, effectiveness, timeliness, patient-centeredness, and efficiency *(1)*. Previous studies have extensively documented the existence of disparities in

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healthcare: minorities have less access to healthcare, greater disease burden, and have poorer outcomes for their health *(2)*. Despite a greater need, minorities receive worse quality care. They are less likely to have good experiences with healthcare providers and to receive recommended processes of care *(3–16)*. Whereas many have described inequities in health and healthcare, eliminating these disparities within healthcare often remains on the periphery of many quality improvement discussions *(17,18)*. Disparity reduction has received even less attention in the burgeoning pay-for-performance and public reporting literature *(19,20)*.

Performance Incentive Programs Seek to Increase Quality

Performance incentive programs—such as pay-for-performance and public reporting programs—are prominent in national discussions about how to improve the quality of American healthcare *(21–24)*. Over 90 "pay-for-performance" programs are underway and the centers for Medicare and Medicaid services have invested 21 million U.S. dollars in several large-scale demonstration programs involving both hospitals and outpatient settings *(25–28)*. Experiences with these programs will likely influence healthcare payment policies in the years to come. Descriptions of current programs provide minimal, if any, information on disparity-reducing efforts *(28–33)*. This lack of attention is salient because racial and ethnic disparities have shown little change in recent years, and because there are theoretical and empirical reasons to believe incentive programs may affect disparities in unintended and undesired ways.

PERFORMANCE INCENTIVE PROGRAMS

Definition

Performance incentives 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) *(33–37)*. Although some programs emphasize the monetary component of their incentives (i.e., pay-for-performance), others highlight reputation-based pressures through intra- or extraorganizational physician profiling (i.e., public reporting). The distinction between these two types of programs is more theoretical than practical. In reality, most current programs use a combination of direct financial and reputation-based incentives. Programs that stress putting reputations at stake are thought to exert financial pressure by facilitating consumer choice and competition for healthcare "business" *(38–40)*. The ways in which these programs may impact disparities are likely to be very similar. Both types of programs will be referred to as "performance incentive programs" from

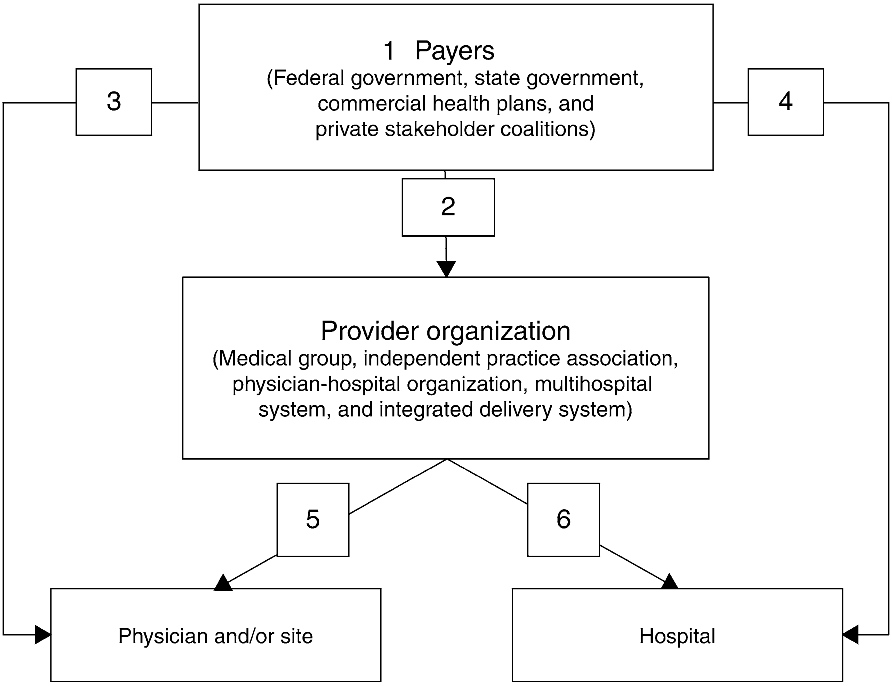

Fig. 1. Flow of incentives.

here onward. Further details regarding the theoretical and practical elements of performance incentives programs can be obtained from other sources *(41–47)*.

Basic Features

Flow of Incentives

The flow of incentives from payers to payees, i.e., to individual physicians and/or hospitals is diagrammed in Fig. 1. Payers of four main types are implementing performance incentive programs: (1) the federal government through the CMS, (2) the state governments through Medicaid, (3) commercial health plans, and (4) private stakeholder coalitions that often include employers who purchase healthcare on behalf of their employees. 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 2–4 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 *(31,32)*. Each of these groups vary in terms of size (e.g., number of physicians used), geographic location (e.g., urban or rural), and underlying market (e.g., fee-for-service or managed care). 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 *(28–32)*.

Incentive Types

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 website) and are considered either "sticks" or "carrots." Programs do not specify the implicit incentives—usually fee-for-service or capitated arrangements—underlying their explicit incentives, although these are recognized as being important features that have not yet been well researched for their potential synergistic or counterproductive effects *(28–32)*.

Incentive Triggers

Programs generally structure their programs around achieving a target or 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. 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. Finally, many programs give rewards noncompetitively—i.e., 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—i.e., only those reaching the top few ranks of performance receive rewards *(28–32)*.

Incentive Measures

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, they believe that it is more valid to hold healthcare providers accountable for what they have control over in the clinical setting, not necessarily what happens as a result of giving those services. Additionally, some believe that incentivizing healthcare outcomes should be avoided because it holds providers responsible over events beyond their influence, and may unduly cause providers to "game" the system by preferentially caring for patients whom they believe will do well *(48–51)*.

Many programs also target aspects of healthcare 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 Consumer Assessment of healthcare Providers and Systems [CAHPS®]), 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 CAHPS *(28–32)*.

POTENTIAL IMPACT ON DISPARITIES

Proponents of performance incentive program movement often quote John F. Kennedy in reference to the expected results from these programs, "A rising tide raises all boats." It implies that everyone's fate is yoked together. Although 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 two-third percent per year between 1990 and 2002, but disparities in mortality grew because declines were greater among the majority than among the minority *(12–13)*. The next section highlights how performance incentives may narrow, widen, or maintain disparities in healthcare.

Neutral

Superficial not Substantive

Disparities in healthcare are pervasive—its roots are found in poor patient–physician communication, cultural and linguistic indifference and/or incompetence, differential care, and decades of institutional and/or overt racism *(3,51)*. 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 change the underlying quality of that care. Of the three randomized controlled trials which demonstrate that financial incentives have a significant impact on desired measures, two attribute much of the significance to better documentation and not underlying quality *(52–54).*

One-Size-Fits-All

Even if performance incentive programs promote improving the underlying quality of care, it may encourage organizations to rely on 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, although it led to an overall 40% improvement across the 8-yr study period *(55).*

Narrowing

The Direct Approach

Healthcare should increasingly measures the things it wants to improve. If healthcare is going to remove the inequities within its system, it must measure race and ethnicity, compare care and outcomes for minority populations with the majority, and assess the disparity between groups, if any. Gathering race and/or ethnic information at the individual or aggregate level can be a social and politically charged topic, and great care must be taken to ensure that this information is used to improve the lives of minorities, and to safeguard against efforts that may inadvertently or purposely cause harm *(56).*

The "Minority Maxim"

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 designing efforts toward meeting the cultural, linguistic, and educational needs of minorities is likely to improve care for both minorities and the general population, whereas the converse may not necessarily be true *(57,58).* 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 antidepressant and psychotherapy use in both minority and nonminority elderly patients while narrowing gaps in care *(59).* Because of its relationship to quality measurement and improvement, performance incentive programs may need to adopt a similar strategy to ensure that incentive programs have the best chance of reducing disparities.

Widening

One-Size-Fits-All

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 for minority subgroups; disparities may widen because minority groups get left behind *(12,13)*. Although 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 and at the same time improve overall quality.

Cherry-Picking

Performance incentive programs can also widen disparities by altering how willing physicians or healthcare organizations are 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 *(60)*. 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 *(61)*.

Widening the Resource Gap Between "Rich" and "Poor"

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 do not—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 work with rising numbers of uninsured and underinsured persons and have significant difficulty recruiting and retaining board-certified physicians *(62–66)*. However, organizations that serve minorities may be judged by the same performance standards as better-resourced ones *(67)*. 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-resourced and minority-serving organizations—in either scenario resource disparities widen *(68)*.

EVIDENCE

Performance Incentives May or May Not Work for Their Intended Purpose

The literature that empirically tests the effect of explicit incentives on targeted measures through physicians includes 13 programs in 15 studies. The literature supporting the effectiveness of incentive programs can be at best described as mixed. Six of these studies demonstrate a significant effect on the intended process *(52–54,69,70)*, four studies demonstrate a partial effect *(37,71–73)*, and three demonstrate no effect *(74–76)*. These programs have been systematically reviewed by others recently *(20,77)*. In terms of setting, four of these studies were done in healthcare settings serving vulnerable populations; two of these four demonstrated a significant effect whereas the remaining two were split equally between having a mixed or null effect *(52,69,71,74)*. 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).

Performance Incentives May Have Unintended Consequences

One of the 15 studies in this small literature suggests evaluation of the existence of cherry-picking—the selection of patients that are perhaps easier to care for. This study evaluated whether substance abuse patients with more severe disease were less likely to be treated after the initiation of a performance incentive program. It found that the more severely ill were less likely to be treated after the implementation of a performance incentive program when compared with a control group *(54,78)*.

Performance Incentives May Negatively Impact Disparities

Only one of the 15 studies examined the effect of performance incentives on racial and ethnic disparities in care. This study examined the effect of public reporting on coronary artery bypass graft reporting (CABG) in New York and found that racial and ethnic disparities in CABG rates widened after a public reporting program was instituted *(61)*. This change 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. Tables 1 and 2 provide 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.

Table 1
Summary of Empirically Tested Performance Incentive Programs

	Effect of program on intended measure			Setting			Condition targeted				
Author/year	Significant	Partial	None	Vulnerable	General primary care	Other	Chronic condition	Screening/ immunization (adult)	Screening/ immunization (pediatric)	Other	Unintended consequence
Beaulieu 2005		•			•		•				
Commons1997/ Shen 2003	•				•					•	Cherry-picking
Fairbrother 1999[a]	•			•					•		Better documentation
Fairbrother 2001[a]		•		•					•		
Grady 1997			•	•				•			
Hillman 1998[a]			•		•				•		
Hillman 1999[a]			•		•			•			
Kouides 1998[a]	•				•			•			Better documentation
Norton 1992[a]	•					•		•		•	Cherry-picking
Pourat 2005	•			•					•		
Rosenthal 2005		•			•		•		•		
Roski 2003[a]		•			•					•	
NY State/ Werner 2005	•					•				•	Racial-profiling
Totals	6	4	3	4	7	2	2	4	5	4	5

[a] Randomized study design.

Table 2
Recommendations for Designing and Implementing Performance Incentive Programs That Reduce Disparities

Proceed with caution
Measure race and ethnicity
Make stratified comparisons within a program—i.e., compare how minorities compare with the majority on targeted quality measures
Make stratified comparisons across programs—i.e., compare how programs cause minorities to shift from one provider organization to another
Critically evaluate programs for their intended effects
Critically evaluate programs for their unintended effects, particularly for disparities
Include providers that traditionally serve racial and ethnic minorities
Promote the "minority maxim," particularly for providers that serve the majority
Reward improvement along with achievement
Develop risk-adjustment strategies that give providers obvious credit for caring for medically and/or socially complicated patients

BASIC PROGRAM FEATURES—DISPARITY HIGHLIGHTS

Flow of Incentives

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 community health centers, and the veterans administration *(62–66)*. 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 *(28)*. 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 setting. On the other hand, those providers lose the opportunity to earn additional bonuses if they indeed do good work or to learn about methods of measuring and improving quality. If the disparities are to be narrowed, programs will need to include ways that traditionally provide care for minorities *and* to level the playing field.

Incentive Types

It is unclear if the type of incentive bears on whether performance incentive programs leads to widened or narrowed disparities, if at all. It would be a distraction 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 early evidence that programs relying on 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.

Incentive Triggers

Two main tactics can be used to reduce the incentive to cherry-pick patients: (1) rewarding improvement and (2) 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 nine in a minority population when the standard is less than eight in the majority population. Based on existing evidence, it is unlikely that performance incentive programs will lead to dramatic improvements in quality by itself. 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 toward 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 toward minorities. Further studies need to be undertaken to better understand if and/or why risk adjustment offers insufficient protection against cherry-picking behavior.

Incentive Measures

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 potential exists for these programs to improve the quality of healthcare delivered to minorities and/or narrow disparities. Other disparity-reducing strategies—such as 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 Medicare and Medicaid service 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, yet more immediate information until individual-level race and/or ethnicity data becomes available.

SUMMARY RECOMMENDATIONS

General

Proceed With Caution

In summary, performance incentives programs offer a new strategy for improving the quality of American healthcare. Unfortunately, much experience is not had with these programs and it is unclear whether these programs work. There are theoretical and empirical reasons to be concerned that they may not work, or 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 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 may seem reasonable, but discount the importance of building equity into the healthcare system. If performance incentive programs are to become a fixture in the future payment systems, then it is essential that this is got right, now. Further, there is risk that these programs could worsen disparities or care for minorities—this scenario should be considered morally unacceptable and much effort should be directed toward ensuring that this does not happen.

Make Stratified Comparisons Within a Program—i.e., Compare How Minorities Compare With the Majority on Targeted Quality Measures

One relatively quick and less onerous way to assess 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—i.e., 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 because of shifts in patient populations. More sophisticated methods will need to be used to determine whether adverse patient selection is occurring. At a crude level, 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 about the factors that contribute to success and/or failure.

Critically Evaluate Programs for Their Unintended Effects

Given the theoretical and empirical evidence that these programs can have unintended effects that are harmful to minorities and are medically complex, research efforts should also be directed at ensuring that these programs 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 to minorities, then they must include provider organizations that 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 underresourced 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"

Evidence from the quality improvement literature may help better understand how to narrow disparities and at the same time 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

Although 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. Because minorities are disproportionately represented among the medically and/or socially complex, they are at highest risk for being avoided and vigorous efforts should be directed toward mitigating this very real threat to minority health and healthcare.

Performance incentive programs have the potential to narrow, widen, or maintain disparities in healthcare. The former is the most preferable effect, but based on the literature to date, it should not be assumed that it will happen automatically. The second scenario—the one in which performance incentives widen disparities is morally unacceptable and much should be done 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 it is necessary for progress in one dimension to lag behind all others. It should be questioned why, with all the promise in the air, it is simply being asked that all the "boats" float higher, when it is conceivable to get them to float at the *same* height no matter what level they started from. Further 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, rather than increase, disparities.

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IV

EXAMPLES OF WHAT WORKS

13

Monitoring Socioeconomic Determinants for Healthcare Disparities

Tools From the Public Health Disparities Geocoding Project

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INTRODUCTION

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 *(1–3)*. 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 *(4)*.

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.

The connections between social determinants of health, health status inequities, and healthcare disparities would seem obvious. After all, our

From: *Eliminating Healthcare Disparities in America: Beyond the IOM Report*
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bodies readily make the connections each and every day *(4–6)*. Yet, in the United States, we confront a major obstacle to counting for accountability: the lack of routinely available good data on the magnitude of socioeconomic inequities in health status and healthcare, overall and in relation to diverse forms of social inequality variously involving racism, gender, sexuality, age, nativity, and immigration status *(7–10)*.

Although hospital records and public health data systems almost always include data on age and sex (typically construed as biological variables only), numerous reports have documented the poor quality and spottiness of data on race/ethnicity, the paucity if not total absence of socioeconomic information, and the invisibility of data on immigrant status and sexuality *(7–10)*. These gaps in the data are not accidental, even if they might not be willful. Instead, they reflect the priorities and frameworks (conscious and unconscious) of the groups who design and implement the data systems *(7,11–14)*. Often these data gaps can be explained by the time-disgraced ruse of "no data, no problem;" however, also at play are the vulnerabilities of those who may be targeted for discrimination if they provide information on aspects of their subjugated social position *(10,13–14)*.

In this chapter, our focus on the lack of socioeconomic data in most US medical records and public health surveillance systems *(7–10)* in no way discounts the importance of discrimination—whether in relation to race/ethnicity, gender, sexuality, age, immigrant status, and so on, and within and across socioeconomic strata—in shaping population health *(4,15)*. However, in a context of an all-too-long misguided legacy of interpreting health disparities in these other dimensions as a function of allegedly innate biology, rather than social inequity *(1–4,11–17)*, it is essential to show the extent to which socioeconomic resources (themselves reflecting the impact of past and present discrimination) are associated with health status and healthcare disparities *within and between* these different social groups, as well as within the population as a whole. Bringing socioeconomic position into the picture is thus one of several critical steps needed to confront naïve causal narratives of "health differences" premised on biological or cultural determinism. The challenge is both conceptual and empirical. It is in this spirit that the ideas and tools of the *Public Health Disparities Geocoding Project* are presented (Table 1) *(18–29)*.

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 *(7)*. 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,

Table 1
Synopsis of The Public Health Disparities Geocoding Project

Background	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
Methods	To address this problem, *The Public Health Disparities Geocoding Project* 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
Results	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
Implications	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

ABSMs, area-based socioeconomic measures; BG, block group; CT, census tract; ZC, zip code.

See refs. *18–29*.

even as they are stratified by race/ethnicity and gender *(30)*. It is also why 70% of the 467 *Healthy People 2010* objectives lack socioeconomic targets *(31)*. Clearly, without data on social class, one can neither monitor progress—or setbacks—in eliminating socioeconomic inequalities in health, let alone ascertain their contribution to racial/ethnic disparities in health.

Our study accordingly systematically investigated a possible solution, drawing on an approach used eclectically in US health research for over 75 yr: that of using geocoding and area-based socioeconomic measures (ABSMs) *(19,32,33)*. 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.

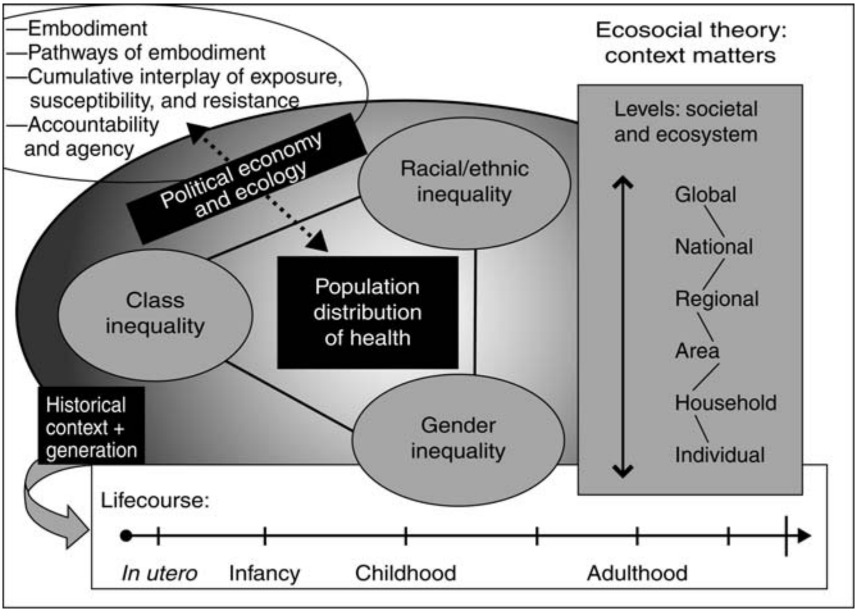


Fig. 1. Ecosocial theory *(34–36)*.

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 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. 1) *(4,34–36)*. Its four core constructs, described in detail elsewhere *(4,34–36)*, pertain to: (1) "embodiment," referring to how we literally embody, biologically, our lived experience thereby creating population patterns of health and disease; (2) "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; (3) "cumulative interplay of exposure, susceptibility, and resistance across the lifecourse," because all three matter; and (4) "accountability and agency," both for social inequalities 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 *(7)*. 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 *(37)*:

> " … 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, 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"*(38)*.

These kinds of comments, however, were comments 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 2000 years, in the 16th century CE, that the question of how work affects health would first attain sustained treatment in European medical texts *(39,40)*. It was not until the early 19th century that studies systematically began to explore links between poverty and health and between slavery and health, and not until the later 19th 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 *(15,16,39–41)*. Interest in the 20th century in social inequalities in health, moreover, has waxed and waned *(16,40,41)*, 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 (31)*.

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 *(4,13,14)*. 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 *(42)*. The fundamental tension, then and now, is between individualistic vs contextualized theories, in other words, theories that seek causes of social inequalities in health in innate vs imposed, and individual vs 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 19th 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 *(43,44)*. 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 *(43,44)*.

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 or the natural environment, but instead were profoundly patterned by poverty and wealth *(13,41,43,44)*. 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 (45)*. 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 *(2,3,39–41,45)*. 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 *(46)*, 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 *(45)*. 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 *(47–49)*.

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 *(18–29)*, while at the same time availing ourselves of recent advances in computer technology

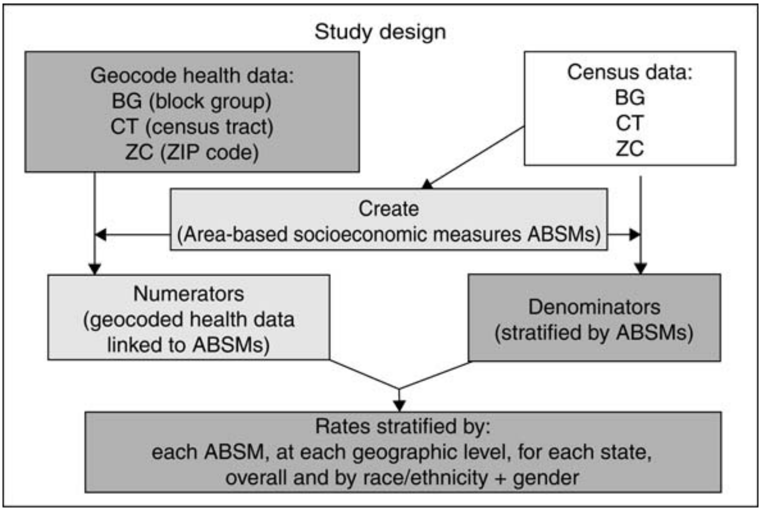


Fig. 2. Public Health Disparities Geocoding Project: study design *(19–23)*.

and software, geographic information systems, statistical methods, and ease of accessing public health surveillance data and US census data *(12,50)*. 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. 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%) *(25)*. 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 *(18)* (http://www.hsph.harvard.edu/thegeocodingproject), as are downloadable pdf files of our *Project's* published scientific articles *(18–27)*.

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 *(18–22)*:

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. 3 illustrates the relationship of the census-defined units *(26,51)*. The basic census-building block is literally the census block, with an average population of approx 85 persons. It is nested within the next unit, the census BG, which on average contains 1000 persons and is the smallest census unit for which estimates of socioeconomic characteristics are released. Census BGs in turn are nested within CTs, which typically include 4000 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" *(51)*. 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 *(19,52,53)*. 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 *(24,54)*.

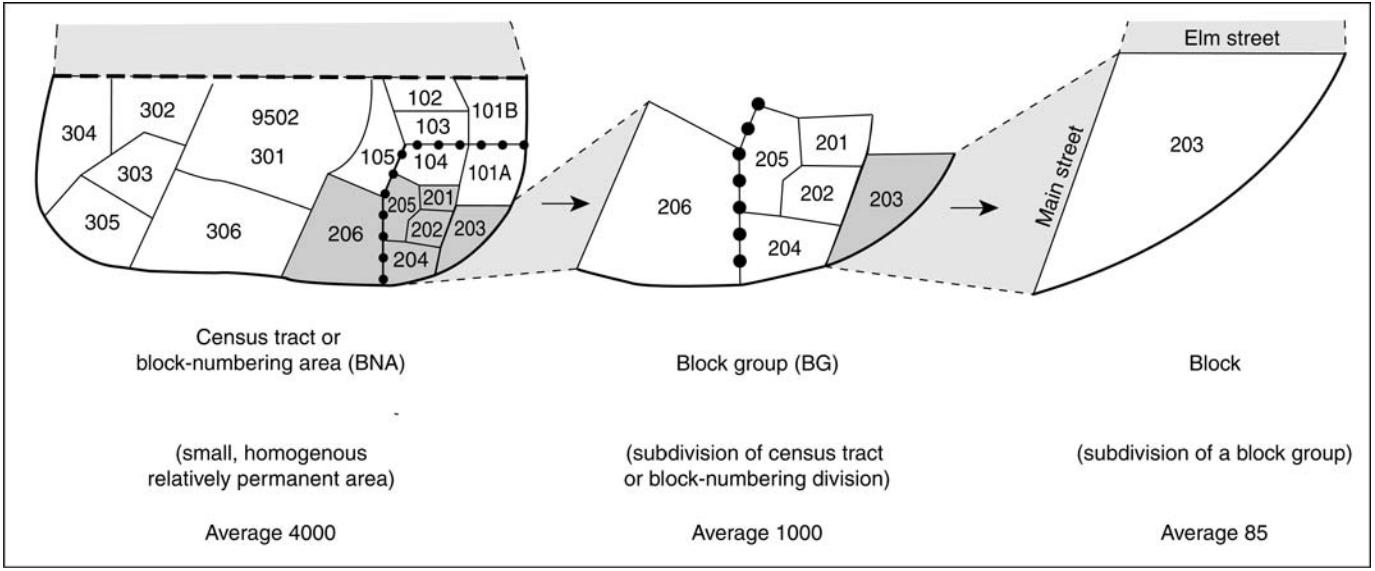


Fig. 3. US census building blocks *(51)*.

Table 2
Public Health Disparities Geocoding Project: Study Population in Terms of Population—Massachusetts and Rhode Island, ca. 1990 US Census

	MA	RI
1990 Population	6,016,425	1,003,464
Mortality data[a] (1989–1991)	155,764	27,287
Cancer data[b] (MA: 1988–1992; RI: 1989–1992)	140,610	19,798
Birth data (MA: 1989–1991; RI: 1987–1993)	267,311	96,138
Childhood lead screening (RI only: 1994–1995)	–	62,514
STIs (MA: 1994–1998; RI: 1994–1996)	39,144	6403
TB (MA: 1993–1998; RI: 1985–1994)	1793	576
Nonfatal weapons-related injury (MA only: 1995–1997)	5517	–

MA, Massachusetts; RI, Rhode Island; STIs, Sexually Transmitted Infection; TB, Tuberculosis.

[a] All-cause plus analyses of top five causes by race/ethnicity: heart disease, malignant neoplasm, cerebrovascular disease, pneumonia and influenza, chronic obstructive pulmonary disease, unintentional injury, diabetes, HIV, and homicide and legal intervention.

[b] Primary invasive, all-site plus five key sites: breast, cervix, colon, lung, and prostate.

See refs. *19–23*.

Table 2 presents data on the study population, defined in terms of people. In 1990, the population of Massachusetts was approx 6 million persons and that of Rhode Island, about 1 million. The number of records obtained from each surveillance system varied by outcome, with the total equaling nearly 1 million. Table 3 in turn provides data on the study base as defined by geographic units. As expected, BGs and CTs on average contained approx 1000 and 4500 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) *(16,55)*. 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 *(55)*. 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 *(55)*.

Table 3
Public Health Disparities Geocoding Project: Study Population in Terms of Areas—Massachusetts and Rhode Island, 1990 US Census

State	Geographic level	N	Mean population size N	Mean population size Standard deviation	Range
MA	BG	5603	1085.40	665.20	5–10,096
	CT	1331	4571.80	2080.00	15–15,411
	ZC	424	12,719.70	12,244.10	14–65,001
	BG	897	1,137.70	670.80	7–5,652
RI	CT	235	4,325.30	1,810.90	26–9,822
	ZC	70	14,335.20	13,234.80	63–53,763

MA, Massachusetts; RI, Rhode Island; BG, block group; CT, census tract; ZC, ZIP code. *See* refs. *19–23*.

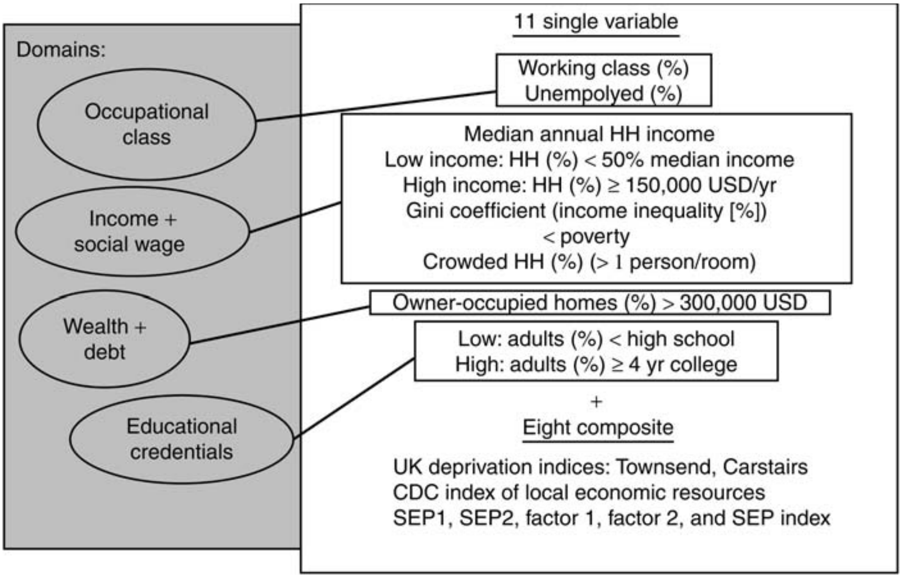
From this vantage, we generated 19 census-derived ABSMs, 11 single variable and eight composite, intended to capture diverse domains of socioeconomic position relevant to health *(18–23,26)*. Listed in Table 4, these included: occupational class, income and income inequality, poverty, wealth, education, 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 1 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 *(24)*.

Key Methodological Results, Caveats, and Recommendations: for Routine Monitoring, Use the CT Poverty Measure

As discussed in the *Project's* publications *(18–29)*, our key findings (Fig. 4), based on analyses for each outcome by each state for the overall population and by racial/ethnic-gender group, were that:

Table 4
Public Health Disparities Geocoding Project: ABSMs



HH, household; CDC, socioeconomic position.
See refs. *18–23, 26.*

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 *(19,55–59)*. Additionally, CT data can provide important information on social context that may affect population health *(19,47–49,55–59)*, even as we recognize that this etiological hypothesis can only be tested in data sets that contain both individual- and area-level socioeconomic data.

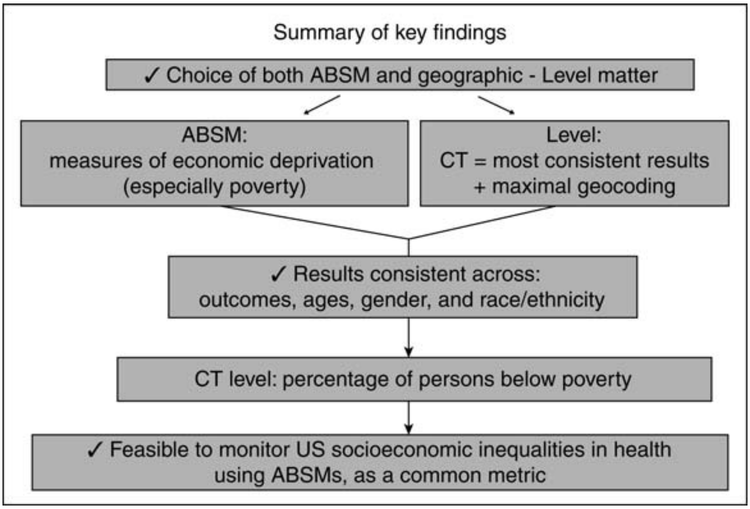


Fig. 4. Public Health Disparities Geocoding Project: summary of key findings *(19–29)*.

Despite these appealing features, four caveats pertain to 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 *(19–23,48–50,60)*. The second is the "modifiable areal unit problem," *(60,61)* 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 *(19,56,62,63)*. 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 *(19–23)*. The fourth concerns omitted variables and selection bias, whereby both can yield biased estimates of exposure-outcome associations and jeopardize valid causal inference *(60,64–67)*.

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 *(19–23,28,29)*. Thus, for analyses for the two outcomes for which we had individual as well as CT socioeconomic data, i.e., 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 *(28,29)*. 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 yr of college *(29)*. This discrepancy was likely due to selective misclassification of the individual-level educational data *(29)*, an inference supported by other mortality studies that have compared results based on verified educational data vs educational data from the death certificate *(68,69)*. 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 *(68,69)*.

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 *(19,51,p. A-5)*. Thus, in addition to the various federal programs that use CT data to target resources for medical care, housing, and employment *(52,53)*, cities use CT boundaries to define neighborhoods for public health department programs, school districts, and other municipal programs *(19,50)*.

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 *(19)*. 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 *(6,55–59)*, 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-yr rolling averages) from the American Community Survey, starting in 2010 *(70)*.

The fourth and final set of caveats, regarding the separate problems of omitted variables and selection bias *(60,64–67)*, 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: (1) 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 (2) the specified health outcome *(55,58,59,71)*. The growing body of lifecourse research nevertheless indicates that cumulative disadvantage, not just early life or adult conditions, is a powerful determinant of many health outcomes *(2–6,72–74)*. 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 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 *(19–23)*. For each outcome, we show the 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.
4. *Weapons-related injury:* gunshot wounds.
5. *Cancer incidence:* lung cancer, colon cancer, breast cancer, cervical cancer, and prostate cancer.

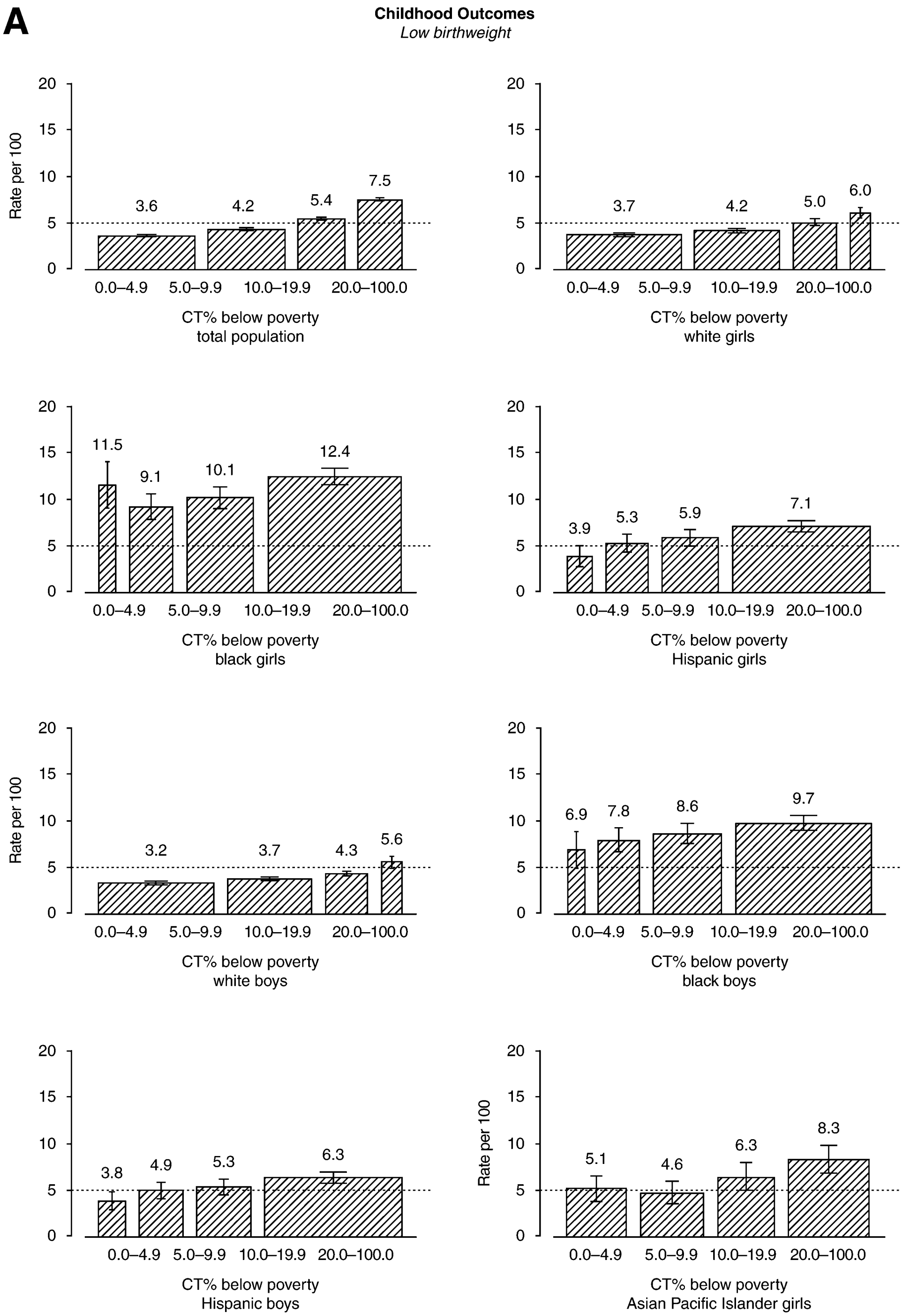
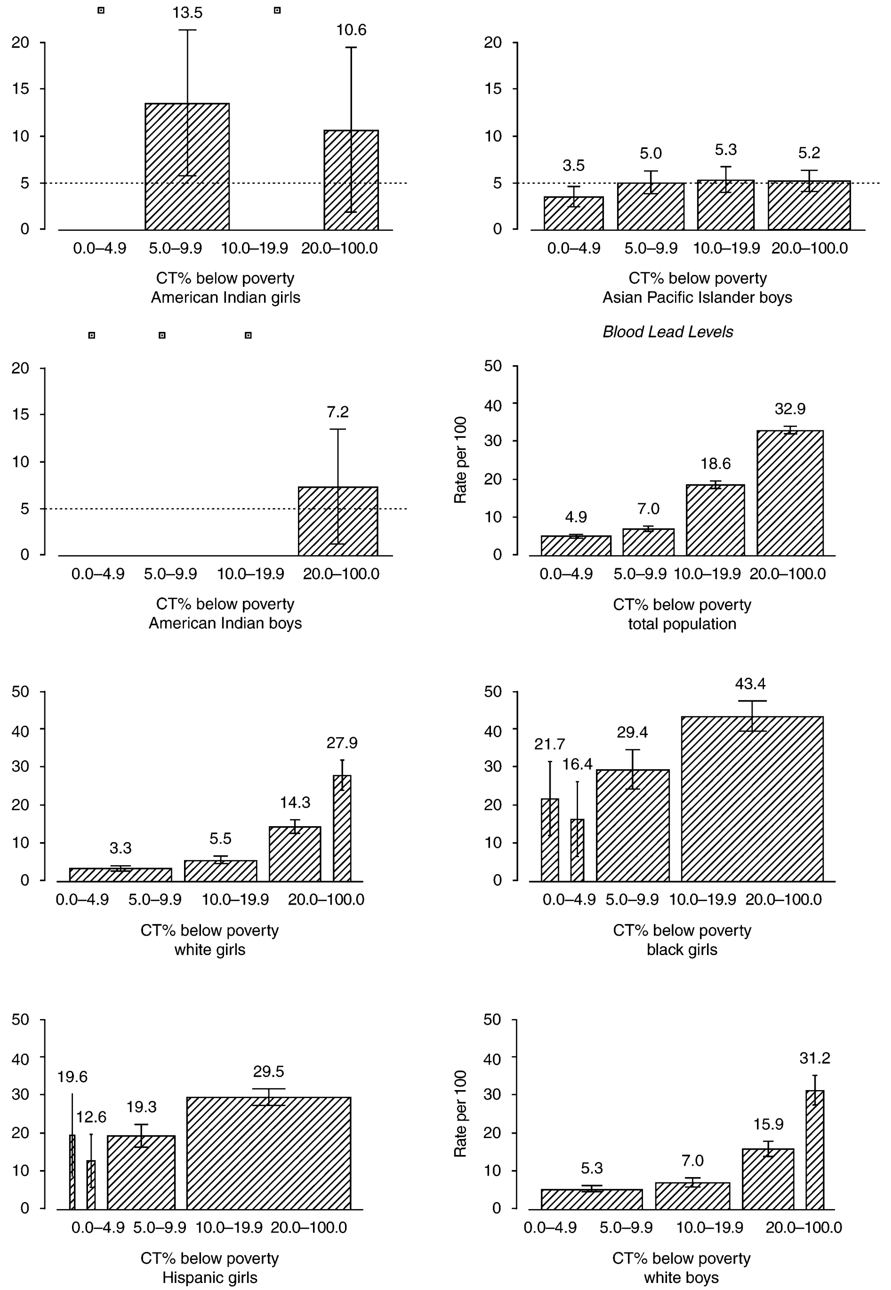


Fig. 5. *(Continued)*



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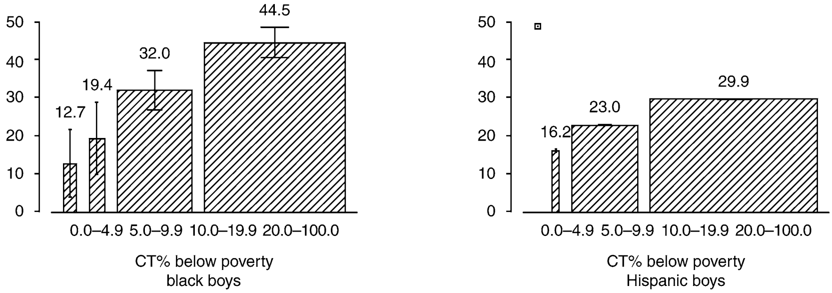
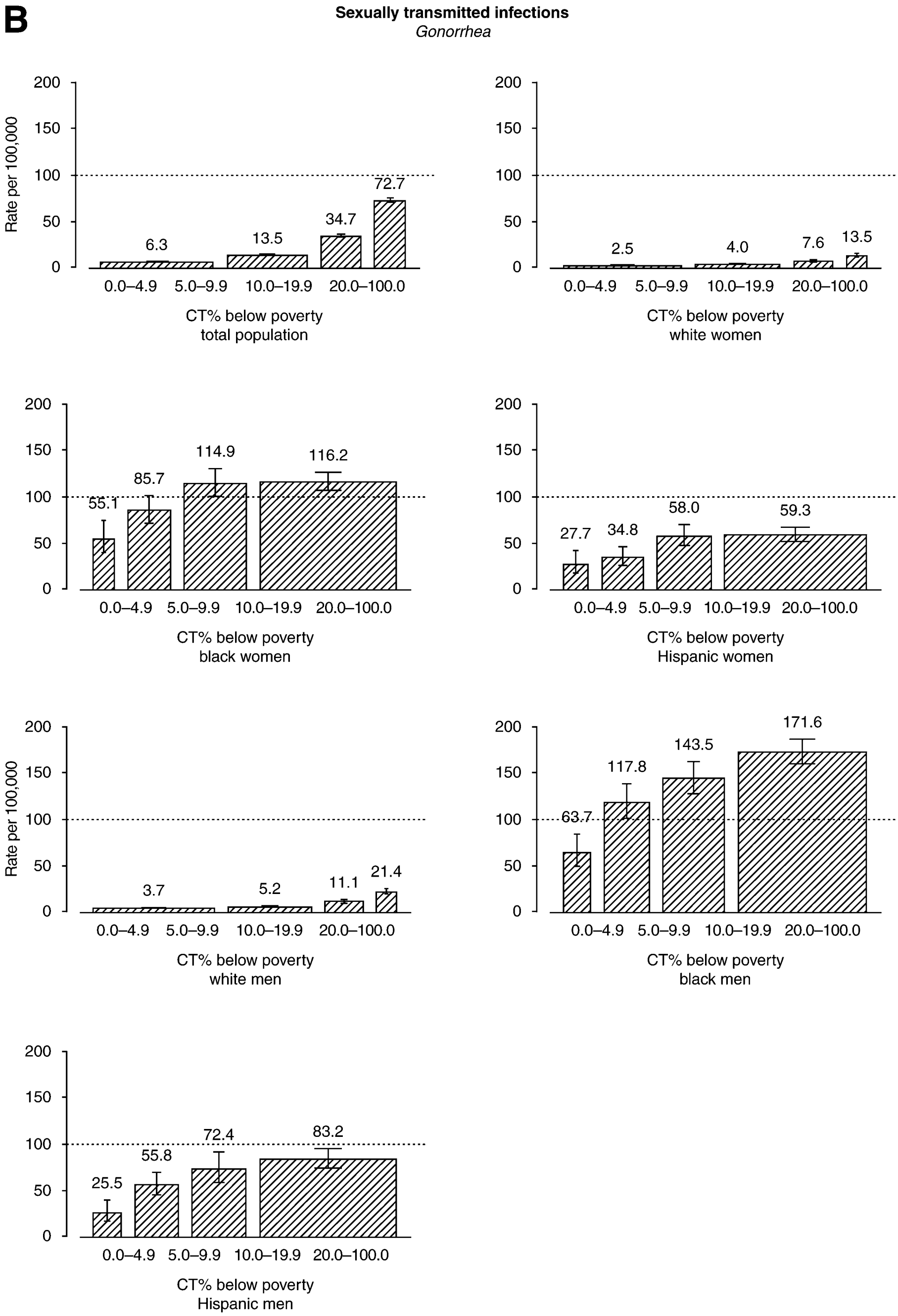


Fig. 5. *(Continued)*

6. *Mortality:* premature mortality (death before age 65), heart disease mortality, cancer mortality, diabetes mortality, HIV mortality, and homicide.

In all cases, except for the childhood outcomes, rates are age-standardized to the 2000 US standard million *(75)*.

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” *[76]*). 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. 5 accordingly enables simultaneous presention 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) *(19–23,77)*. 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 *(78)*.



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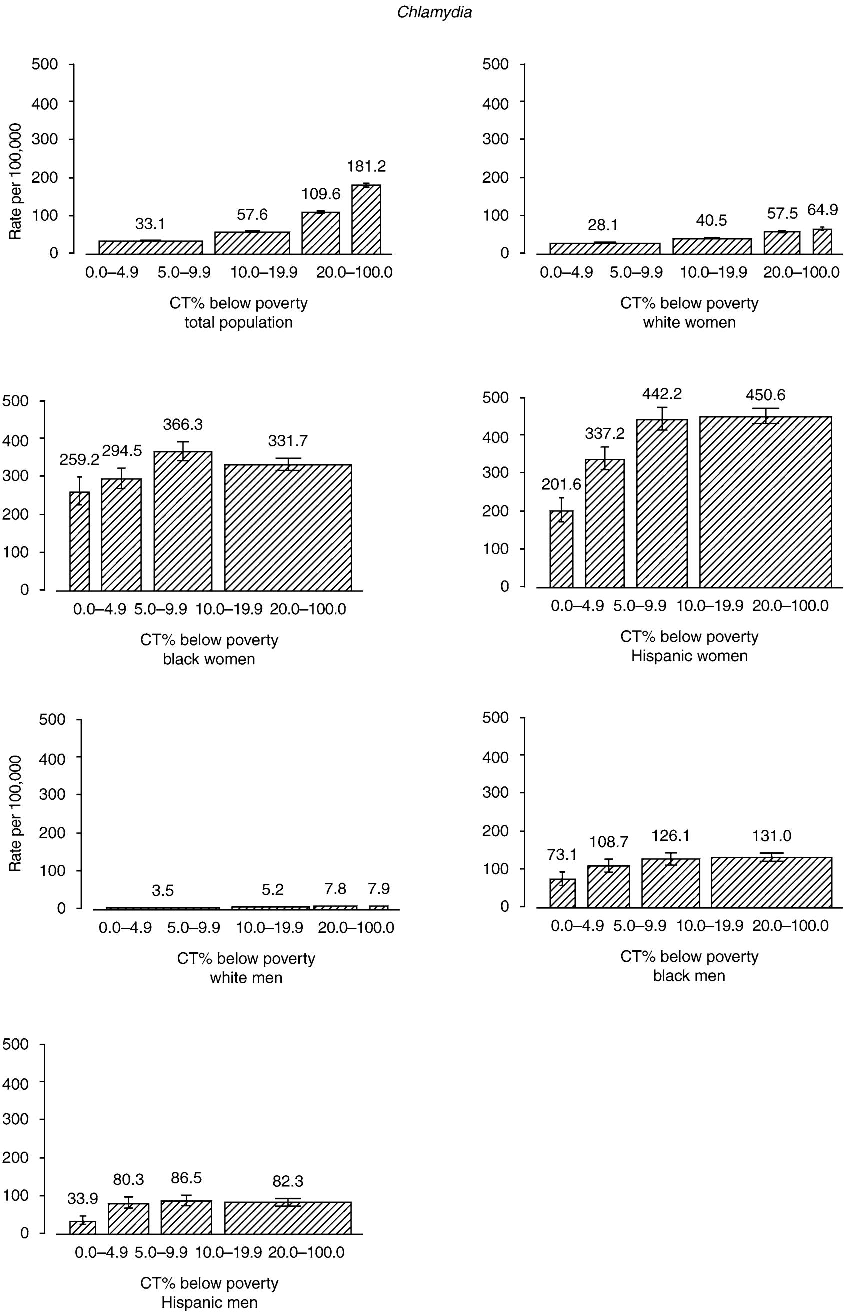

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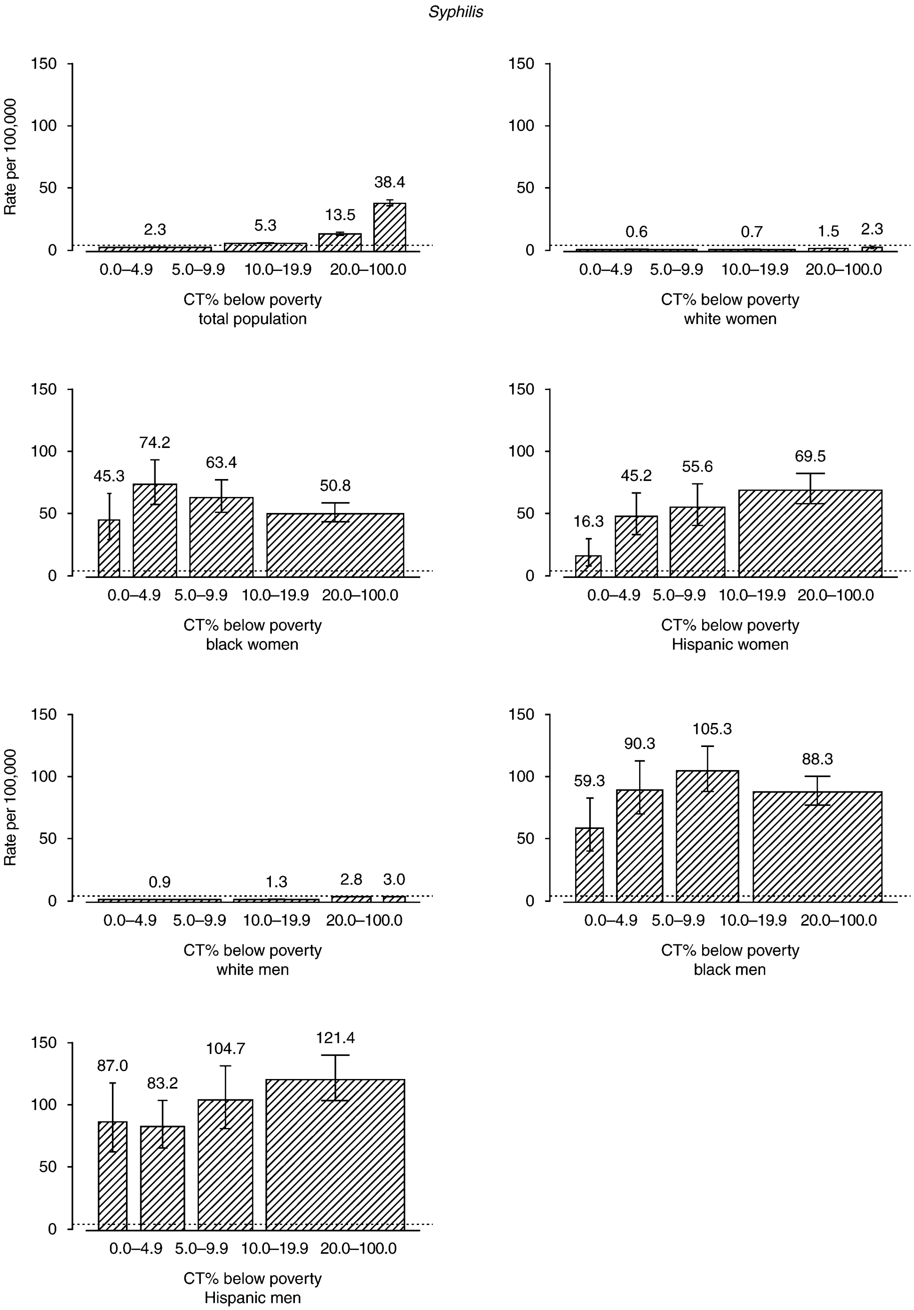

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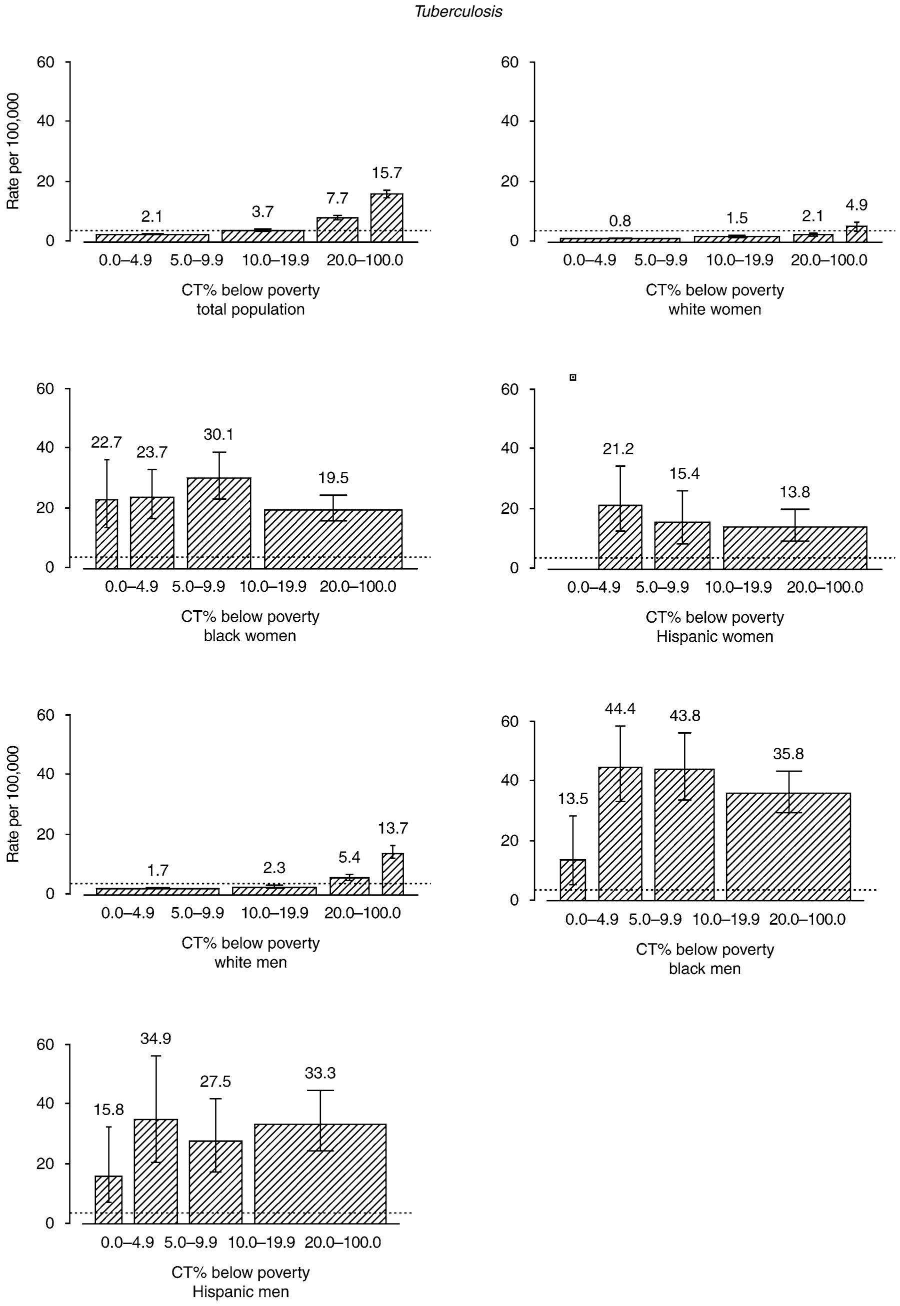

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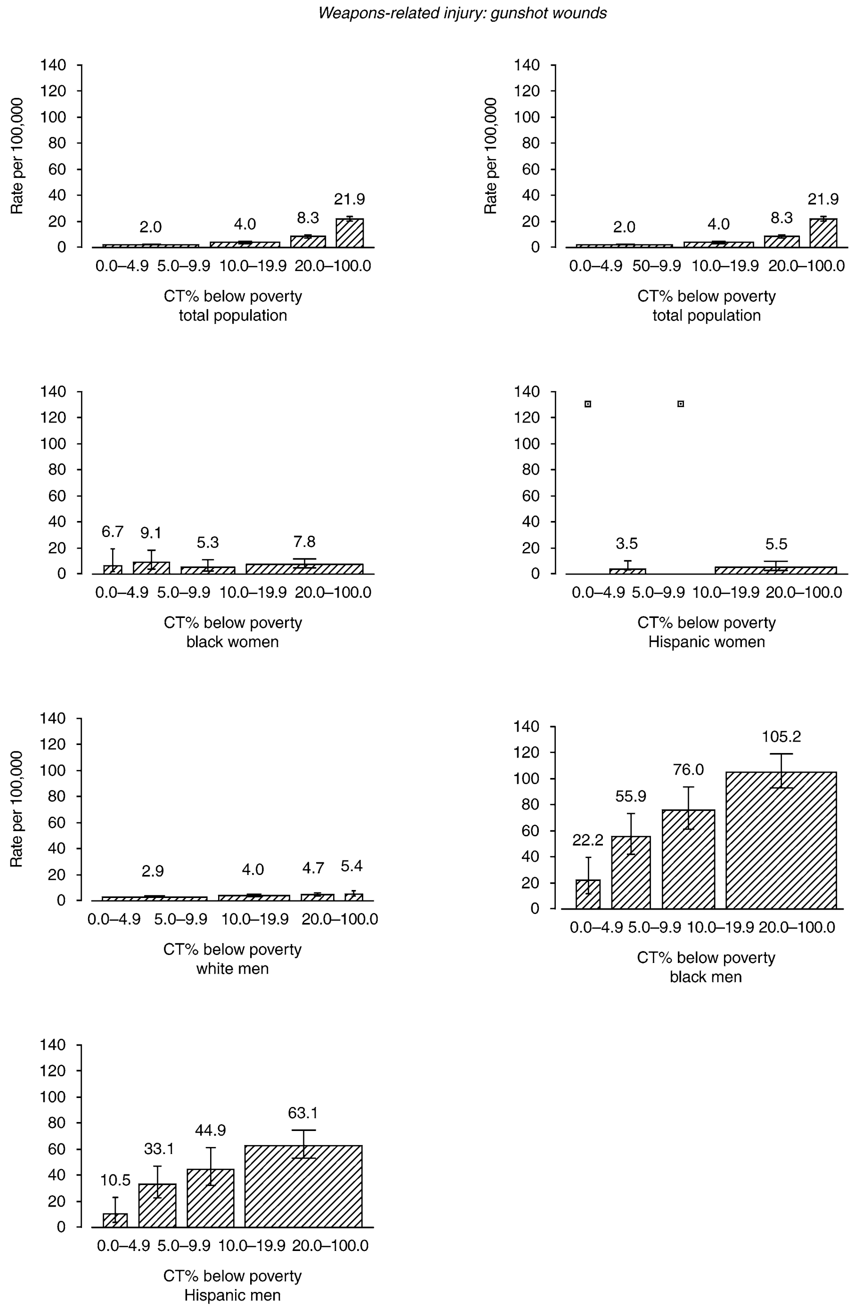
Weapons-related injury: gunshot wounds

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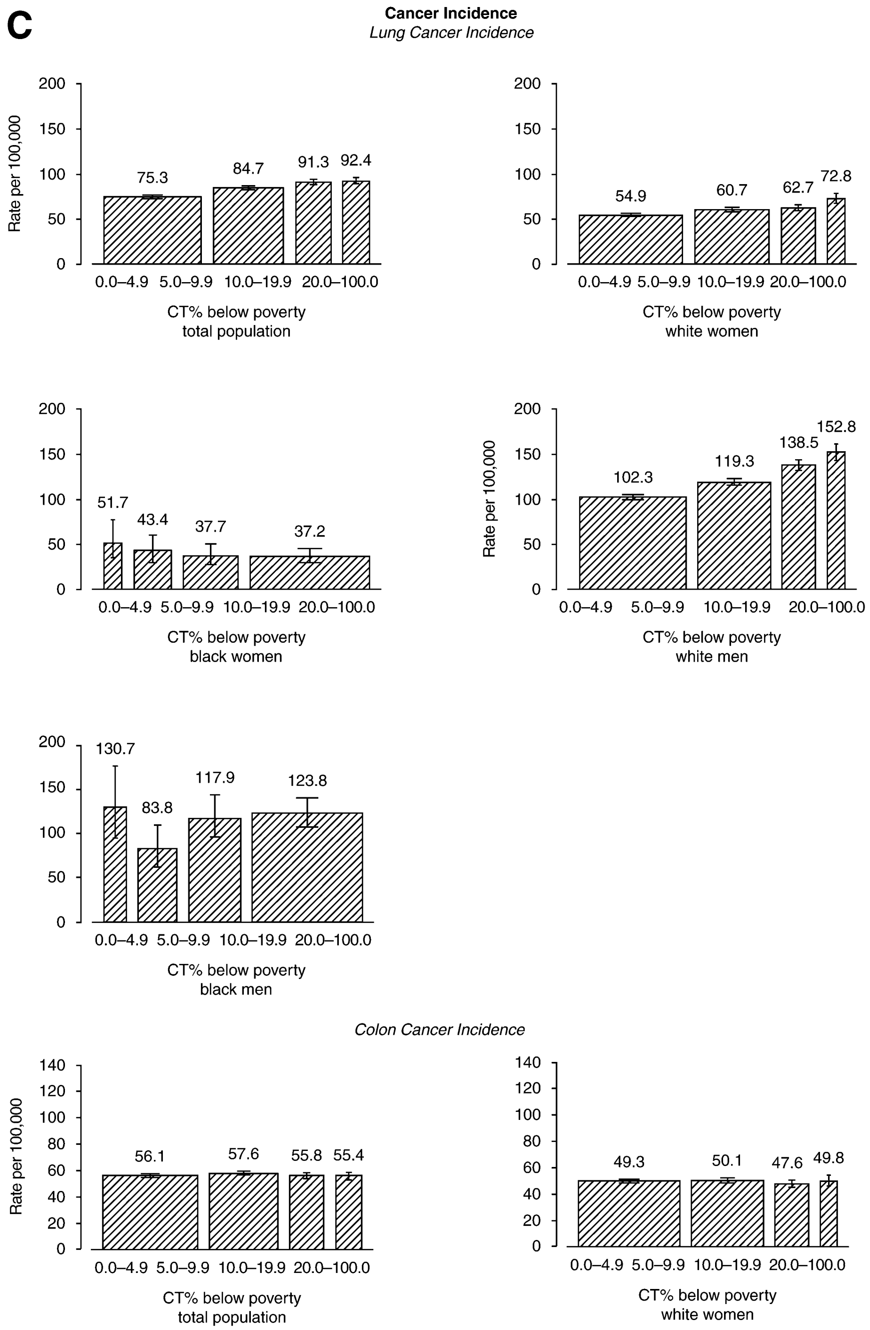

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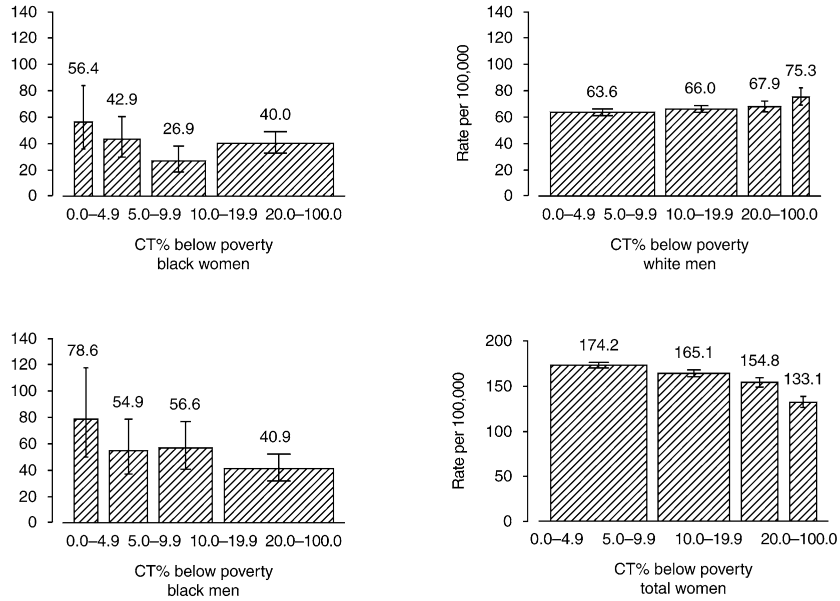
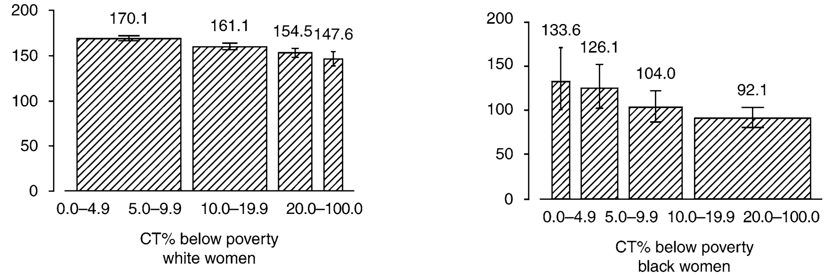
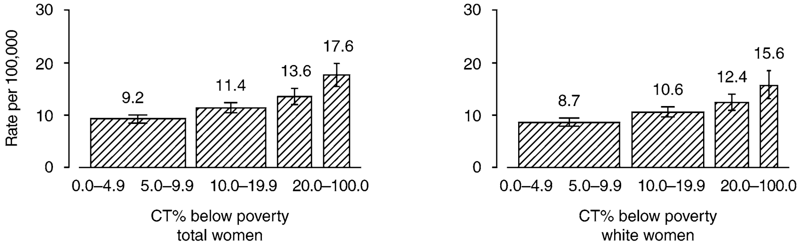


Breast Cancer Incidence



Cervical Cancer Incidence



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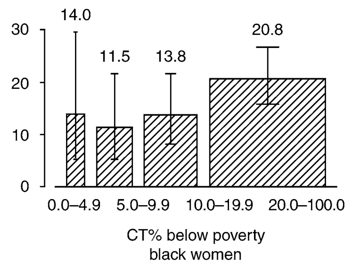


Prostate Cancer Incidence

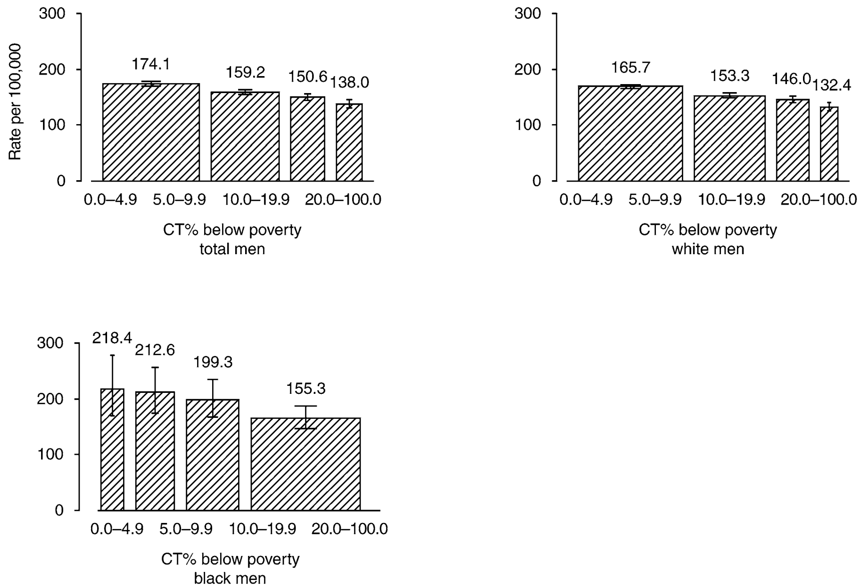
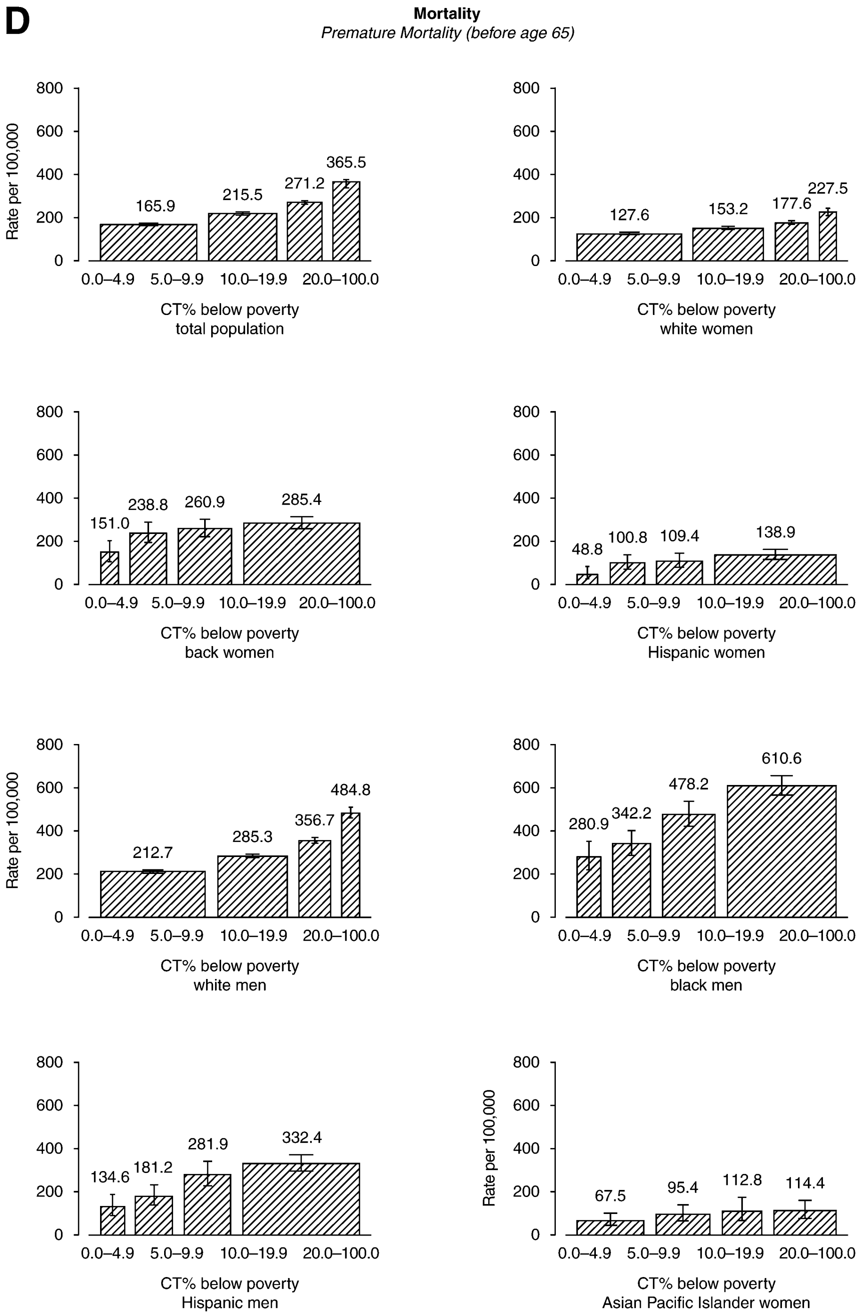


Fig. 5. *(Continued)*

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 vs 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 vs least



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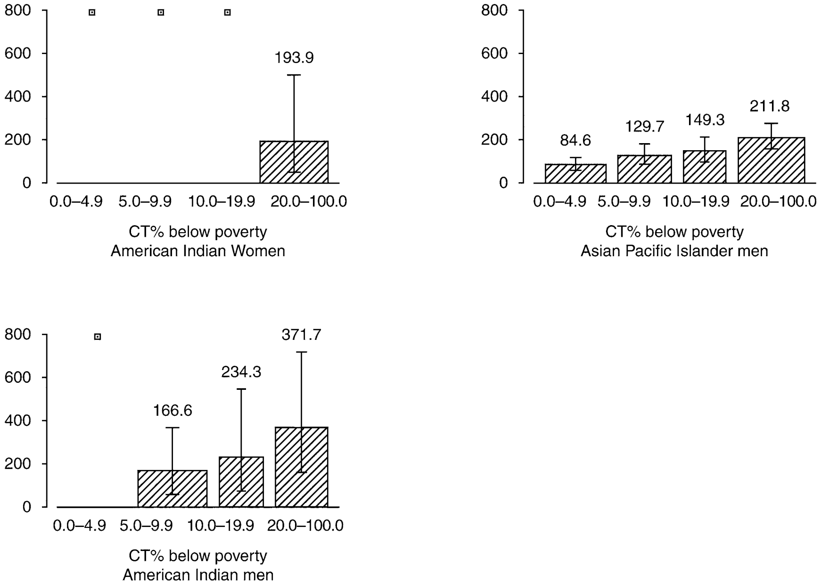
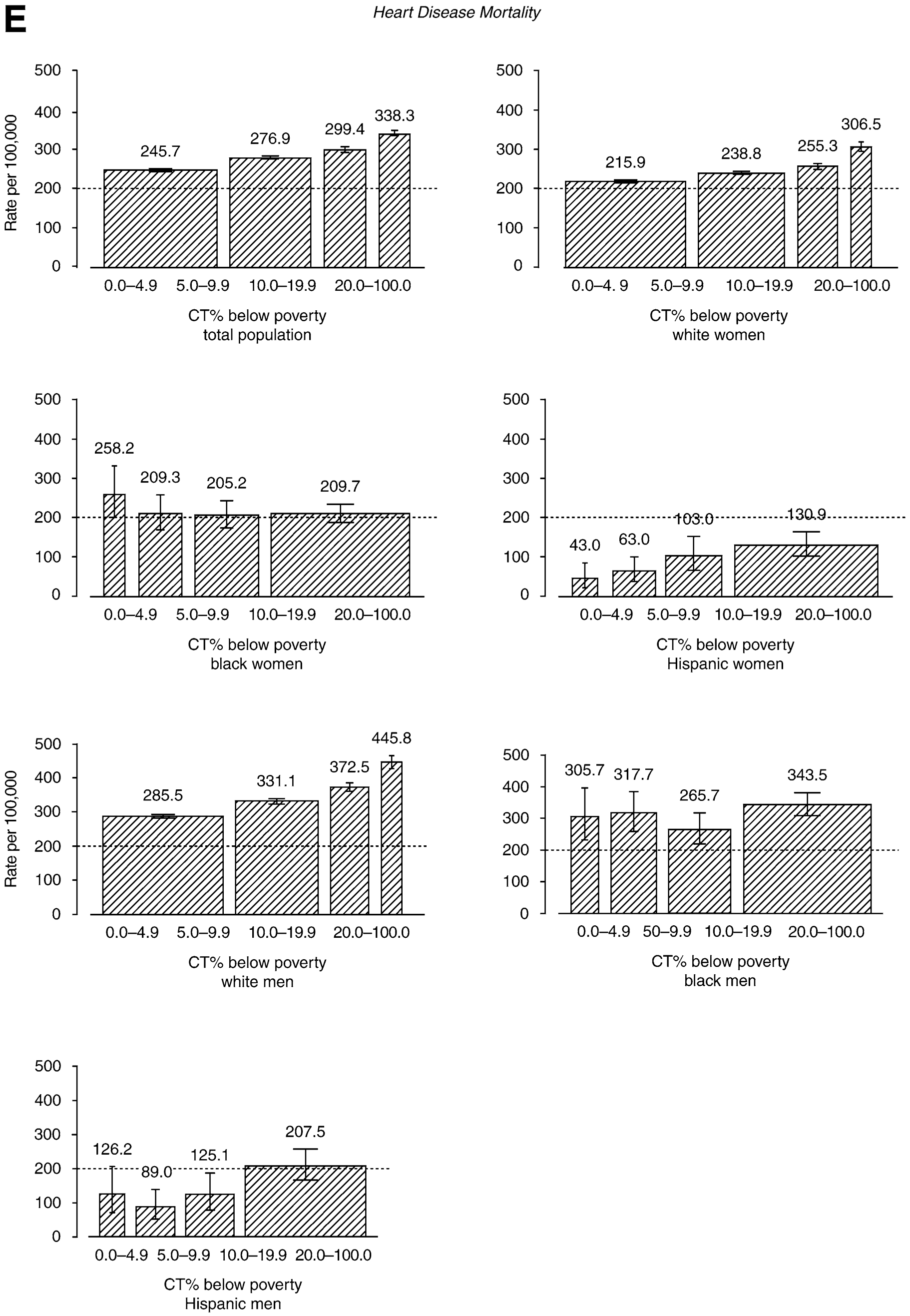


Fig. 5. *(Continued)*

impoverished CTs, i.e., 33 vs 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 compared 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 gun shot injury, within the total population, the relative risk, comparing persons in the most to least poor CTs was 11-fold, or about



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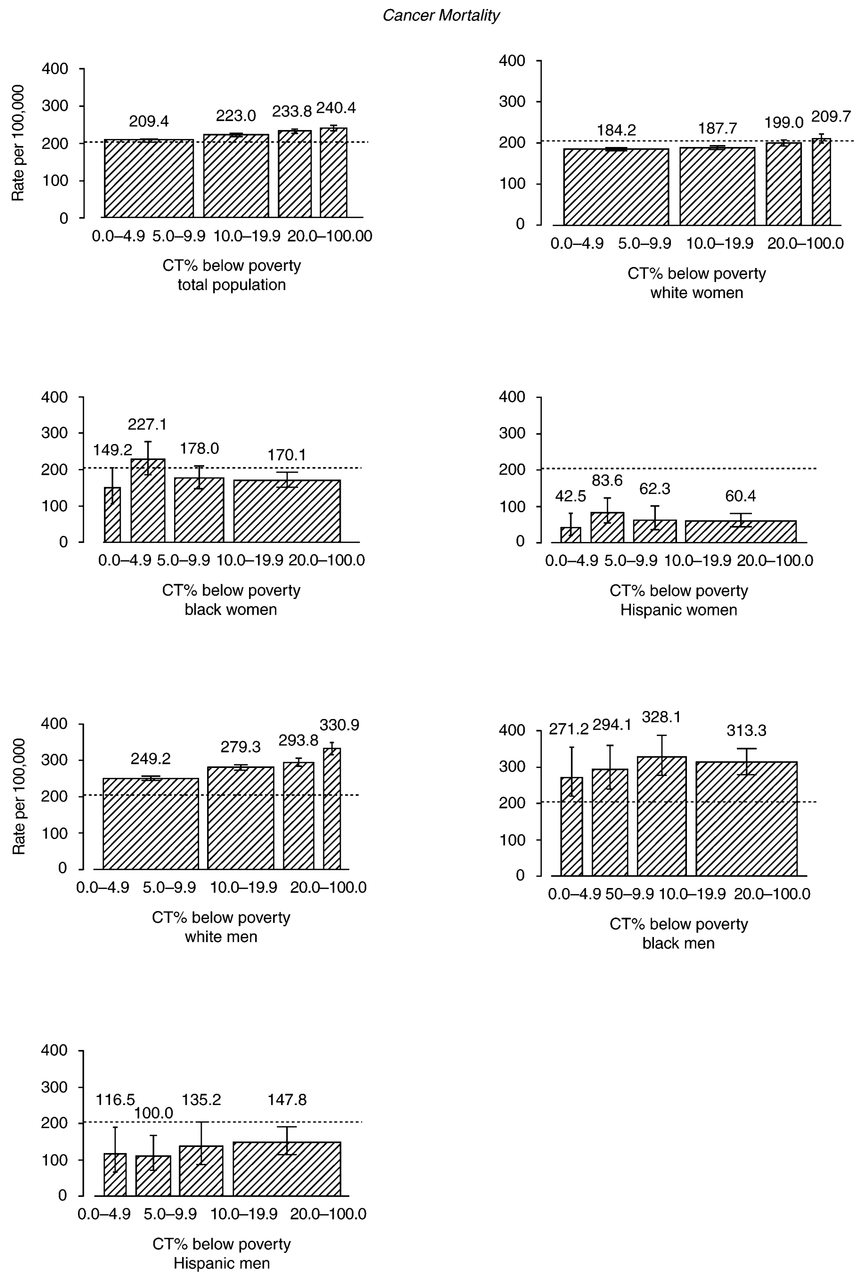

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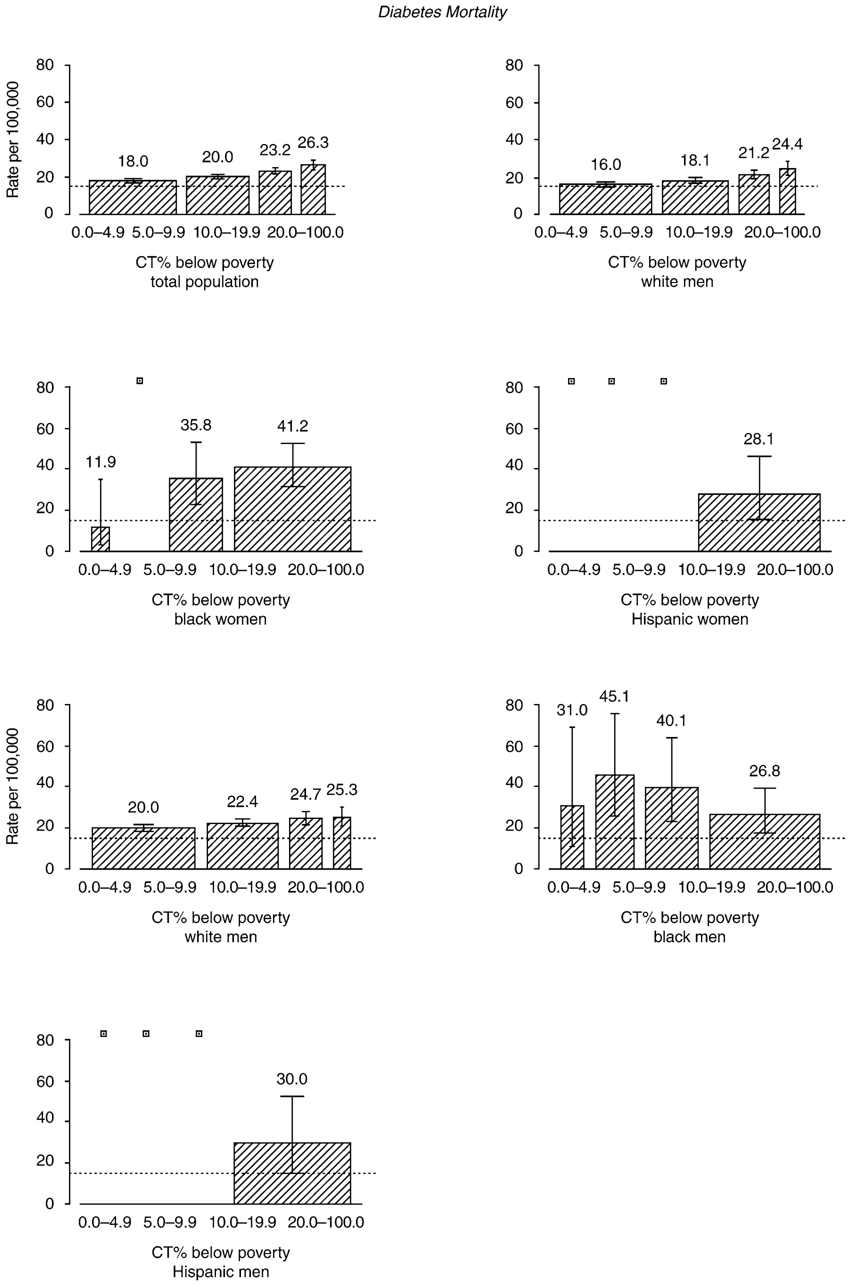

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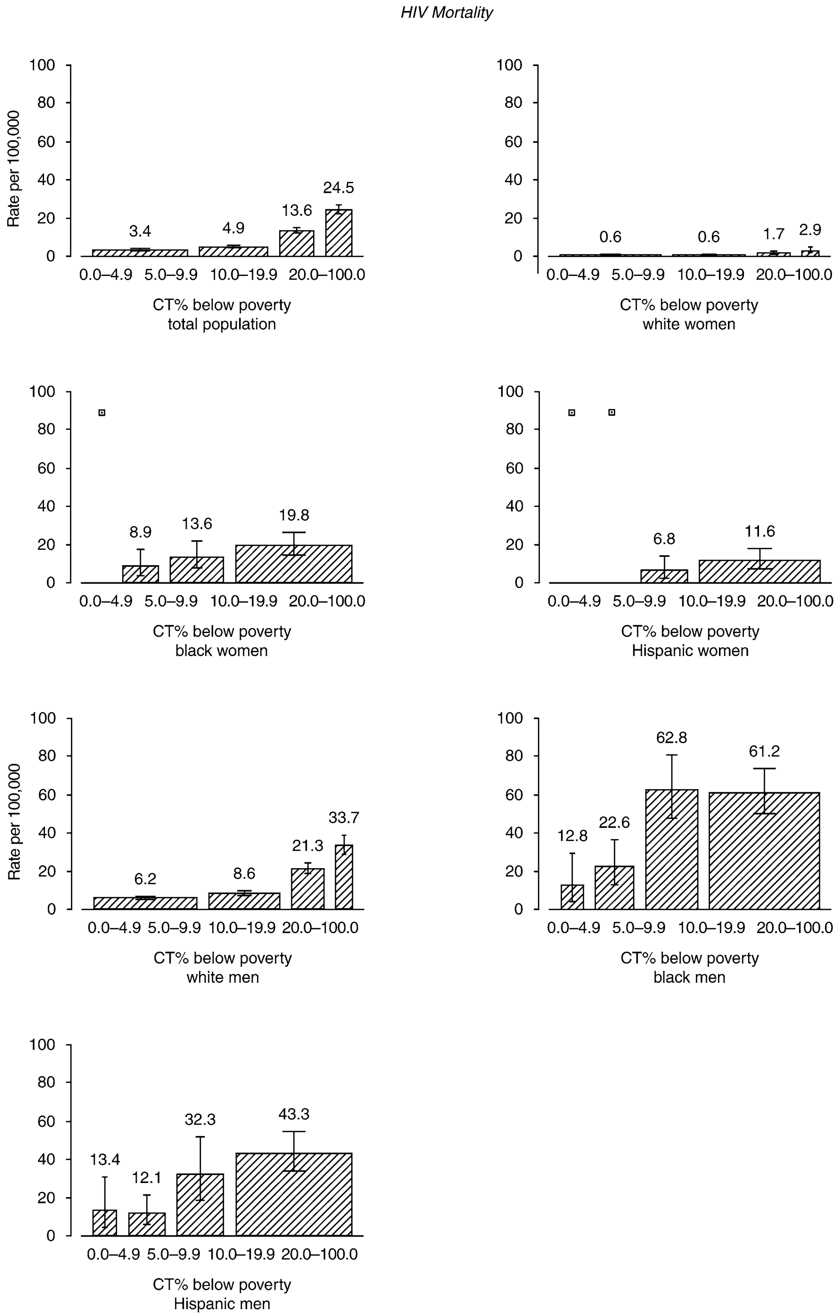

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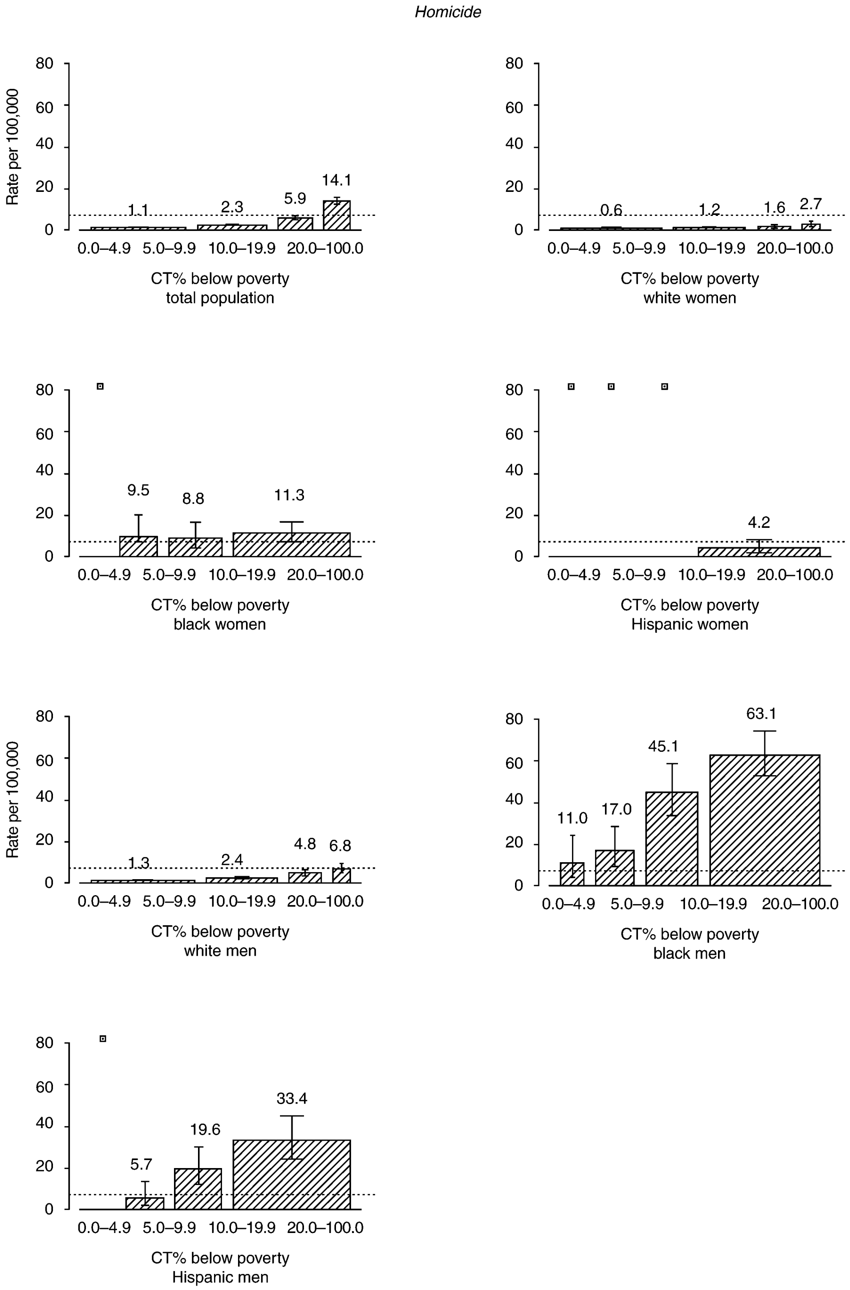

Fig. 5. *(Continued)* Public Health Disparities Geocoding Project: socioeconomic inequalities in health, from birth until death, for total population and by race/ethnicity and gender, Massachusetts and Rhode Island, ca. the 1990 US census *(19)*.

22 vs 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 clearcut 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, i.e., rates of 18 vs 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. 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 *(19)*. To our knowledge, our *Project's* analyses are the first to calculate state-level PAFs in relation to poverty.

Tables 5 and 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 5 shows

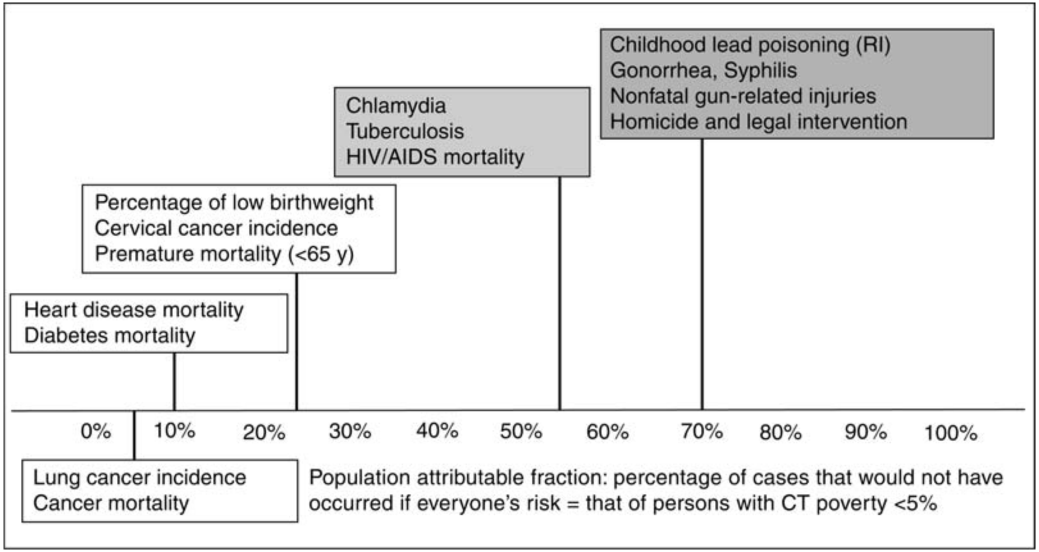

Fig. 6. Public Health Disparities Geocoding Project: PAF in relation to CT poverty, Massachusetts and Rhode Island, ca. the 1990 US census *(19)*.

Table 5

Public Health Disparities Geocoding Project: Premature Mortality Rates (death before 65 yr of age), by Race/Ethnicity, Gender, and CT Poverty Level, Massachusetts, 1989–1991 *(19)*

Persons below poverty (CT [%])	N	Percentage	Rate[a]	IRR (95% CI)	RII (95% CI)	N	Percentage	Rate[a]	IRR (95% CI)	RII (95% CI)
			White men					White women		
<5	3,203,500	47	212.7	(1)	2.6	3,234,468	46	127.6	(1)	1.9
5–9.9	2,145,999	31	285.3	1.3 (1.2, 1.4)	(2.5, 2.8)	2,205,174	32	153.2	1.2 (1.1, 1.3)	(1.7, 2.0)
10–19.9	983,442	14	356.7	1.7 (1.5, 1.8)		1,012,152	14	177.6	1.4 (1.2, 1.6)	
≥20	537,120	8	484.8	2.3 (2.0, 2.5)		535,689	8	227.5	1.8 (1.5, 2.1)	
			Black men					Black women		
<5	42,777	11	280.9	(1)	2.7	34,530	8	151	(1)	1.6
5–9.9	69,978	17	342.2	1.2 (0.7, 2.1)	(2.2, 3.2)	696,663	16	238.8	1.6 (0.8, 3.2)	(1.3, 2.0)
10–19.9	96,048	24	478.2	1.7 (1.0, 2.8)		101,934	24	260.9	1.7 (0.9, 3.3)	
≥20	197,895	49	610.6	2.2 (1.4, 3.4)		220,539	52	285.4	1.9 (1.0, 3.5)	
			Hispanic men					Hispanic women		
<5	41,931	11	134.6	(1)	2.8	37,938	9	48.8	(1)	2.4
5–9.9	64,854	16	181.2	1.4 (0.6, 3.0)	(2.2, 3.6)	64,392	16	100.8	2.1 (0.6, 7.2)	(1.7, 3.4)
10–19.9	81,999	21	281.9	2.1 (1.0, 4.4)		84,606	21	109.4	2.2 (0.7, 7.6)	
≥20	205,635	52	332.4	2.5 (1.2, 4.9)		221,898	54	138.9	2.8 (0.9, 8.0)	

Table 6
Public Health Disparities Geocoding Project: Black/White Disparities in Premature Mortality IRRs for Death Before 65 yr of Age, by CT Poverty Level, Massachusetts, 1989–1991

Persons below poverty (CT [%])	Black/white IRR[a] (95% CI) Men	Women
<5	1.4 (1.3, 1.5)	1.4 (1.2, 1.5)
5–9.9	1.5 (1.4, 1.7)	1.6 (1.4, 1.8)
10–19.9	1.3 (1.1, 1.5)	1.7 (1.4, 2.0)
≥20	1.3 (1.1, 1.6)	1.2 (1, 1.6)
Overall	2.0 (1.9, 2.1)	1.9 (1.8, 2.0)
Adjusted for percentage below poverty (CT)	1.4 (1.4, 1.5)	1.5 (1.4, 1.6)

IRR, incidence rate ratios; CT, census tract; CI, confidence interval.
[a] All models adjusted for age, using Poisson regression models.
See ref. *19*.

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 1.6–2.8.

Additionally, as shown in Table 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 *(55,58–59)*, 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 *(79–80)*.

IMPLICATIONS OF THE PROJECT FOR MONITORING AND ANALYZED HEALTHCARE DISPARITIES

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 *(81,82)*. 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? *(82–88)*.
2. What is the magnitude of socioeconomic disparities in health status, health behaviors, and treatment outcomes among patients enrolled in a particular health plan? *(89–93)*.
3. Should data on the socioeconomic composition of health plan members be included as an adjustment factor for comparing health system performance? *(94)*.
4. Are there socioeconomic inequities in performance of procedures, referrals, and other outcomes indicative of healthcare system performance (independent of patient health status)? *(83,92,95)*.

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 *(81)*. 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 socioeconomic data *(81,88,91,94,95)*. 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 *(12)*. 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 *[24]*). 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 *(24,54)*. 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" *(96, p. 22)*. To "overcome the difficulties in precisely defining the land area covered by each ZC" *(54)*, starting with the 2000 Census, the US Census Bureau accordingly created a new statistical

Table 7
Technical Definitions of and Distinctions Between ZCs and ZCTAs.

Definition of ZCTA	Distinction between ZCTA and ZC
"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"	"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 yr. 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"

PO, post office; USPS, US postal service; ZC, ZIP code; ZCTA, ZIP code tabulation areas. *See* refs. *54* and *97*.

entity built from census blocks: the five-digit ZIP code tabulation area$^{\mathrm{TM}}$ (ZCTA) *(97)*. Of note, ZCTAs and ZCs sharing the same five-digit code may not necessarily cover the same area (*see* Table 7) *(98)*, such that ZCs obtained by self-report or from addresses in medical records cannot be assumed to correspond to census-defined ZCTAs.

New interest in improving hospital records, to improve understanding of healthcare disparities *(1,12,99)*, 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 *(99)*. 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 *(100)*. 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 the responsibility, as public health and medical professionals, to end the pernicious cycle of "no data, no problem" *(13,14)*. 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 *(4,101)*. 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.

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14

The Association of Black Cardiologists

A Small-Group Success Story

Richard Allen Williams, MD

INTRODUCTION

Thirty-three years ago, the author founded an organization consisting primarily of African American cardiologists, and named it the Association of Black Cardiologists (ABC) at its inaugural meeting in Dallas, TX. The author was joined in this effort by about 12 other cardiologists attending the annual scientific sessions of the American Heart Association, and all of them 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. Considering high blood pressure as an example, despite the fact that it was recognized that this cardiovascular disease disproportionately affected the African American population, little was being done to increase awareness of this fact or to bring blacks to medical attention for treatment of this devastating disease. In addition, stroke, often a consequence of hypertension, was uncontrolled and was having destructive effects in blacks; and coronary heart disease was not generally believed to be an important cause of illness in this population, although most black cardiologists believed that it was. They were also concerned about the shortage of African Americans trained to treat cardiovascular disease, and one of the mandates was and is to spur efforts to increase the number (at that time, it was estimated that there were only a few dozen black cardiologists in the country compared with thousands of predominantly white cardiovascular specialists, and they could count only eight fellows in training programs).

With almost no funding and very little moral support, they managed to create an energetic, innovative, efficient, and fiscally sound organization,

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which is regarded as a model that is arguably the best small minority medical group in the country. Those bragging rights are based on the impact of a number of community-based programs, which have allowed patients to benefit from the knowledge possessed by the member cardiologists and other healthcare professionals of the ABC. This chapter details some of those programs, which represent outreach into the African American community to decrease cardiovascular healthcare disparities among African Americans.

INTERNAL STRUCTURE

At present, the ABC is a membership body that operates from its headquarters in Atlanta, Georgia, in a new state-of-the-art building on 127 acres of land. It is a nonprofit 501(c) (3) organization governed by a Board of Directors, and is led by a president who is elected by the membership every 2 yr. The ABC has 25 dedicated employees who are specialists in various pursuits such as nursing, sociology, business, education, public relations, women's studies, and many other "people skills" so important for communicating with health clients. The ABC is led by an energetic Chief Executive Officer, Dr. B. Waine Kong, who has been at the helm for 20 of the ABC's 33 yr. Under his leadership, the organization pioneered hypertension and other cardiovascular risk factor screening programs in inner-city barbershops, beauty salons, supermarkets, and churches, and developed something that the American Heart Association and other groups 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 and attract to a professional medical office setting. In addition to its administrative offices and a Board of Directors that provides oversight of all of its functions, the ABC has three centers of excellence, which form the organization's operational core. They are described as follows:

The Center for Women's Health

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 yr, it has produced outstanding national, as well as local and regional symposia and meetings on the subject, and has raised awareness among practitioners and the community. As a stalwart member of the national Heart Truth campaign and under the leadership of L. Neicey Johnson, vice president of public affairs, the ABC has exemplified 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, and that African American women have a death rate that is almost 70% higher than Caucasian women.

The Epicenter

Collection of epidemiological data on cardiovascular disease in African Americans is an essential function of the ABC, as well as analysis of the impact of various influences on the subject population. These operations are carried out by an expert staff headed by a well-trained full-time epidemiologist and a cardiovascular nurse educator. Much of the work performed in this center is done in conjunction with the Centers for Disease Control and Prevention, especially in collaboration with Dr. George Mensah, and Dr. Maleeka Glover. Other functions carried out by the Epicenter include surveys of doctors' treatment patterns, community attitudes toward health, and involvement in faith-based community screening and education. The ABC has received funding from another pharmaceutical company for its Changing Health Outcomes by Improving Cardiovascular Education and Screenings (CHOICES) program that is a faith-based initiative of national scope. The Epicenter has been a valuable resource for soliciting and distributing financial aid and direct physician assistance during the aftermath and devastation of Hurricane Katrina through Project Hope. The Epicenter is also responsible for organizing and executing community education and outreach programs and clinical trials involving the ABC membership. This includes the African American Heart Failure Trial (A-HeFT) Study (the pivotal African American Study of Heart Failure) for which Dr. Anne Taylor, an ABC member, was the principal investigator.

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. The ABC holds at least three national scientific sessions per year and through these sessions 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 has recently granted "Accreditation With Commendation" status to the ABC, a distinction, which is directly owing to the tireless and unselfish efforts of Dr. Luther Clark and Cassandra McCullough, vice president for extramural programs. As a result of their dedicated work, the ABC is ranked in 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 33 yr 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 that feature nationally recognized experts speaking mainly to audiences of 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 multimodality imaging in ischemic heart disease. The Center for Continuing Medical Education 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. As a result, it has enjoyed phenomenal growth of its assets. Looking at the last decade, assets increased from just over USD 500,000 in 1996 to almost USD 12 million in 2005, representing an improvement of over 400%, and revenue grew from about USD 180,000 to almost USD 7 million in that same time period. Most of the revenue has been produced from educational, epidemiological, and financial investment activities. The major distribution of income has been principally in these same categories.

SPECIAL ABC INITIATIVES

Community Education Projects

1. CHOICES is a faith-based program, which allows ABC to provide training in cardiovascular screening to lay health promotion specialists in screening for hypertension, diabetes, dyslipidemia, obesity, and other health problems. In 2005, over 3800 individuals were screened and 14,000 received information and education about cardiovascular conditions, which 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 have been carried out with thousands of individuals.
3. Super Weekends engage community residents in various national locations for a 3-d period during which they attend a Community Leaders Forum on health on Friday evening, a Patient Education Event and Health Screenings on

Saturday, and a spiritual health encounter on Sunday. So far, this program has reached over 150,000 lives with its direct messaging and screened nearly 2000 people in cities around the country.

4. A Special Heart program partners with local supermarkets to bring awareness and blood pressure screening directly to shoppers. Healthy food choices and label reading are key components of this in-store education. ABC cardiologists and pharmacists present easy-to-understand cardiovascular risk factor identification information and are available for individual consultation during the event.
5. ABC Project HOPE embodies the Katrina Relief efforts. ABC raised USD 300,000 under the leadership of Dr. Keith Ferdinand, and much of this money was used for direct support of Katrina victims and organizations involved in the relief effort.

Participation in Clinical Trials

It is well recognized that African Americans are underrepresented in research studies and trials that 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 celexitil in the treatment of hypertension in blacks.
2. The A-HeFT Study, referred to Chapter 3, was cosponsored by the 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 1000 patients were recruited by the 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 for public use.
3. The American Rosuvastatin Investigation of Efficacy and Safety (ARIES) Trial is the first prospectively designed study of dyslipidemia in African Americans. It uses statin therapy. The ABC members constituted 44% of the investigators, and the ABC recruited half of the patients. The principal investigator, Dr. Keith Ferdinand, is the Chief Science Officer for the ABC.

Other ABC initiatives include development of a practice management system involving electronic medical records, which will be mandatory for medical practices in the not too distant future. The ABC advocates the electronic medical records system because it has the potential for improving patient management and decreasing healthcare disparities. It will also make possible the development of a data warehouse and central repository of information (handled in accordance with Health Insurance Portability and Accountability Act [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 which includes healthcare professionals from several nonblack races and ethnicities. The membership is also multidisciplinary 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 should be a member of the ABC.

CONCLUSION

The ABC 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 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!!”

ACKNOWLEDGMENT

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Breathe Easy in Seattle

Addressing Asthma Disparities Through Healthier Housing

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INTRODUCTION

Asthma is a common chronic health condition that disproportionately affects low income people and people of color. The prevalence and morbidity of asthma in the United States have increased dramatically in the past two decades and remain high *(1)*. Relative to wealthier and white populations, disadvantaged populations have higher asthma prevalence and experience more severe impacts such as severe attacks leading to emergency department visits and hospitalizations *(2–12)*. Two recent publications summarize the disproportionate asthma morbidity found among black, Native American, and some Latino populations *(13,14)*. Non-Hispanic blacks and American Indians of all ages had current asthma prevalence 30% higher than non-Hispanic whites in 2002 *(15)*. The emergency department visit rate among blacks was 380% higher than that among whites, the hospitalization rate was 225% higher, and the mortality rate was 200% higher *(15)*.

Many factors interact to produce these disparities *(12,14,16)*. Living in substandard housing leads to exposure to indoor asthma triggers and higher rates of allergen sensitization *(12,17–23)*. As much as 40% of the excess asthma risk in minority children may be attributable to exposure to residential allergens *(24)*. Populations affected by disparities are more likely to live in areas with high air pollution levels. Social features of the environment, *(25)* including exposure to violence *(26)*, contribute to asthma morbidity. Disadvantaged populations experience suboptimal medical care more frequently, including lower use of anti-inflammatory medications, less continuity

From: *Eliminating Healthcare Disparities in America: Beyond the IOM Report*
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of care, and lower rates of pulmonary function testing *(13,17)*. Lack of insurance and logistical barriers reduce access to primary care *(27)* and medications, leading to crisis-oriented emergency department use. Belief that one has asthma only when symptoms are present is common *(28)*. Social stressors interfere with adherence to asthma control regimens and may directly affect airway function *(29)*. 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 *(13)*. 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 *(30)*.

The projects described in this chapter focus on addressing disproportionate exposure to asthma triggers as a strategy to reduce disparities. Being poor or a person of color is associated with increased rates of sensitization to several asthma-associated allergens found in homes *(23,31–37)*. Sensitization to aeroallergens is one of the main risk factors for developing asthma and its complications *(38–40)*. Strong evidence has linked exposure to dust mites, cockroaches, rodents, mold, tobacco smoke, and pet dander to the development of asthma *(41)* or asthma morbidity *(42,43)*. There is still considerable controversy over the role of exposure timing, specific antigen loads, and endotoxin in development of asthma. Some studies show a protective effect of endotoxin and cat and dog antigen depending on age and exposure, and presumably, genetic predisposition *(44,45)*.

Disparities in asthma morbidity and allergic sensitization may be due, in part, to disproportionate exposure to indoor environmental asthma triggers associated with living in substandard housing *(46,47)*. Moisture and dampness, poor ventilation, crowding, pest infestations, residence in multiunit dwellings, deteriorated carpeting, and structural deficits can contribute to high levels of indoor asthma triggers *(25,48–52)*. A strong parallel thus exists between exposure to indoor 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 *(53)*.

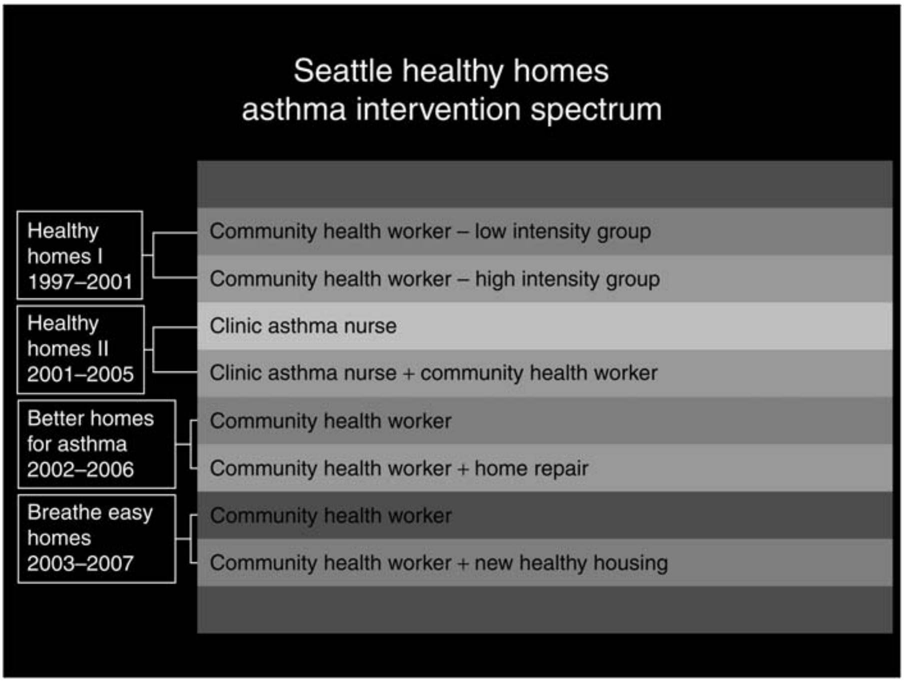
Over the past decade, knowledge of how to reduce exposure to indoor asthma triggers has increased dramatically *(42,54–65)*. While approaches targeting individual triggers have met with limited success *(66,67)*, comprehensive approaches addressing multiple triggers and the total housing environment have been more successful *(42,68–70)* in reducing morbidity. Given the widespread prevalence of indoor asthma triggers in the home *(71)*, and their contribution to disparities, decreasing them has potential for reducing asthma disparities.

Home visitation by asthma specialists has emerged in recent years as a promising strategy for reducing indoor asthma triggers *(72–80)*. The foundation of this approach is the home visit in which a specialist conducts a home environmental audit to identify triggers and suggest simple, low cost actions to decrease them. The specialist offers advice and social support to family members and often provides advocacy for other issues of importance to the household, such as working with landlords. This model has been successful in influencing behavior change, reducing in-home exposure to multiple asthma triggers, and improving asthma outcomes among low-income and minority families. However, a strategy based primarily on education and behavior change is limited in its ability to reduce exposures because of structural housing deficits, such as leaking building envelopes, deteriorated carpet harboring reserves of allergens, or housing conditions that provide havens for pests.

We and others have described the attributes of housing that make homes "asthma friendly" and sought to provide such housing to people with asthma. Focusing on new home construction, groups such as the National Center for Healthy Housing *(81)*, *US Green Building Council's Leadership in Energy and Environmental Design (LEED) for Homes (82)*, the *National Association of Home Builders' Green Home Building Guidelines (83)*, *Enterprise Community Partner's Green Communities Criteria (84)*, the *US Environmental Protection Agency's Energy Star™ with Indoor Air Package (85)*, the American Lung Association's *Health House Builder Guidelines (86)*, and the Energy Efficient Building Association have developed recommendations for constructing sustainable healthy homes. 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 using products that minimize emission of volatile organic compounds.

Three projects in Seattle, Washington will be described where attempts have been made to reduce exposure to indoor asthma triggers in homes of low-income families with children affected by asthma. The first intervention, developed in 1997, used a *home visit* approach with Community Health Workers (CHWs) working with families to adopt behaviors aimed at reducing triggers *(69,70)*. A second intervention, begun in 2004, added *remediation* of existing substandard housing to the CHW intervention. The deconstruction and rebuilding of a public housing site, financed through the Urban Revitalization Demonstration (HOPE VI) program, offered a unique opportunity to develop a third intervention. It was one that would build *new* affordable, asthma-friendly housing for low-income people and people of color and provide them with CHW in-home support for trigger avoidance.

Table 1
Seattle Projects and Intervention Strategies



Seattle healthy homes
asthma intervention spectrum

Project	Intervention
Healthy homes I 1997–2001	Community health worker – low intensity group
	Community health worker – high intensity group
Healthy homes II 2001–2005	Clinic asthma nurse
	Clinic asthma nurse + community health worker
Better homes for asthma 2002–2006	Community health worker
	Community health worker + home repair
Breathe easy homes 2003–2007	Community health worker
	Community health worker + new healthy housing

Taken as a whole, the interventions constitute a continuum of strategies that operate at multiple socioecological 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. All of the interventions include rigorous scientific evaluation and community-based participatory research methods. These projects and intervention strategies will be described (*see* Table 1) emphasizing the lessons learned from this work.

THE SEATTLE-KING COUNTY HEALTHY HOMES PROJECT (1997–2001)

The *Healthy Homes* Project provided two levels of home visits by CHWs to reduce asthma morbidity among children with asthma living in ethnically diverse, low-income households. A 1-yr long, high-intensity intervention was delivered by a CHW. During the first home visit, the CHW conducted a structured home environmental assessment. Each assessment finding generated specific actions for caregiver, family members, and CHW and followed standard recommended practices (for exposure reduction protocol, *see* ref. *69*).

When advising the family on moisture and mold, for example, it was 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% *(87–89)*. The CHW role was to educate, demonstrate, assist in getting landlord repairs as appropriate, and refer the caregiver to a Public Health Environmental Inspector. The CHW and caregiver prioritized actions and prepared a mutually agreed upon plan, based on the scientific basis for selecting those actions *(42,90–93)*. The CHW made an average of seven additional visits to encourage caregivers to complete their plans, to provide additional education and to 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 low-intensity group received one CHW visit and bedding encasements only.

The benefits of the high-intensity relative to the low-intensity intervention were assessed using a randomized, parallel group study design. At the end of the project, all low-intensity group members received the full benefits received by the high-intensity group. Changes were compared in asthma-specific quality of life of the child's caretaker, the child's asthma symptoms, and use of urgent asthma health services across the groups. A cost analysis assessed the cost-effectiveness of the high-intensity relative to low-intensity intervention.

The Community Health Workers

A distinguishing feature of the Healthy Homes Project was its use of a CHW. This in-home asthma specialist shared language, ethnicity, culture, and a personal or family experience of asthma with participants. Each one completed 40 hours of training with follow-up continuing education, followed a protocol and manual, and discussed challenging cases with other team members. During the in-home intervention, the CHW served as a role model in demonstrating actions to reduce exposures, such as vacuuming and cleaning mold. In addition to information and instrumental support, they provided emotional support through a caring, empathetic attitude and genuine interest in the well being of the families (for information on CHW role, *see* ref. *69*). 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, and 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. Details of eligibility criteria are described in the publications *(69,70)*. 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%). About 75% of their homes had at least one asthma trigger present, whereas 36% had two or more.

The Home Assessment

Central to the *Healthy Homes* intervention was a comprehensive home environmental assessment completed by the CHW and caregiver at the first home visit. The assessment consisted of a verbal questionnaire and a visual inspection of the home with family members. Portions of the assessment were repeated at subsequent visits to assess progress in resolving problems or to address new concerns. The CHW asked caregivers about indoor asthma triggers, for example, dust mites, 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, 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 control mold.

The Action Plan

Following the assessment, the CHW developed an initial Home Action Plan that captured the range of protocol-specified actions to address the triggers and behaviors found by the assessment *(17,42,54,68,91,94,95)* (*see* Table 2). The CHW and caregiver prioritized actions that were most feasible and of most interest to the family arrive at an 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.

Table 2
Actions to Reduce Exposures

	Action	
Exposure	Participant	CHW
Moisture and mold	Use ventilation properly, avoid fish tanks and plants, clean mold with detergent solution, heat all rooms and closets, dry water damaged objects promptly or discard, repair leaks, install vapor barrier in crawl space, vent dryers, close windows during seasons of high outdoor spore levels, keep humidity less than 50%	Educate, demonstrate, assist in getting landlord repairs as appropriate, refer to Public Health Environmental Inspector as appropriate
Dust	Vacuum and dust, use double-layer vacuum bags and low emission vacuums, use doormats, remove shoes	Educate, demonstrate, provide with low emission vacuum with dirt finder, vacuum bags, "green" cleaning kit, mop and bucket, gloves, door mat
Mites[a]	Vacuum and dust, wash bedding weekly in 130°F+water, replace or vacuum/steam clean upholstered furniture, carpet and drape removal, keep humidity less than 50%	Educate, provide and install allergy control bedding covers
Roaches	Clean counters and dishes daily, store food in sealed containers, clean up clutter, remove garbage daily, eliminate water sources (leaks, etc.)	Educate, assort with extermination using IPM methods (caulk and foam to seal small defects, Abamectin gel bait, boric acid, vacuuming and cleaning pre- and posteradication), repeat if roaches persist after 3 mo, provide food storage containers

(Continued)

Table 2 ***(Continued)***

Exposure	Action: Participant	Action: CHW
Rodents	Clean counters and dishes daily, store food in sealed containers, clean up clutter, remove garbage daily, remove outdoor excessive vegetation	Educate, seal defects with mesh and foam, provide glue board and snap traps or Contrac Blox (bromadiolene 0.005%) in kitchen
Tobacco smoke	Quit smoking. Encourage other household smokers to quit or smoke outside using smoking jacket	Assess stage of change, counsel, refer to free telephonic smoking cessation program
Pets	Remove from home or keep outside bedroom, vacuuming and carpet removal, bedding covers	Educate
Viral infections	Hand washing, influenza immunizations	Educate
NO_x	Ventilate kitchen	Educate on combustion sources
Wood smoke	Avoid using fireplaces and wood stove unless air tight and properly ventilated	Educate
Irritants	Dispose of properly and switch to less irritating alternative, ventilate if must use	Encourage use of safer alternatives
Occupational take-home hazards, hobbies	Identify potentially hazardous work or hobbies	Educate on hazard reduction, occupational medicine referral if appropriate

[a] Whereas controversy continues regarding the efficacy of various interventions to reduce mite exposure and related morbidity, it is believed that there is sufficient evidence to justify inclusion of simple measures for mite-sensitized persons.

As the project was implemented, we learned that not all households could carry out the recommended actions. Mites, for example, are killed when bedding is washed with hot water at a temperature of 130°F. However, when measuring the temperature of hot water in homes the CHWs found that 74% had temperatures below 130°F. The suggestion to those caregivers was to use alternative methods for killing mites. Not all homes with visible mold were able to eliminate it through cleaning practices. A high-efficiency particular air (HEPA) filter was recommended if mold, pets, or tobacco smoke were present, but most participants could not afford one *(96,97)*. Although free telephone smoking cessation counseling and nicotine replacement patches were provided, only 20% of smoking caregivers quit. The suggestion to smoke outside the home with a smoking jacket was useful in reducing indoor smoking. A quarter of smokers who did not go outside to smoke before the intervention did so after education by the CHW. Eliminating roaches in homes in multiunit structures without treating the entire building was an underlying condition that was addressed with landlords with minimal success. It was difficult for pet owners to give up their animals, rendering ineffective a recommendation to remove pets from the home. In addition to reducing asthma triggers, the CHW helped clients reduce exposure to hazardous household products by identifying and suggesting less-toxic alternatives, such as substituting nontoxic, baited roach traps in place of pesticides. They looked for unsafe storage and suggested proper disposal of all products and safer alternatives *(98,99)*.

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. Most homes (85%) had carpets, but few families were able to remove them as they were in rental units. Moisture problems were present in 77% of homes, contributing to exposure to mites, molds, and roaches. While some participants did increase ventilation in their homes, others felt unsafe with open windows. Most of the structural conditions associated with exposure to asthma triggers were not addressed, because 86% of participants were renters, and in most cases, landlords did not make suggested improvements, such as removing old, deteriorated carpets. When a home lacked ventilation fans or had structural problems, such as water intrusion or mold contaminated wallboard or carpets, these were rarely remediated by landlords. In some cases, tenants were afraid to approach landlords because of fear of retaliation. In other cases, the CHW assisted tenants in approaching landlords and some landlords did make changes to improve the indoor environment. The Seattle Housing Authority (SHA) immediately repaired unhealthy conditions and gave priority to eradicating 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 Results

The high-intensity intervention yielded significantly greater benefit in caregiver quality of life ($p = 0.005$) *(70)*. Urgent health services use declined significantly more in the high-intensity group ($p = 0.026$). Symptom days decreased more in this group but the difference between groups was not significant ($p = 0.138$). There were no interaction effects between group allocation and child's age, child's asthma severity, caregiver's educational attainment, or caregiver's race/ethnicity. 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 per 2 week period and caregiver quality of life score increased by 1.6 points (a change of 0.5 point is clinically significant *(100)*. 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 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 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 USD per child in the high-intensity group and 185–315 USD per child in the low-intensity group when comparing the 2 months before the intervention with the final 2 months of the intervention year.

Although the in-home behavioral intervention was effective, it was limited in its ability to modify the relationship between housing conditions and asthma outcomes. As noted earlier, the behavioral intervention could not eliminate substandard housing conditions, such as water intrusion or lack of ventilation systems, that resulted in exposure to asthma triggers. The association between substandard housing and health, especially with asthma and other allergic diseases, has been well established *(101–105)*. As substandard housing is often the only housing available to low-income populations, a program was developed to remediate substandard condition. This was the next logical step toward implementing a comprehensive approach to addressing indoor environmental asthma triggers.

The Better Homes for Asthma Project (2002–2006)

The *Better Homes for Asthma* Project assessed whether the remediation of structural deficiencies related to exposure to asthma triggers adds *additional* benefit to the 1-year intervention provided by the Healthy Homes CHW model previously shown to be effective. Using a randomized controlled trial approach with a delayed remediation control group, 34 homes were assigned 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, and 1 year later, remediation. The average cost for remediation was 4529 USD per unit. Only 21 homes ultimately had remediation, largely because of attrition of tenants and inability to obtain owner consent for repairs. Currently data from these homes is being analyzed.

Participants and Selection of Homes

Participants were families in households with incomes less than 200% of the poverty level, and with children aged 3–17 years with persistent asthma. They were recruited from King County clinics as in the previous *Healthy Homes* project. Housing units were eligible if several criteria were met and housing code violations for structural conditions did not exceed the capacity of the program. A street-side exterior visual inspection determined whether the home was too deteriorated for the scope of the program (maximum of 9000 USD in estimated repairs). Similarly, an in-home screening assessment determined whether conditions needing repair were beyond the scope of the program. Unit owners 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 could participate if they agreed to remain in the unit for 1-year. Information about the study was sent to 854 families. Study staff contacted the 398 families that responded. They made 115 street-side assessments and conducted 43 baseline in-home screening assessments.

The Assessment

The component that distinguished *Better Homes for Asthma* from the earlier *Healthy Homes* intervention was structural remediation. All homes received a detailed inspection by a Remediation Coordinator, a public health expert in housing, who identified conditions associated with exposure to asthma triggers. The inspection included an assessment of water infiltration and damage and the source of the water problem. Damage to roof or exterior surfaces, drainage issues (gutters, downspouts, standing water, grading near house, splash pads), earth-wood contact, water penetration, wet or water stained/damaged surfaces, rust on metal surfaces, deteriorated window frames, and plumbing leaks were conditions that qualified for remediation. The Remediation Coordinator used the results of the inspection to develop a specific remediation work order for each home. In both early and late intervention groups, the CHW baseline inspection also generated an action plan to guide subsequent educational visits, as in the previous project.

The Intervention

Appropriate interventions were selected from among those listed in Table 3. Professionals also cleaned all homes following remediations.

Table 3
Environmental Interventions

Description of intervention	
Vent clothes dryer to exterior	Clean evaporator pan under refrigerator
Crawlspace—seal/cover soil with poly vapor barrier	Seal all wall openings, especially in kitchen and baths
Crawlspace—seal from house air	Repair dry floor drain traps if sewer gasses found
Downspout—assure adequate runoff away from house (only if moisture problem in basement/crawlspace)	Repair plumbing leaks
Caulk windows	Install gas range hoods that vent directly to exterior
Caulk wood siding vertical seams	Undercut all bedroom and bathroom doors
Caulk door seams	Install quiet, continuously operating whole-house exhaust ventilation system
Seal roof and chimney flashing if evidence of interior leaking	Assure that one window per room can open and install security stop
Check furnace chimney draft and if inadequate, check and clean opening	Remove bird, rodent, or insect debris from attic
Install pleated filter in forced air heating system	Seal tub/wall surround joint and toilet/floor spaces
	Remove child's bedroom, basement, and bath and kitchen carpet
Mold remediation—hard surfaces: clean, disinfect, dry and seal surfaces. Absorbent surfaces: remove extensive mold or water-damaged material. Replace drywall if wet for more than 48 h, wood if mold penetrates greater than 3 mm. Other materials: Clean, disinfect, and dry, vapor barrier seal	Install carbon monoxide monitor

Baseline Information

Participants were similar to the *Healthy Homes* group. Two-thirds had incomes below the poverty level, and 47% of the primary caregivers had less than a high school education. Seventy-nine percent lived in rental housing, mostly public housing. The average age of the asthmatic child was 10 years, 70% were male, 45% were Hispanic, and 27% were African American. Sixty-three percent of the housing was built between 1951 and 1978 with 20% built since that time. Housing conditions indicated significant hazards at baseline. Over half the homes had water damage or leaks, with just over 10% showing visible mold. Forty-four percent had smokers in the home and nearly all had carpets in the child's bedroom. There were few homes with pets. Roaches were reported in 27% and rodents were found in 13%. Significant differences at baseline were seen between the two groups in housing ownership and ethnicity. Otherwise, the populations and homes were very similar.

Preliminary analysis indicates that asthma outcomes improved in both groups, although controller medication use improved only in the late-intervention group. A shift from moderate or severe persistent asthma to mild intermittent asthma was seen in those with home remediation; an improvement in asthma severity occurred in 85% of those whose homes received remediation compared with 15% of those without remediation, although this difference was not statistically significant. Symptom days and nights and caretaker quality of life improved in both groups.

Limitations

Substantial difficulties were encountered in implementing this project, which limit the study conclusions. The institutional review process caused a 1-year delay in starting the study, interfering with the timeline for recruitment. Once initiated, recruitment and retention were 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. Maintaining remediation contractors with adequate mold insurance (which protects the contractor from mold-related health claims) was a challenge because in Seattle this costs several thousand dollars a year. Because of these factors, only 35 homes enrolled in the program (50% goal). The randomized controlled trial study design was preserved, but at the expense of remediating more homes. With attrition of participants and refusal by landlords to allow remediations, only 21 homes were completed. Of those, 15 had complete exit evaluations, well below the number needed for an adequate study. A final limitation was that a number of homes were excluded because the structural issues were too pervasive to address with limited remediation funds and interventions. Families in these homes were assisted to find more suitable housing. However, the tight housing market in Seattle, coupled with rapidly rising housing prices and rents, limited their options in finding better homes. Therefore, an opportunity was sought to develop *new* and *affordable* healthy housing for low-income families affected by asthma.

THE BREATHE EASY HOMES PROGRAM (2003–2007)

The opportunity to do so occurred in 2000. The SHA received a 35 million USD HOPE VI grant to replace deteriorating public housing built in the 1940s at the High Point garden community 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 *(106)*. Designed initially as a rebuilding endeavor, HOPE VI also promoted social change in public housing by hoping to eliminate pockets of concentrated poverty in public housing sites through creating mixed income communities. Congress initially authorized 300 million USD in demonstration funding; over 6 years, funding grew to 4.2 billion USD *(107)*.

The High Point community is located on 120 acres in West Seattle, 6 miles from Seattle's downtown and harbor. The original 716 units were built for Boeing World War II workers and became public housing in the 1950s. Redevelopment began on the site in 2004, and as SHA's largest rebuilding project, will include 1600 mixed income housing units by 2010. Out of 796 *affordable* housing units, there will be 350 public housing units for very low-income people (30% of median income), 250 tax-credit units for working families (60% of median income), 116 units of independent and assisted-living housing for very-low-income seniors, and 80 home ownership units. An additional 804 housing units are for sale at market rate to independent and assisted living seniors, and the general population. High Point is the first large-scale development in the country to feature low-impact sustainable design in a dense urban setting. The model includes housing meeting *BuildGreen*™ (Buildgreen is an industry-driven voluntary that promotes "Green" building practices to reduce the impact that building has on the enviornment while choosing healthy building materials) standards, an innovative natural drainage system to protect local salmon habitat, new municipal infrastructure systems, neighborhood facilities, and 20 acres of land for parks, open spaces, and playgrounds.

At the time of site deconstruction, High Point was predominately 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 sensitivities, 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 by improving access to transit choices, making widespread use of soft drainage techniques and minimally impervious surfaces to improve water quality in nearby Longfellow Creek, building a network of open spaces and trails to encourage active living, and incorporating state-of-the-art resource conservation elements in housing unit design. The project manager contacted us to see if they 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 to evaluate the impact of the new homes on asthma outcomes. Together they developed the Breathe Easy Homes Program, whose goal is to assess whether moving into a new *Breathe Easy Home* provides additional benefits in controlling asthma relative to home visits by CHWs working with clients in old, substandard homes.

During the first phase of construction (2005–2006), the contractor built 35 homes with special features designed to reduce the impact of asthma. It was anticipated that this number of homes would provide housing for the estimated number of families affected by asthma that would live in the new community. SHA, with support from the Enterprise Foundation, will build 25 additional *Breathe Easy Homes* during the second phase of construction in 2007.

The Participants

Initially, *Breathe Easy Homes* were offered to families and individuals with asthma who were living in the old High Point community before the HOPE VI project. The 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. However, not all residents wished to return so additional recruitment efforts were made through local hospitals, clinics, asthma specialists, flyers, and word-of-mouth. A family was eligible for a *Breathe Easy Home* if it included a child, 3–17 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. Some families found this difficult as their incomes might fluctuate from month to month, affecting eligibility.

The Intervention

The High Point design team 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 (*see* Fig. 1). 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, sealed cabinets, and cement board exterior siding to reduce the moisture hazard. The upgraded design features of the Breathe Easy units include enhancements in the exterior envelope, foundation, interior finishing and flooring, and ventilation system.

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. To ensure 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 1250 USD per unit.

The team felt that it was important to minimize or eliminate the use of carpets, because they 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. Marmoleum™ (Marmoleum is a linoleum-type flooring material made from natural products [linseed] that does not off-gas potentially harmful substances such as volatile organic compounds) a surface made up of linseed, was chosen. The team also selected low/no emission and nontoxic finishes and materials to minimize exposure to irritants that can trigger asthma. The cost for this group of upgrades is 3250 USD 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 system has a HEPA filter that removes most particulates and allergens from the fresh outdoor air that is coming in. The heating system includes a hydronic (not 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 timer controls in bathrooms with showers. The cost for this group of upgrades is 2500 USD per unit.

A landscape design team developed plans to reduce outdoor asthma triggers in yards and outdoor spaces with low allergen ratings. Integrated Pest Management Strategies are used to minimize or eliminate the use of toxic pesticides.

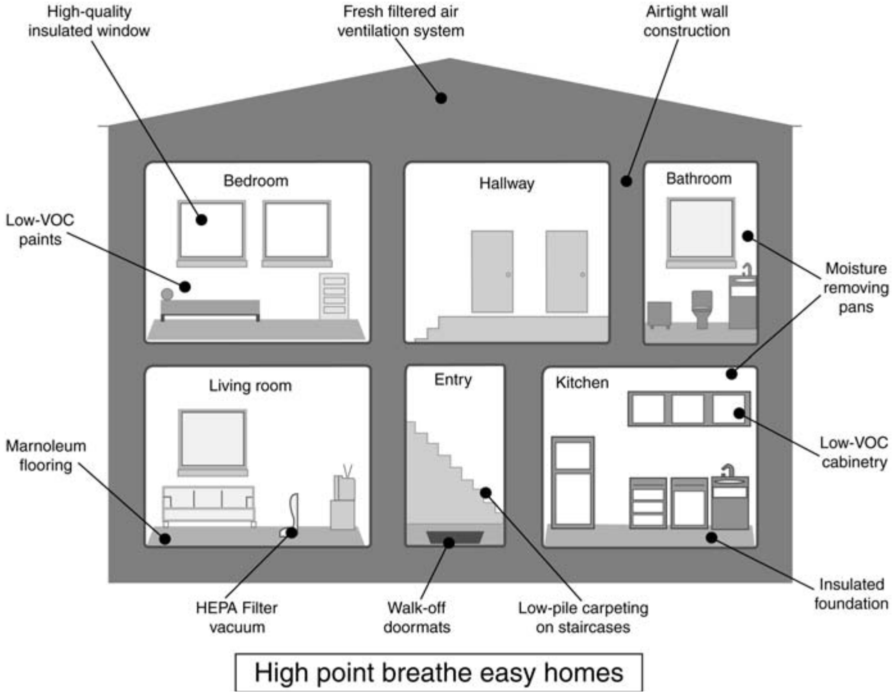


Fig. 1. Design and construction elements.

Home Visits by CHWs

We began working with families a year before they moved into their new homes. A Community Asthma Team, made up of a CHW and translator, conducted a home environmental assessment, collected a dust sample from the child's bedroom, and provided education using the established protocol. The team provided the family with allergen-proof bedding and a pillow cover for the child's bed, a vacuum with a HEPA filter, doormat, and bucket of environmental-friendly cleaning supplies as in the previously described studies. Additional educational visits were conducted in the new home to ensure that the participants optimize the home's new features to reduce asthma triggers, such as the best practice with the ventilation system and proper maintenance of the new features. Additionally, they will received reinforcement for the *Healthy Homes* behaviors learned in the first year.

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. The guidelines were reviewed by the CHW during the educational visits.

The next step will be for SHA to write a *Healthy Homes* protocol with a commitment to maintain the units for families with asthma. The SHA application will add a question on child/family asthma history with medical confirmation of the illness to identify new occupants of Breathe Easy Units.

Evaluation

Clinical evaluation includes a detailed assessment of asthma severity, medication and health services use, the Juniper scale quality of life measurement, skin test sensitization, and a methacholine challenge. This latter physiological test is the "gold standard" test for airway sensitivity and a measure of the child's current asthma activity. These evaluation measures were made at the beginning of the 1-year CHW intervention in the old home. Additional data was collected after 1 year of working with the CHW in the old home, and after participants move to their new homes, and will be collected after 1 year in the new home. This will enable a pre- and post-comparison between the established CHW intervention in the old home and the impact of the new home on the same asthma end points described in the previous studies with the addition of the very sensitive methacholine challenge test.

Lessons Learned

Over the past decade, we have had an opportunity to try a spectrum of approaches to addressing disparities in asthma health outcomes related to housing conditions. Some of the strategies were successful, while others fell short of the goals. This chapter concludes with a discussion of some of the lessons that we have learned.

Home Visits by CHWs

Home visits by community home workers are effective in reducing exposure to asthma triggers and improving asthma-related health disparities. In particular, it was found that the CHW might 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. Clients might be more likely to heed their advice and learn new skills as the CHW models effective trigger control behaviors. CHWs 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 or employment in order to bring the family to a place where it can focus on asthma. The CHW tends to function more as a peer and coach than a more distant professional.

A less intensive CHW intervention may be a useful alternative to a full year, multivisit program. The program, like others, observed 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.

Resources and incentives 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. Not having these tools available initially may lead to family frustration. Monetary rewards, such as gift certificates, proved highly useful for encouraging participants to complete challenging tasks, such as regular cleaning and mold removal. Parent satisfaction from seeing their actions benefit their families is a powerful verbal, nonmonetary incentive.

Addressing multiple triggers. The interventions supported the value of strategies aimed at reducing exposure to multiple indoor asthma triggers rather than focusing on a single trigger.

The CHW developed marketable skills that are sustainable. The CHWs developed a new set of marketable skills, such as client counseling and motivational interviewing, scheduling and organizational practices, and 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 their 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 agree to 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.

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, discrimination in housing markets, and limited understanding of what makes for unhealthy home conditions give low-income people and people of color few options to seek healthy housing. Yet evidence from this work *(108)* and the literature *(109)* demonstrates that living in substandard housing is associated with poor health, be it asthma, depression and stress, or lead poisoning. Low-income and minority people are more likely to live in such housing.

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 was that, "I can't give a tenant something that I don't give to all the others." Renters were also not invested in the property improvements and frequently move before benefits accrued. Many logistical challenges were encountered in attempting to locate and remediate substandard houses where low-income children with asthma lived. Although this approach was conceptually appealing, it might not be feasible to implement on a scale broad enough to make a significant impact on asthma disparities.

More success was found in partnering with a public housing agency to build new, affordable, asthma-friendly housing. SHA approached us with the idea for this project and remains enthusiastic about its goals, thereby minimizing potential conflict with the landlord. Residents are supported in a consistent manner by SHA rather than the varied level of interest expressed by private landlords. An on-going 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 professions that inspect homes (e.g., sanitarians, plumbing, or electrical inspectors) in healthy homes practices could be useful, so that they may in turn educate homeowners and renters. 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 disparities. Living in substandard housing is a circumstance all too common among low-income people and people of color who may also lack skills for reducing exposure, exacerbating the consequences. The value and challenge of providing in-home support from CHWs, remediation of existing substandard housing, and building new asthma-friendly public housing have been described as three strategies to reduce exposure to asthma triggers. In-home support is effective for helping people gain skills to successfully reduce exposure to triggers. 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, although its impact on asthma morbidity is not yet known. In conclusion, housing-focused interventions have potential to reduce asthma disparities and deserve wider study and implementation.

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16

Access Health Solutions

A Minority Physician Network Model That Works

Kathy B. Jackson, PhD

INTRODUCTION

The goal of Florida Healthy People 2010 is to educate professionals, culturally and linguistically, about methods to reduce the negative health consequences that impact racial and ethnic cultures. Opportunities and barriers to achieving this goal, and potential partners, have been identified. It was concluded, in the Florida Department of Health December 2004 Florida Healthy People 2010 Program Implementation Report, that the support of minority physician networks (MPNs) is necessary to achieve the Florida Healthy People 2010 goal of reducing healthcare disparities. The MPNs consist of “practitioner-experts” who are the vanguard against the health conditions found in minority, underserved communities wherein valuable experience, insights, and guidance might be gained and shared. Many physicians interested in accessing statewide initiatives also want to link service training to minority neighborhoods. The Access Health Solutions’ (AHS’) MPN recognizes that these initiatives are currently in place and facilitates a vital link between the Department of Health and the Agency for Health Care Administration (AHCA), the latter of which contractually administers the services provided by the MPNs.

According to the Florida Department of Health December 2004 and 2005 *(1)* Florida Healthy People Reports, the MPNs are uniquely positioned to affect change as prescribed in Section 381.736, Florida Statutes. Working in close collaboration with AHCA and the MPNs, the Department of Health has made significant advances toward the elimination of health disparities between minorities and nonminorities, and recommends innovative programs to educate professionals about ways to reduce negative health consequences that

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result from ignoring racial and ethnic cultures. (Minority Health: Florida Healthy People 2010 Program)

The AHS' MPN, formerly known as Access IPA, was founded by Drs. Adams, Moise, and Ikpe (who is now deceased), three highly recognized physician leaders in Miami-Dade County, Florida. These physicians have been dedicated providers in Minority Communities, who have used their skills, talents, and celebrity to be leaders in the fight against healthcare disparities and other minority healthcare issues. They have formed solid collaborative relationships with the entities that have traditionally and historically addressed minority healthcare issues. Along with Dr. James Brookins, Richard Powell, and the author of this chapter, they have been successful in obtaining and managing a Minority Physician Program for MediPass/Medicaid beneficiaries through a contract with the AHCA in the state of Florida. In conducting its business, senior management noticed that the continuity of care in the Medicaid population is particularly susceptible to disruption, owing to a number of systemic factors that cause repeated episodes of lost eligibility for even minor lapses, such as failing to keep an appointment with a case worker.

Following such an episode of lost eligibility, a prospective beneficiary would subsequently be reinstated and assigned to a new primary care physician (PCP) and/or health plan in Florida. Subsequently, all Medicaid beneficiaries are assigned either to a Health Maintenance Organization (HMO) or to MediPass without consideration of continuity of care or ethnicity. Based on management observations, AHS approached AHCA and designed and implemented a MediPass Pilot Project, which became contractually effective by proviso language on November 1, 2001 and was institutionalized as a program in Florida Statue 409.912 in June 2004.

The AHS philosophy is that waste in the healthcare system is driven by the fact that patients do not have a close and trusting relationship with a PCP who knows their illnesses and who is accessible to them. Based on analysis, AHS utilizes the following, simple but often-ignored, principles:

1. The culturally competent doctor–patient relationship must represent the center of the healthcare delivery system.
2. Only physicians have both the technical knowledge and the relationship with the patient to manage care optimally.
3. In order to achieve optimal managed care, physicians must be supported with:
   a. Information on their patients' treatments and outcomes.
   b. Administrative infrastructure to implement and monitor the care process.
   c. Financial incentives to spend the time necessary to coordinate patient care.
4. Radically increasing patients' access to care will both improve outcomes and save money in the long run because patients will become more compliant with prescribed treatment, will avoid unnecessary visits to emergency rooms and

unnecessary hospitalizations, will experience improved health outcomes, will avoid complications of their diseases, and will, in short, stay healthier.

5. By keeping patients with physicians that have traditionally treated them, and therefore understand them, there are better outcomes in the delivery of care.

AHS' network services was created with these principles in mind as a vehicle to deliver quality and affordable healthcare.

The Florida MediPass contract effectively outsourced medical management to AHS for the MediPass beneficiaries. After demonstrating medical cost savings for each quarter and expanding the MPN model to additional counties within Florida, the AHCA is confident that the model is innovative, cost effective, of high quality, culturally competent, scalable and reproducible.

THE METHOD

Qualitative and quantitative research techniques were used to evaluate the program. The access MPN was evaluated by the Center for Research, Evaluation, Assessment, and Measurement in conjunction with the Department of Measurement and Research within the College of Education at the University of South Florida, Tampa, FL, for patient and provider satisfaction. The ability to communicate the necessary information to the provider of care is important to the success of any type of a quality, cost-containment program. It is important to have a vehicle to do so. The MPNs appear to address the issues faced by the administration of the Agency. Therefore, the Agency contracted with the University of Florida, Gainesville, FL, to conduct an evaluation of MPNs. The evaluation was guided by the following research questions:

1. What are the MPNs and how do they work?
2. What are the financial implications or savings achieved by the MPNs?
3. Do the MPNs maintain access and quality standards comparable or better than those required in the MediPass HMO managed care program?
4. What are the beneficiary and provider satisfaction outcomes for participants in the MPNs?
5. Are healthcare disparities being reduced and outcomes measured?

It has been a priority of the Medicaid/MediPass Program to implement programs that are cost effective and at the same time able to address the issues faced in healthcare delivery systems without compromising quality. The focus of this study is to show that AHS, an innovative MPN model, is such a program. AHS offers an enhanced primary care case management (PCCM) program for Medicaid that maintains existing reimbursement levels with physician incentives for quality care, improved access, and cost effectiveness. All care is managed to ensure the provision of a medical home, access to preventive care, early intervention and appropriate healthcare services utilization, the reduction of health disparities, and the program works within the existing Florida Medicaid/MediPass infrastructure.

Because there is no restrictive provider network, patient choice is preserved. The PCP serves as the easily accessible point of entry to care for all recipients and, as the care manager, ensures a better coordination of services across the fragmented healthcare delivery system that exists in Florida. AHS uses state-of-the-art information systems and management reports to give PCPs timely and relevant data on patients' medications, hospital admissions, specialty referrals, emergency room utilization, and other medical interventions. The reports are hand delivered once a month to the provider by the Provider Representative. The AHS' model philosophy is that by radically increasing patient access to culturally competent care, outcomes are improved and money is saved, because patients will become more compliant with prescribed treatments, will avoid unnecessary hospitalizations, will experience improved health outcomes, will avoid complications of their diseases, and will, in short, stay healthier.

THE SCOPE OF THE STUDY

The study uses a traditional analytic framework to examine healthcare access and service use among Medicaid/MediPass beneficiaries in the AHS Program. Potential access and realized access are defined to determine whether or not this access is delivered in a cost-effective way using an innovative minority physician-managed model. It compares results with other Medicaid managed care programs. This study is limited to a specific population of providers and patients. Most of the participants are minority group members, either African/Caribbean Americans or Hispanic Americans. All participants have been recipients for a period of 6 months or greater.

THE RATIONALE OF THE STUDY

AHS' network of minority physicians has developed a model of healthcare that emphasizes primary care, which reduces healthcare costs, improves outcomes of care, preserves the centrality of the doctor–patient relationship, and simultaneously empowers physicians by making them accountable for the quality and outcomes of the care they provide their patients.

The major principle of the model is that by radically increasing patients' access to care, they are maintained in better health. Thus, savings on medical costs are achieved. Most of the expensive interventions that patients receive are because of hospitalizations or complications of chronic diseases that are not adequately controlled. The physicians control these costs by careful monitoring of patients' conditions and treatments, and by being more accessible to patients. The hypothesis of the study is that AHS, an MPN, compared with other managed care programs, saves the State of Florida money. The MPN appears to offer improved quality of care and more appropriate use of services through the use of beneficiary information and local management of providers. The MPN providers have a high degree of satisfaction with the program, especially when compared with their previous experience with MediPass. There is evidence that MPNs bring innovation to the Medicaid Program by use of sophisticated information technology and medical management expertise. The AHS' MPN reduces healthcare disparities by keeping the patient with the provider who has historically taken care of the patient and understands the culture, and therefore, is able to establish the trusting physician–patient relationship that is needed to manage care.

The review of literature gives a description of the challenges faced in trying to administer and ensure access to care for a diverse population. In this chapter, factors that influence service are discussed. These factors include, but are not limited to: disparities in healthcare, an individual's basic need for services, stress on the system by the safety nets, and access and use of services by the beneficiary. Through the aggressive movement to managed care, Medicaid has had a significant effect on the safety nets (hospitals and other entities that serve the underserved) because of the discounting that occurs. HMOs have focused on cost-containment and there has been no real effort to ensure that appropriate services are provided in a consistent fashion. Research shows that HMOs have had a negative impact on healthcare delivery in minority communities *(2)*. The Institute of Medicine (IOM) *(3)* report suggests that HMOs disrupt traditional community-based care and displace providers who are familiar with this patient population, therefore, contributing to healthcare disparities instead of reducing them.

AHCA has been given oversight of the Medicaid Program according to the Florida Office of Program Policy Analysis and Government Accountability (OPPAGA). Despite a number of cost-reduction initiatives, anticipated savings have not been realized and expenditures continue to increase, surpassing appropriations. In the MediPass Program, Disease Management Organization initiatives were not reported regarding whether or not health outcomes had been improved. Barriers that could hinder access were not addressed and case management did not emphasize a proactive approach that would prevent lower-risk patients from becoming higher-risk patients. AHCA is slow in implementing programs to address healthcare disparities.

The mission of AHS is to reduce healthcare disparities and increase access to care by providing quality healthcare through strong doctor–patient relationships. Working with over 500 minority physicians, large and small community and faith-based organizations, the Florida Department of Health, and AHCA, both locally focused and national in scope, AHS seeks to build on

Table 1
Fostering Understanding

Cultural competency assessment determined	Providers complying (%)
The number or proportion of LEP persons eligible to be served or likely to be encountered by the provider by area using the eligibility data provided by the state	60
Identification of language assistance measures	43
The usage of the two predominant ways to provide language services—oral interpretation and written translation	50
Internal processes in place for surveying, collecting and/or recording primary/preferred language, race, and/or ethnicity data	60
Access to needed resources to provide meaningful access for patients	100
Provider's office staff who speak fluently a language other than English	56
Ability to access providers who are qualified as interpreters	100
Ability to identify and access staff training	100

the knowledge of culturally competent service delivery. The sample report identifies the strengths and weaknesses within the MPN in key areas of culturally competent healthcare, based on the responses captured from the "Fostering Understanding: Cultural Competency Assessment" distributed to the entire MPN in April–May 2005. Based on the results, it appears that AHS providers are culturally competent (*see* Table 1).

An evaluation of the AHS' MPN was conducted by the Center for Research, Evaluation, Assessment, and Measurement in conjunction with the Department of Measurement and Research within the College of Education at the University of South Florida. This evaluation used information from patient and physician satisfaction surveys administered during the second quarter of 2003. An evaluation of the AHS of Florida's MPN Program was conducted by The Department of Health Service Administration and The Florida Center for Medicaid and the Uninsured College of Public Health and Health Professions, University of Florida. This evaluation was requested by The Florida AHCA. The report concluded that:

- AHS' physicians are extremely satisfied with the program relative to their experience with MediPass and Medicaid HMOs.
- AHS' patients receive enhanced quality care resulting in high levels of patient satisfaction.
- AHS saves AHCA money when compared with MediPass.
- The AHS model MPN manages patient populations that address the reduction of healthcare disparities.

According to the Center for the Advancement of Health, March 2002, eliminating health disparities requires community involvement. Successful programs to lessen racial and ethnic health disparities share common traits of establishing strong ties between health providers and the community members they serve. Enrollment in the AHS' Program is based solely on AHS' enrollment of the primary care case manager, a physician who functions similarly to a PCP in general-managed care terms. Unlike Medicaid HMOs, which benefit from positive selection because of enrollment of healthier Medicaid recipients, the enrollment in the AHS' Program is random in the sense that the morbidity-mix of the recipients should be consistent with that under the traditional Medicaid /MediPass Program. AHS' involvement is completely transparent to the recipient and both the recipient and the physician are free to choose any physician/specialist to perform services.

The source of the data for the review of the Medicaid medical claims attributable to the AHS Program is the Florida AHCA. The data was reviewed for reasonableness. The methodology for the evaluation used information from patient and physician satisfaction surveys and claims data administered during the second quarter of 2003. Patients and physicians from Miami-Dade County and the Tampa region of Florida provided the data used in this evaluation. A comparison of costs under the traditional Medicaid/MediPass Program and the AHS Program were made. Costs were itemized by quarter as well as by eligibility category and county. All values were displayed on a per-member-per-month (PMPM) basis and included all adjustments discussed in this chapter.

An analysis of the provider satisfaction was conducted by a survey that was completed by the providers at their quarterly dinner meetings. The questions used were consistent with the ones used in the Hu, Duncan, and Porter report. Therefore, a brief comparison can be made of the five subscales between the MediPass Program overall and AHS. Satisfaction with AHS by physicians was strong. All respondents indicated satisfaction with services and products provided by AHS. In addition to analyzing the satisfaction with the program by both patients and physicians, a psychometric analysis was conducted on the survey instrument used to gather patient data.

In this analysis, focus is placed on a defined segment of the population over a period of 2 years. Data sets are analyzed that are extracted from claims and patient and physician surveys. For purposes of this analysis, a comparison is made of all care received by Medicaid recipients by payment source. The payment sources are traditional MediPass and HMO managed care. An analysis of the characteristics of the patient sample was conducted using descriptive statistics. The AHS' Program provides medical management services to the Florida AHCA in exchange for a percentage of the medical claim savings of those enrolled in the AHS Program. The analysis compares the AHS' MPN model of managed care with the existing MediPass Program and HMO model.

RESULTS OF AHS PATIENT SATISFACTION SURVEY

An analysis of the characteristics of the patient satisfaction survey was conducted using descriptive statistics. Composition was by ethnicity, language, gender, and age.

Sample Description

A total of 615 surveys were contained in the final analysis, 460 (~75%) were from Miami-Dade and 155 (~25%) were from Tampa for a ratio of Miami-Dade to Tampa respondents of 3:1. Therefore, overall means and other statistics are dominated by the Miami-Dade responses. In consideration of this imbalance, descriptive statistics are presented for the overall demographics and results as well as by location. Of the final sample, 552 surveys contained complete information for each item and, as a result, the psychometric analyses were conducted using only these results.

Ethnicity

The sample contained primarily individuals from minority populations. However, there were notable differences in the proportion of members of different ethnic backgrounds depending on which region, Miami-Dade or Tampa. The figures included percentages of those who indicated their ethnicity and excluded those who did not answer this question. Overall, a large proportion of the responses came from Hispanics (46%). However, the difference in Hispanic representation by region should be noted. Almost half of the Miami-Dade respondents (46%) chose Hispanic as their ethnicity compared with only 18% of Tampa respondents. Conversely, 42% of Tampa respondents identified themselves as Caucasian compared with 16% of the Miami-Dade respondents. Both regions had similar proportions of respondents who identified themselves as African American (40% Miami-Dade and 32% Tampa). The regions also had similar results for the category of other, 7% of those from Tampa identified themselves as some ethnicity other than African American, Hispanic, or Caucasian, and 5% of those from Miami-Dade considered themselves to be of some other ethnic background. Tampa respondents tended to skip this item more often than those in Miami-Dade, 17 and 6%, respectively.

Language

The majority of respondents were English speaking (68%), although Miami-Dade had a higher proportion of Spanish-speaking respondents than Tampa (36 and 24%, respectively).

Gender

The majority of respondents (62%) were female with slight differences depending on location.

Age

Almost three-quarters of respondents (62%) were between 21 and 50 years of age with slight differences depending on location; 6% of the Miami-Dade respondents indicate an age of 10 years or younger.

Means and Distributions of Scores

The mean scores for each item tended to be high, with overall means ranging from 3.02–3.59 for items measured with four-point response scales (i.e., items addressing satisfaction with promptness of care, provider communication, and staff helpfulness). Similarly, item means ranged from 2.58–2.72 for items measured with three-point response scales (i.e., items addressing satisfaction with Access to Needed Care and Health Plan Member/Customer Service). In general, patient satisfaction as measured by all items was strong. A comparison of item means across locations suggested consistently higher means from Tampa, with the exception of item 8, which showed a higher mean from the Miami-Dade respondents (M = 3.04) than from the Tampa respondents (M = 2.94). The individual items were aggregated into mean scores for each of the subscales.

The distributions of these composite scores indicate a negative skew with a preponderance of high satisfaction across all five subscales. However, these illustrations also tend to indicate that, based on location, satisfaction differed with a greater proportion of Tampa respondents indicating high levels of satisfaction, especially on the accessibility and helpfulness subscales. Subsequent statistical analyses confirmed this finding. When interpreting these figures, keep in mind the scale differences for the subscales. The first and last subscales, accessibility and service, are measured on a three-point scale, whereas the other three subscales are measured using a four-point scale.

An initial comparison of mean scores for various subpopulations of the sample indicated a potential for interactions between location and the other three independent variables. For example, scores for females and males tended to be consistently different based on location. These preliminary indications of location impact resulted in the decision to conduct initial inferential analyses using one-way analysis of variances (ANOVAs) for each independent variable, followed by a two-way ANOVA to explore potential for interactions between location and the other independent variables.

Location

An ANOVA was conducted on location and statistically significant differences were found between respondents in Tampa and Miami-Dade on all five subscales, as suggested by the previous examination of descriptive statistics as well as the distribution of scores by location. In each case, respondents from Tampa reported higher satisfaction than those from Miami-Dade.

Ethnicity

The results of a one-way ANOVA based on ethnicity was statistically significant for only one subscale, service, $F(3541) = 3.29$, $p = 0.0205$. A follow-up contrast comparison using the Tukey test indicated that the only two groups with statistically significant mean differences were Caucasians and Hispanics, with Caucasians indicating a higher level of satisfaction with service than Hispanic respondents.

A two-way ANOVA was conducted on the five subscales by location and ethnicity to determine if the ethnicity differences remained after adjusting for differences in location and to test for the presence of interaction between ethnicity and location. No significant main effects for ethnicity were obtained after adjusting for location differences, and no significant interaction effects were obtained. However, the main effect of location continued to show statistically significant differences on all five subscales.

Language

The initial one-way ANOVA on language found statistically significant differences between English- and Spanish speakers on the subscale of promptness, $F(1598) = 17.29$, $p < 0.0001$; communication, $F(1599) = 6.88$, $p = 0.0090$; and service, $F(1556) = 6.73$, $p = 0.0097$. In all cases, the English-speaking respondents reported higher satisfaction than those who spoke Spanish. A two-way ANOVA was conducted on the five subscales by language and location to determine if these differences remained after adjusting for location, and to test for interactions between language and location. Results of the two-way ANOVA indicated no significant interaction between language and location for any of the subscales, although statistically significant differences were noted for the main effects. Specifically, location again had a statistically significant main effect for each of the five subscales, and statistically significant main effects were found on the subscales of promptness, communication, and helpfulness.

Gender

The initial results for the ANOVA conducted to examine differences in satisfaction based on gender found statistically significant differences regarding satisfaction with communication, $F(1547) = 4.55$, $p = 0.0033$. A two-way ANOVA was conducted on the five subscales by gender and location to determine if there were statistically significant differences in satisfaction levels as a function of gender and location. Again, location was statistically significant for all five subscales, although gender did not indicate statistically significant results as a main effect. However, there was an interaction effect between location and gender on the subscale of helpfulness. Females in Miami-Dade tended to have higher satisfaction than males on this subscale (means: $F = 3.53$, $M = 3.43$) whereas males in Tampa had higher satisfaction scores on this subscale than females in Tampa (means: $F = 3.71$, $M = 3.95$).

Age

For the purpose of statistical analysis, respondents were grouped into six categories, consistent with the age groupings provided by AHS in their database:

1. Infant, less than 1-yr old.
2. Child, 1–5-yr old.
3. Adolescent, 6–13-yr old.
4. Young adult, 14–21-yr old.
5. Adult, 22–54-yr old.
6. Mature adult, 55 yr and older.

Results of the one-way ANOVA based on age revealed statistically significant differences in satisfaction on the subscales for accessibility $F(5530) = 2.58$, $p = 0.0255$. However, follow-up Tukey tests did not identify significant differences between any pairs of age ranges. Again a two-way ANOVA was conducted to test age difference after adjusting for location and to identify possible interactions between age and location. This analysis indicates a lack of main effect for age as well as interaction. Location continued to impact levels of satisfaction. The psychometric properties of the patient survey were examined for subscale reliability through the determination of the internal consistency of the items in each of the five subscales using Cronbach's alpha. Additionally, correlations between the subscales were calculated and an exploratory factor analysis was conducted.

In general, the subscales displayed moderate-to-strong internal consistency both overall and disaggregated by location. All but one of the subscales had α-coefficients of 0.91 or above overall, indicating acceptable levels of internal consistency. The only subscale that did not meet this level of reliability was the promptness scale. An examination of the total item correlations within the subscale suggested that a single item evidenced a substantial detrimental impact on internal consistency. When item 8, “In the last 6 months, how often did you wait in the doctor’s office or clinic more than 15 minutes past your appointment time to see the person you went to see?” was removed from the analysis, the internal consistency for this subscale rose to 0.91 overall. When these results were examined as a function of location, results were similar for most subscales, although on two subscales Tampa had lower measures of internal consistency. Internal consistency measures for access dropped to 0.81 and for service to 0.76, as compared with the results from Miami-Dade of 0.92 on both. Correlations using Pearson correlation coefficient were calculated. The subscales correlated fairly strongly with each other. In particular, the Pearson (r) values between the subscales for accessibility and service was quite strong at 0.73 and the lowest correlation of 0.475 resulted between the subscales for promptness and service.

Factor Analysis

An exploratory factor analysis was conducted to determine the extent to which the patterns of item intercorrelations reflected the nominal domains of the instrument. Squared multiple correlations (the extent to which responses to each item were predictable from responses to the other items) were used for initial estimates of common variance. An oblique rotation (correlated factors) was used as the factors tended to have moderate-to-strong correlations. Four factors were retained, representing more than 95% of the common variance in the set of items. Three of the five subscales tended to load clearly on their own factor, whereas the subscales for promptness and communication loaded together on a single factor. Only one item did not load well on any factor, i.e., item number 8 (the same item that had such a notable detrimental impact on the internal consistency of that subscale). When this item was removed, the other items still tended to load concretely on the same factors.

In general, the findings in the patient satisfaction indicated that survey respondents were strongly satisfied with the care they received. AHCA calculates the expected PMPM cost under the traditional Medicaid/MediPass Program based on an recipient’s location (district), eligibility category (temporary assistance for needy families, supplemental security income), age, and gender for the fiscal year (July–June). AHCA then calculates a similar PMPM cost for the AHS’ population. The difference between the two is considered the savings attributable to the AHS Program. Overall the AHS Program appears to produce significant savings (52.83 USD PMPM or 20%) from the traditional Medicaid/MediPass Program. The claim payments under the AHS Program were 10.6% lower than the amount that would have been paid to an HMO in the form of capitation payments for the same population (*source*: AHCA).

Technical-assistance programs should promote rather than prevent the development of partnerships to build safety net capacity and improve the management and operating capabilities of safety net providers. Technical-assistance programs should give specific attention to the management of service delivery, the development of new business skills, the collection of reliable data on which to calibrate reimbursement rates, and nonmedical issues that affect utilization and health outcomes of low-income and other vulnerable patients.

The Florida Department of Health has published the fact that AHS' MPN recognizes that there are different ways for providers to develop their skills, outlooks, or knowledge. Because of the wide range of learning styles and subjects, a variety of strategies are used, including periodic physician education meetings, seminars, classes, onsite technical assistance, and practice observations. Meetings, publications, and other materials are also used as education tools. The AHS' MPN facilitates the department's efforts in carefully planning and orchestrating network training as an effective mechanism for improving the quality of healthcare whereby the issues are well defined. The partnering entities within the MPN are well matched, and the scope of the support provided is realistically planned. The AHS' MPN identifies and recruits a wider pool of healthcare practitioners within their areas of expertise.

In addition, the AHS' MPN will serve as a mechanism for the promotion and distribution of educational resource materials that impact racial and ethnic health status. The AHS' MPN is in a unique position to apply this information to a defined recipient group consisting of contracted providers and enrolled MediPass beneficiaries who can apply this information to practice patterns to effect change. Whereas there are currently certain system barriers to implementation of such a program, a long-term initiative in support of Healthy People 2010 goals and objectives should include some of the following elements.

Provide healthcare professionals with claims-based, organized information to better facilitate practice patterns that are guided by the impact of race and ethnicity on the specific AHS' MPN's patient population. The Access MPN is able to identify MediPass beneficiaries suffering from the most prevalent chronic conditions and to stratify their claims data into several risk groups through an automated data management system to provide organized, updated, and workable information. Once the data about chronically ill MediPass beneficiaries is identified, stratified, and organized, the updated and targeted information can be distributed to MediPass providers. Best monitoring practices, which are consistent with those recommended for chronic conditions by the various accredited national medical associations, are organized by beneficiary and by disease state. Currently, beneficiaries' claims reports are summarized for the previous 12 months. Quality performance reports are periodically provided to primary care providers and include the same preventive and monitoring indicators. This information can provide primary care professionals and their staff an opportunity to review compliance with evidence-based medical guidelines.

Activities intended to facilitate a physician's medical performance are complemented by education and information to MediPass beneficiaries. Interventions on both sides of the physician–patient relationship increase the chances of reaching proposed quality goals. Such improvements need to be made within the existing PCCM, fee-for-service (FFS) environment. Through the creation of innovative care management methodologies and techniques, the AHS' MPN has succeeded without the benefit of the more traditional and more restrictive managed care techniques. As always, a real-world challenge is to be able to demonstrate the savings compared with the costs of such initiatives. This can be a formidable task because it is sometimes difficult to accurately measure savings derived from program efficiencies. Factors such as actuarially based, case-mix adjustments, or health-based, diagnostic classification methodologies need to be used to ensure the success of programs that manage people with greater needs.

The AHS' MPN has already identified a series of strategies that include expanding the availability of training, diversifying training content according to relevant and specific ethnic minorities, and providing training in a variety of modalities so that diverse learning styles are accommodated. The Department of Health is working with the AHS' MPNs' education initiatives, as well as using the AHS' MPN's resources, to benefit the minority community at large. The Department of Health believes that one of the greatest challenges lies in the AHS' MPN's ability to access and use the wealth of aggregated, cross-cultural data that has already been accumulated by a vast array of private and public sources, and to link that data to the actual claims experience of the provider and beneficiary population it serves. Once some of the systemic barriers have been removed, the addition of procedures that take into consideration racial/ethnic health factors will be a natural adjunct to the population management and educational activities that the AHS' MPN is presently performing. That, coupled with the educational component and collaboration between public and private interests, will make a powerful statement.

FINDINGS

As health plan report cards become more widely available, Medicaid beneficiaries, as the customers of these plans, will begin to carefully consider health plan performance. Enrollee dissatisfaction with health plans can increase disenrollment, and research has confirmed that some Medicaid beneficiaries who read report cards are influenced by this information in their choice of a health plan *(2)*. Like other managed care organizations, Medicaid programs will seek to improve their overall levels of enrollee satisfaction. Because satisfaction depends on factors and characteristics that differ among the various organizational forms of Medicaid, improvement in enrollee satisfaction will require interventions that are unique to specific plans.

AHS believes that its MPN model successfully combines the most effective and efficient attributes of both the HMO model and the traditional physician practice management model, and improves on them in various ways to make the combined managed care system more efficient and, as a result, more affordable. AHCA contracts directly with physicians, who are formed into nonrisk-sharing local networks by AHS. By supporting physicians with a well-defined medical care management process, industry-leading information systems, and a reimbursement mechanism that rewards physicians for spending the time to manage the care of the whole patient, the networks are able to deliver superior outcomes that also reduce healthcare disparities, and at a significantly lower cost than FFS or HMO-managed care Medicaid. The savings achieved are reinvested into the administrative and information system supports, as well as into performance incentives for physicians, designed to allow and encourage them to take the time necessary to optimally care for each patient.

Under pressure from decreasing reimbursements from both HMOs and government programs, many physicians have responded by progressively increasing the number of patients they see each day, leading to the much-decried "assembly line medicine" quality of much of today's medical care. Besides being unpleasant for both the patient and the physician, it leads to generally poorer and higher-cost care. Physicians are not able to adequately know their patients when they are seeing 50–60 patients a day. Patients do not bond as closely with a doctor they see for just a few minutes, especially if subjected to long hours of waiting. As a potential result, physicians may miss subtle and early signs of illness, patients are less forthcoming about their day-to-day functioning, and patients are less trusting of their doctor and less compliant with recommended therapies. When patients see their doctors as remote and inaccessible, they begin to use hospital emergency rooms for minor complaints and are referred to a variety of specialists, all of which results in duplicate costs, higher rates of complications, and higher rates of healthcare disparities. AHS believes that all of the aforementioned are avoidable.

AHS has structured a business model that allows it to pay physicians to spend time with patients and carefully coordinate their care in order to keep them well. Doctors are expected to be "radically accessible" to their patients, for example, by:

1. Having extended office hours including nights and weekends.
2. Offering walk-in appointments.
3. Calling their chronically ill patients to monitor their condition.

4. Giving out their cell phone number to fragile patients who may need urgent intervention in order to avoid an emergency room visit.

In addition to providing financial incentives to the physician, AHS provides physician support services including medical management support staff and advanced information systems to facilitate the process.

Physician Support

The medical management infrastructure that AHS has created is central to the networks ability to successfully manage care under its contracts. AHS believes that it can achieve superior medical cost containment by supporting motivated physicians with leading-edge information systems and highly experienced medical management staff. In providing this level of support, AHS believes that it receives the informed cooperation of its network physicians, and it believes that this level of cooperation has not previously existed in the Medicaid Program.

Case Management Support

AHS seeks to support its physician networks by using highly experienced case managers, who are clinically astute, expert in case management and in moving patients through the medical delivery system, and who are excited about working collaboratively with physicians to reduce cost and disparities without jeopardizing quality. These case managers do all the administrative tasks necessary to get a patient discharged from the hospital at the appropriate juncture. The case managers remove a significant burden from the doctors because physicians tend to be both impatient and unskilled in such administrative tasks. With the physician setting the treatment plan, and the case manager handling the administrative details, the two professionals work symbiotically to deliver efficient medical care to each patient. In deploying AHS' highly experienced case managers to support physicians' treatment plan efforts, AHS performs certain case management functions that it believes will serve to enhance the overall quality of care and effectively reduce costs.

As examples, AHS' case managers perform the following services for the company's network physicians:

- Monitor referrals to specialists, and help direct the physician to the appropriate cost effective panel.
- Identify chronically ill patients, and set up appropriate outpatient care in order to avoid costly hospitalizations.
- Perform onsite, concurrent review of all hospitalized patients in order to facilitate discharge to the appropriate setting, and thus reduce wasted patient days.
- Call the PCP and the attending physician regarding the status of every hospitalized patient, thus serving as a liaison between the hospital and the physicians.

AHS believes that because its network physicians are highly motivated, they will constantly develop innovative ways to avoid unnecessary costs. These approaches can then be shared with other network physicians during the regular physician meetings, as examples of best practice for others to emulate.

Information Systems

AHS supports its physicians with information relevant to the progress of their patients. On a monthly basis, the company receives data files from the state Medicaid Program and its proprietary information systems to create standard reports for the PCP. AHS believes that all doctors are trained fundamentally to respond to data, whether it is the results of a lab test, or a finding on a physical examination. Unfortunately, most managed care organizations fail to provide physicians with relevant, timely data in a form readily understandable. Too often, doctors receive no information, or voluminous, incomprehensible computer print outs designed by computer programmers and HMO financial analysts who are unfamiliar with what constitutes the most relevant data for the physician. By providing physicians with readable reports that include relevant data on their patients and about their own performance as compared with benchmarks, AHS believes that it is able to stimulate a powerful mechanism for influencing practical change in physician practices. AHS information reports provided to physicians include the following:

- Data on all medical interventions for each patient during the past month. This data allows the PCP to be an informed participant in coordinating the care of each patient.
- Lists of each drug filled by each patient each month. This data enables the physician to know, probably for the first time in his or her practice, exactly which medications the patient actually takes, regardless of who prescribed them. For various reasons, patients are not the best source of detailed information on drugs prescribed and taken. Through the accurate reports, the doctor has the tools to design an optimal drug regimen that the patient will actually comply with.

This feedback, when provided in the cooperative context of the physician's relationship with AHS, and in the context of a peer influenced network centered on improvement in cost effectiveness of care, is believed by AHS to be extremely effective in containing medical costs.

Physician Practice Patterns

AHS' comprehensive medical quality management program aims to promote best practices among its contracted physicians, monitor practice patterns for evidence of optimal care, and continually seek improvement in processes and outcomes. AHS, with its MPN, has developed protocols for optimal management of common chronic conditions based on best evidence

Table 2

Study	National (%)	Florida (%)	AHS (%)
Breast cancer screening	55.9	N/A	48
Asthma screening combined	–	N/A	70.8
Chlamydia Screening (21–25-yr olds)	46	N/A	49.3
LDL-C Screening	75.9	N/A	80
LDL < 100[a]	27.8	N/A	25
LDL < 130	47.8	N/A	87.5
HbA1c testing	74.8	N/A	76.7
Poor HbA1c control[a]	48.6	N/A	45.5
Nephropathy	43.7	N/A	56.7
Eye examinations	45	N/A	66.7

Source: From ref. *58*.

AHS, Access Health Solution.

[a] HEDIS data per state not found online. Florida Health Statistics does not include above data sets (lower is better).

and prevailing standards of care. The protocols are given to each contracted physician, who receives periodic in-service educational programs to explain the theory and practice underlying the protocols. In addition, AHS has conducted outcome studies on the four diseases that have been identified to have the greatest potential for disparities (Tables 2 and 3).

The most extensive management study has been identified as diabetes management. AHS statistically shows results which are better than average national results in diabetes management. AHS monitors the practice patterns of its contracted physicians through a variety of means, including claims analysis, onsite office visits, medical records review, physician satisfaction surveys, patient satisfaction surveys, and patient complaints, as examples. This information is relayed to the individual physician as a tool for continual improvement. AHS also engages in a number of quality improvement studies at any given time, in an effort to continually improve the quality of care offered to patients. Physicians who come to the attention for possibly offering suboptimal care are evaluated in depth, and are visited by an AHS medical director to discuss concerns and plans for improvement. Those physicians, who over time do not meet the standards, are no longer retained in the network.

Finally, although most patients simply want a dedicated healthcare provider, many minority patients prefer a healthcare provider of the same ethnicity. Other research has demonstrated that patients seeing physicians of their own race rate their physicians as more involved in their care *(4–57)*.

Table 3
Effectiveness of Care Measures in Comprehensive Diabetes Care For 30 Randomly Selected Diabetic Members[a]

	2003 National average: Medicaid (%)	AHS (%)
LDL-C screening[b]	75.9	80
LDL < 100[c]	27.8	25
LDL < 130	47.8	87.5
HbA1c testing[d]	74.8	76.7
Poor HbA1c control[e,f]	48.6	45.5
Nephropathy[g]	43.7	56.7
Eye examinations[h]	45	66.7

Source: From ref. *58*.

AHS, access health solution.

[a] For all tests and examinations listed next, a universal population was determined by finding current diabetics (eligible as of 5/1/05) having six consecutive months of eligibility between 12/1/04 and 5/1/05. Diabetics were determined by matching claims to 60 diabetic ICD-9 codes and/or over 2000 diabetic NDC codes per HEDIS requirements. Out of this universal population, 30 members were randomly selected for this analysis (hereafter referred to as "the population").

[b] To find LDL-C screenings, per HEDIS requirements, claims were matched against the following CPT codes: 80061, 83715, 83716, or 83721. *Numerator:* the number of members having at least one of these codes in the measurement period. *Denominator:* the population. Measurement period: 4/1/2004–3/31/2005.

[c] LDL-C screening results were manually collected from chart reviews. *Numerator:* the number of test results under 100 and under 130, respectively. *Denominator:* the total number of test results collected for the population. Measurement period: 4/1/2004–3/31/2005.

[d] To find HbA1c tests, per HEDIS requirements, claims were matched against the following CPT code: 83036. *Numerator:* the number of members having this code in the measurement period. *Denominator:* the population. Measurement period: 10/1/2004–3/31/2005.

[e] Lower is better.

[f] HbA1c test results were manually collected from chart reviews. *Numerator:* the number of test results over 9 Per HEDIS, members receiving a test without the results documented in the chart are counted as a test result over 9. *Denominator:* the total number of test results collected for the population. Measurement period: 10/1/2004–3/31/2005.

[g] To find members who had a documented test for microalbuminuria or evidence of nephropathy, per HEDIS requirements, claims were matched against the following CPT and ICD-9 codes: *CPT:* 82042, 82043, 82044, 84155, 84160, 84165, 81050, 36800, 36810, 36815, 50300, 50340, 50360, 50365, 50370, 50380, 90920, 90921, 90924, 90925, 90935, 90937, 90945, 90947, 90989, 90993, 90997, 90999. *ICD-9:* 39.27, 39.42, 39.43, 39.53, 39.93, 39.94, 39.95, 54.98, 405.01, 405.11, 405.91, 581.81, 583.81, 403, 404, 584, 585, 586, 588, 55.4, 55.5, 55.6, 250.4, 582.9, 753.0, 753.1, 791.0. Also, any member treated at a nephrologists' office. *Numerator:* the number of members having at least one of these codes in the measurement period. *Denominator:* the population. Measurement period: 4/1/2004–3/31/2005.

[h] To find eye examinations, per HEDIS requirements, claims were matched against the following CPT codes: 67101, 67105, 67107, 67108, 67110, 67112, 67141, 67145, 67208, 67210, 67218, 67227, 67228, 92002, 92004, 92012, 92014, 92018, 92019, 92225, 92226, 92230, 92235, 92240, 92250, 92260, 92287, 99204, 99205, 99214, 99215, 99242, 99243, 99244, 99245, G0117, G0118. *Numerator:* the number of members having at least one of these codes in the measurement period. *Denominator:* the population. Measurement period: 4/1/2004–3/31/2005.

CONCLUSIONS

On April 6, 2004, an evaluation of the AHS of Florida's MPN Program was conducted by The Department of Health Service Administration and The Florida Center for Medicaid and the Uninsured, College of Public Health and Health Professions, University of Florida. This evaluation was requested by The Florida AHCA.

The report summary stated: "Florida's Minority Physician Networks appear to offer an alternative to traditional MediPass that result in savings for the agency."

- The MPNs manage primary care provider networks locally, enabling better communication between networks and the Florida AHCA. Important beneficiary information is provided in a timely manner. The networks improve monitoring and support of network providers, and create a high level of satisfaction among network physicians.
- Shared savings and incentives enhance quality of care. The pilot program payments to the MPNs include a management fee paid on a PMPM basis, FFS reimbursement for medical services, and payment for shared savings:
    - *Savings:* AHS vs UPL (based on 63,793-member months): 3,370,055.27 USD.
    - *Savings:* AHS, PMPM: 52.83 USD.
    - *MediPass paid claims (mean):* 354.99 USD PMPM.
    - *AHS paid claims (mean):* 325.64 USD PMPM.

Additional savings were realized by the reduction of "full-time equivalents" needed for administering the MPNs and MediPass.

- AHS develops quality-based incentives. The report characterizes AHS' incentive plan as "multifaceted" noting that physician incentives are determined by efficiency performance, and a "Quality Adjustment Score" based on six measures, including child health check-ups, adult health screenings, welcome letters, provider education meetings attended, authorized referrals notified to AHS, and beneficiary satisfaction with care.

Other factors that contribute to AHS achieving cost savings are:

- Computer systems to track and analyze beneficiary and provider data resulting in timely, detailed, and structured beneficiary utilization of information to its providers.
- Strong organizational and clinical support, especially among physicians in solo practice or who are new to the United States.
- Experience with managed care organizations and proven, effective strategies. One example cited is AHS' case management use of nurses in hospitals to monitor beneficiary progress, communicate with PCPs, and develop discharge plans. Also cited is AHS' ability to make sure hospital services are delivered as ordered and to provide feedback to the PCP on beneficiary progress, needs, and discharge.

The report concluded that:

- AHS' physicians are extremely satisfied with the program relative to their experience with MediPass and Medicaid HMOs.
- AHS saves AHCA money when compared with MediPass.
- AHS reduces healthcare disparities through culturally competent medical management and community involvement.
- Recommend that AHCA allow AHS to expand into additional Medicaid areas within Florida.

Based on the success of the pilot phase in the South Florida region of Florida, AHS was awarded 2-year provider contracts in July 2003 and July 2005. In August 2003, AHS began contacting other states in the Southeastern United States to explain the MPN model. In the 2004 legislative session, AHS authored the Florida SB 1178, the minority health bill that addresses healthcare disparities and expands the MPN into the entire state of Florida. This bill was signed into law in June 2004 and amended the Florida Statutes to address the reduction of healthcare disparities.

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Carolinas Association for Community Health Equity-CACHE

A Community Coalition to Address Health Disparities in Racial and Ethnic Minorities in Mecklenburg County North Carolina

Yele Aluko

INTRODUCTION

This manuscript will describe the evolution of a unique community model in Mecklenburg County, North Carolina, designed to provide educational empowerment to the healthcare consumer around the area of health disparities. The model has also effectively raised the level of awareness of the social responsibility of the healthcare delivery system to hold itself accountable in the provision of equity in healthcare. This community model brings together all stakeholders in the healthcare delivery and consumer equation, around a common goal of communal stewardship, emphasizing community and corporate obligation and responsibility.

DEFINING RACIAL AND ETHNIC HEALTHCARE DISPARITIES

The National Institutes of Health has defined health disparities as differences in the incidence, prevalence, mortality, and burden of disease and other adverse health conditions that exist among specific sub populations in the United States. Concurrent with the US Department of Health and Human Services goal to eliminate health disparities by the year 2010, the State of North Carolina has also defined the elimination of health disparities as a priority focus. This vision has been embraced at the county level by the Mecklenburg County Government, and the Mecklenburg County Health Department, both of whom

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along with several other community partners to be described in this article are collectively instrumental in the development of this unique community model.

DEMOGRAPHICS: MECKLENBURG COUNTY

Mecklenburg County, North Carolina, has seen a 9% growth in its population between the years of 2000 and 2004. The ethnic complexion of the county is increasingly becoming more diverse in composition. Based on 2004 US Census Bureau statistics, racial and ethnic minorities constitute 43% of the county's population of 756,016 residents. Of this, black persons represent 30%, Latino/Hispanics 9%, Asians 4%, and Native American Indians 0.5% of the county's overall population. The health statistics in North Carolina parallel several Southern States where racial and ethnic minority populations have a disproportionate representation, and are adversely affected by a broad spectrum of disease entities and processes. These include but are not limited to cardiovascular disease, cancer, diabetes, HIV/AIDS, infant mortality, and obesity.

HISTORICAL PERSPECTIVE

The history of medicine in Mecklenburg County, as in most of the United States has a painful past of racial segregation in healthcare. This experience was characterized by limited patient options for choice of providers, resulting in an often disenfranchised minority patient population. Such was the experience in Mecklenburg County, North Carolina, where a separate hospital dedicated specifically for the treatment of African American patients was erected in Charlotte North Carolina in 1926 and only deactivated as recently as 1982. Therefore, it is no surprise that integration in medicine in Mecklenburg County was slow to come at the healthcare provider/healthcare system level, with African American physicians finally being allowed privileges at other area hospitals only in 1963.

It has now become understood that an individual's health is determined by a complex interaction of several interdigitating factors that include individual behavior/personal choices, and physical, biological, psychosocial, and environmental issues. That being said, this culture of segregation in healthcare albeit no longer legally present, has undoubtedly played a role in the overall development of healthcare disparities in the community, inasmuch as perceptions of the healthcare system by minority patients might be instrumental in small or large ways in the choices they make. Understanding that concept, one then appreciates that a population's health is then determined in a large way by the ability of healthcare delivery systems to provide equity in access and delivery of healthcare. This ability is influenced by governmental and healthcare policies, protocols, procedures, and interventions that combine to provide a more efficient healthcare delivery system that is more likely to eliminate health disparities.

Since the release of the 2003 Institute of Medicine Report *"Unequal Treatment,"* the problem of HealthCare Disparities among racial and ethnic minorities in the United States has received both focused and fragmented attention from several areas. Several recommendations have been put forth by a myriad of regulatory and governmental organizations. The healthcare delivery system has been challenged to not only implement programs and processes to correct these inequities, but to also provide accountability metrics to ensure judicious application of these recommendations. Multiple call-to-action agendas have been put forth. Indeed a cottage industry of so-called "experts" on Health Disparities has evolved across the United States. At the risk of denying the true victims of health disparities the benefits of these call-to-action agendas and the wisdom of these experts, the grassroots community must be meaningfully engaged in this process.

HISTORY OF EFFORTS TO ADDRESS HEALTH DISPARITIES IN MECKLENBURG COUNTY

The history of efforts to address racial and ethnic disparities in Mecklenburg County, North Carolina, dates back to the year 2000, when North Carolina's State Health Director prioritized elimination of health disparities as a critical issue. The Mecklenburg County Health Department created a new position of Community Health Administrator, and hired a long time grassroots advocate for health equity, *Ms. Cheryl Emanuel* as its first administrator. Ms. Emanuel began an aggressive program of "Community Think-Tank Dialogues" designed to bring together a diverse representation from health groups, minority organizations, universities, community, and faith based organizations as well as the private sector. In June 2004, these grassroots efforts, in addition to growing interest and concern from local Charlotte Universities, resulted in the creation of a leadership symposium initiated by the Mecklenburg County Health Department in cooperation with Johnson C. Smith University, Pfeiffer University, and University of North Carolina Charlotte, all being local Universities in the Charlotte-Mecklenburg County area of North Carolina. The symposium agenda addressed health disparity issues in Charlotte-Mecklenburg and its surrounding communities.

Strong collaborative leadership was exercised by Cheryl Emanuel of the Mecklenburg County Health Department, *Professor Vernease Miller* of Pfeiffer University, *Drs. Diane Bowles and Charlotte Cobb-Grant* of Johnson C. Smith University, and *Dr. Jackie Dienemann* from the University of North Carolina, Charlotte. The symposium and collaboration resulted in the formation of the *Educational Collaborative for the Elimination of Health Disparities in*

Mecklenburg County. Unlike most initiatives the “Collaborative” was unique; in that, it sought to build a constituency base, so that all concerned voices within Mecklenburg County could be heard on the issues of disparities.

In October of 2004 the Educational Collaborative for the Elimination of Health Disparities hosted a successful community health summit, *“Our Health, Our Priority, Our Policy,”* to raise awareness, prioritize solutions, and forward an agenda for policy development to reduce health disparities in the communities. Over 300 at risk citizens including representatives from federal, state, and local government, community leaders, and public officials encompassing all racial/ethnic minority and age groups, attended and actively participated. Minimal attendance or involvement from local hospitals and health care providers was observed. It was becoming apparent that although important and valuable constituents were at the table in this collaborative, certain key stakeholders were absent.

In a separate, independent and parallel process that began in 2003, two concerned African American cardiologists, members of the Charlotte Medical Society and of the Mecklenburg County Medial Society, *Dr. Yele Aluko* and Dr. *Jerome Williams Jr.*, had begun working together and strategizing methodologies to raise community awareness about health disparities in minority populations. It was apparent to these physicians that empowering patients through health education was instrumental in providing the requisite insight needed to reduce health disparities. Having identified this lack of community participation or involvement in several disparity initiatives in existence, their focus was to provide educational empowerment to the community’s citizens more likely to be at risk for experiencing healthcare disparities. Their vision was to provide an annual series of *Minority Health Symposia* designed specifically for the consumer of healthcare, with a special focus on the racial and ethnic minority population. The goal was to target one organ system each year for a minimum of 5 yr, and deliver a first class, well advertised, and well attended community symposium that had broad spectrum support and leadership participation from a cross-section of the corporate and local business, academic, healthcare, and faith-based organizations in Charlotte.

Partnering with the two hospital systems in Charlotte, *Presbyterian Hospital* and *Carolinas Medical Center*, and with the two medical societies, the *Charlotte Medical Society* and the *Mecklenburg County Medical Society*, in addition to several other medical and corporate supporters, this initiative resulted in the inauguration of the first in a series of annual Minority Health Symposia evaluating disparities in healthcare in minority populations. The overarching theme for these symposia was entitled *“Minority Health: Defining the Disparity Dilemma.”* Each annual symposium would be designed to have a separate disease focus. The symposia were designed to start with breakfast, after which several breakout sessions pertinent to the disease process being discussed would be delivered by local healthcare providers and community leaders. These breakout sessions would run concurrently till lunch, after which a nationally acknowledged expert would deliver a keynote speech, followed by a panel of discussion patterned as a town hall meeting to engage the attendees in frank and open dialogue on the issues.

The inaugural conference was held in September 2004 at the Westin Hotel Charlotte, with a focus on Cardiovascular Disease. About 510 concerned citizens, public officials, healthcare providers, and corporate leaders attended this inaugural symposium. Several corporate, community, local business, and pharmaceutical sponsorships were aggressively sought to support the program. Breakout sessions on diet and nutrition, healthier lifestyles, exercise, smoking cessation, and yoga were well attended. *Carmen Hooker Odom*, the North Carolina Secretary for Health and Human Services, was the keynote speaker. *Barbara Pullen Smith*, the North Carolina Director for the Office of Minority Health and Health Disparities and *Dr. Waine Kong* the CEO of the Association of Black Cardiologists, were special guest speakers. Effective media partnership was solicited, resulting in pulsed messaging through the print media, television, and radio about the issue of health disparities. Twenty five thousand dollars ($25,000) was raised from this effort, all of which was donated to fund programs within Mecklenburg County that enhanced access to prescription plans and physicians offices for uninsured and underinsured patients.

EVOLUTION OF THE MODEL

The organizers of these strategically similar, yet operationally distinct conferences soon became aware of the others' activities and quickly realized that both initiatives had commonality of vision and purpose, with a primary goal of eliminating health disparities in Mecklenburg County. Although both initiatives had some overlap in support, the one had the support of the universities and community, whereas the other had the support of the hospitals, healthcare providers, and community. It became immediately obvious that a coalescence of these independent efforts would provide greater synergy and more productive use of available resources to effectively address the problem of health disparities. In January 2005, these efforts combined to form the *Carolinas Association for Community Health Equity* (CACHE) (www.cachenc.org). The regionality of the organization's name was purposely chosen to reflect and anticipate the potentially larger geographical scope for future growth and sphere of influence of the organization.

Incorporated as a North Carolina Corporation with 501© 3 tax exempt recognition, CACHE is governed by its Board of Directors under the inaugural Chairmanship of *Ms. Pat Lambright*. The Vision of CACHE *"is to be the* *leading partnership organization for achieving health equity in Mecklenburg County."* Its Mission *"is to improve health by eliminating health disparities that affect racial and ethnic and other at risk populations through collaborative partnerships."* The strength of this effort is the unprecedented commitment by individuals, institutions, and governmental and business organizations that have entered into partnership, working for the greater good of all constituents in Mecklenburg County. This collaboration includes local and state government, health professionals, institutions of higher learning, community associations, faith-based groups, and other public and private health-related organizations. The *Minority Health Symposium*: *"Defining the Disparity Dilemma"* has evolved to be an educational and fund raising activity for CACHE, with monies realized from the event being used to fund CACHE, its Mission, and its programs.

The goals of the symposia are:

1. To increase awareness of, and provide an understanding of the contributing factors, which result in disparities in healthcare outcomes that exist within minority populations.
2. To provide a forum to facilitate a better understanding of the need for preventive modalities, and the importance of early detection and initiation of treatment programs.
3. To foster dialogue geared toward educating minority populations on how to more efficiently access and navigate the healthcare systems.
4. To facilitate the development of more effective strategic partnerships between the CACHE and other organizations, to create processes for the eradication of health disparities among at risk populations.
5. To obtain funding to support the mission of CACHE and its programs.

In 2005, the focus of the symposium was Cancer, drawing an attendance of 650 people. Breakout sessions on prostate, breast, colorectal, and female reproductive organ cancers, were presented and well attended. Sessions on alternative and integrative medicine and end of life issues in cancer care were exceptionally well received. *James R. Gavin MD*, Professor of Medicine at Emory University, provided the keynote address. *Donna Christensen MD*, Congresswoman from the US Virgin Islands, was the special guest. A vibrant panel discussion and question and answer session was moderated by *Kenneth Olden, PhD*, past director of the National Institute of Environmental Health Sciences. Thirty two thousand dollars ($32,000) were raised from this effort to fund CACHE and its programs, and also enabling the implementation of a part time administrative office for CACHE.

In 2006 the symposium focus was Diabetes, with a peak attendance of 820 registered guests. Breakout sessions on "a day in the life of the diabetic heart," "losing limbs to diabetes," "losing vision through diabetic eyes," "diabetes causes kidney dialysis," "obesity and diabetes," "diabetes and the kitchen," "insurance coverage and diabetes," "diet and drugs, herbs and spices in diabetes," and "living successfully with diabetes" were all well attended. The keynote address was given by *Sam Dagogo Jack, MD,* Professor of Medicine at the University of Tennessee, Memphis. *Yvonne Maddox, PhD*, Deputy Director of the National Institute of Child Health and Human Development at the National Institutes of Health, Bethesda MD, was the special guest. *Kristy Woods, MD*, Professor of Medicine and Inaugural Director of the Maya Angelou Research Center on Minority Health at Wake Forest University School of Medicine in Winston Salem, North Carolina, moderated an enthusiastic panel discussion and engaged the public in an exhaustive town hall dialogue on the issue of health disparities. Ninety five thousand dollars ($95,000) were raised from this symposium to support CACHE's Mission and fund its programs.

The existence of CACHE has been acknowledged in Mecklenburg County as a forward thinking, community oriented, and participatory organization that intends to provide structure and voice to the issue of health disparities in this community. Its Board of Directors reflects broad community spectrum involvement as follows:

1. *Vernease H. Miller, MHA. JD.* Pfeiffer University. *Board Chair.*
2. *Linda K. Gallehugh, MHA.* Teen Health Connection. *1st Vice Chair.*
3. *Yele Aluko, MD.* Mid Carolina Cardiology. *2nd Vice Chair.*
4. *Tina Hunt.* Metrolina Native American Association. *Secretary & Archivist.*
5. *Lillian Herron, MSN, RN.* CN Jenkins Memorial Presbyterian Church Health Ministry. *Assistant Secretary.*
6. *Mark Martin, MBA, MHA.* Novant Healthcare. *Treasurer.*
7. *Willie Garner.* Lincoln Heights Neighborhood Association. *At-Large.*
8. *Jesus A. Hernandez, APRN, BC.* Queens University. *At-Large.*
9. *Jerome Williams Jr, MD.* Mid Carolina Cardiology. *At-Large.*
10. *LaTonya Chavis, MS.* Charlotte Director Reach 2010. *Chair: Access Council.*
11. *Byron Grimmett,* Mecklenburg County Medical Society. *Chair: Quality Council.*
12. *Deborah J. Walker, PhD.* VISIONS, Inc. *Chair: Cultural/Linguistic Competence Council.*
13. *Ruth Greene, PhD.* Johnson C. Smith University. *Chair: Education, Research & Science Council.*

EXECUTIVE COMMITTEE
Vernease Miller
Linda Gallehugh
Yele Aluko
Tina Hunt
Mark Martin

CACHE's strategic and financial partners include the following:

1. Abbott Pharmaceuticals
2. American Cancer Society
3. American Diabetes Association
4. American Heart Association
5. Amylin Lilly
6. Bank of America
7. Blue Cross and Blue Shield of North Carolina
8. Carolinas Medical Center
9. Coca Cola Consolidated
10. GlaxoSmithKline
11. Harris Teeter
12. Hearst Corporation
13. La Noticia
14. Lash Group
15. Mecklenburg County Medical Society
16. Mecklenburg County Government
17. Mecklenburg Pulmonary Specialists
18. Mid Carolina Cardiology
19. National Kidney Foundation
20. Nitromed
21. Novo Nordisk
22. Pfeiffer University
23. Pfizer
24. Presbyterian Hospital
25. Pride Magazine
26. REACH 2010
27. Takeda Pharmaceuticals
28. Urban League of Central Carolinas

FUTURE DIRECTIONS

The CACHE Board of Directors has engaged in a formal strategic planning session and has outlined four overarching strategic goals. As a result of this, CACHE envisions being organized into four councils, each with a priority area of focus related to improving the health status of racial and ethnic minorities (Fig. 1).

1. Council for improved access to healthcare.
2. Council for improved quality of healthcare.
3. Council for improved cultural and linguistic competence in healthcare.
4. Council for education, research, and science in healthcare.

Future programs are being designed specifically around these strategic goals. For example, current work in progress in the *Access Council* intends to connect people to healthcare services and healthcare services to people,

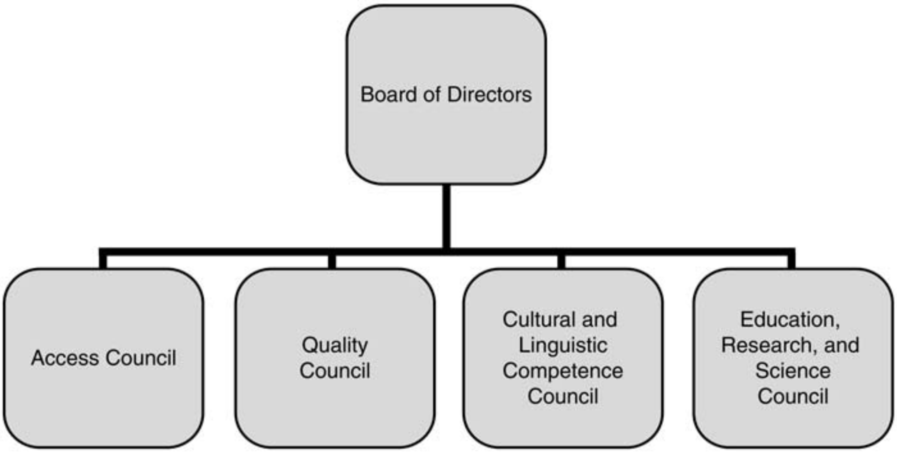

Fig. 1.

utilizing Parish Nurse Ministries and Lay Health Advisors, and by developing links to community resources on the CACHE website. An increase in the number of primary and specialty care visits by at risk population groups will be observed as an indicator of successfully improving access to healthcare in these populations. The *Cultural and Linguistic Competence Council* intends to facilitate an increase in the number of minority healthcare providers and allied health professionals by partnering with high schools and healthcare administrators to introduce minority students to the healthcare profession. Increased numbers of students enrolled in medical education and the number of minority representation in healthcare administration over time will be used as indicators of success. The *Quality Council* intends to educate consumers on identifying lower quality healthcare by improving their knowledge base and strengthen communication skills through hosting town hall meetings and conduction of focus groups. The *Education, Research, and Science Council* intends to develop an interdisciplinary academic community research partnership in health disparities and identify mechanisms to foster awareness of health disparities education and training. The fall minority health symposium will continue to be an educational and fundraising activity for CACHE through this council. Increasing attendance at this symposium serves as a barometer of increasing awareness of health disparity issues. A partnership with local news media is being explored to broadcast monthly Public Service Announcements sponsored by CACHE, directed to public education and awareness on health disparity issues.

In October 2005 the Mecklenburg County Government declared the elimination of health and mental disparities, a priority for Mecklenburg County. *The Health Parity Vision of Mecklenburg County* states that, “everyone in Mecklenburg County will enjoy good health regardless of their race/ethnicity, disability, or socioeconomic status” It is for this reason that the visionary leadership of *Harry Jones*, the Mecklenburg County Manager, and *Wynn Mabry MD*, the Health Director of the Mecklenburg County Health Department is applauded. Building on the work of the North Carolina Office for Minority Health and Health Disparities, and the North Carolina Department of Health and Human Services, the Mecklenburg County Health Department has been charged with the responsibility for providing avenues to monitor and address health disparities in Mecklenburg County.

CACHE has evolved into a unique community model, which can act as an example for other counties and Health Agencies. CACHE invites the participation of all interested individuals of any race, color, gender, or religious background, and all supportive organizations interested in eliminating health disparities and to provide a strategic community involvement with the Mecklenburg County Health Department to enable it to achieve the parity vision for Mecklenburg County. It no longer serves to regurgitate ineffective statistical data on health outcomes in minority communities. It is time to put programs and processes in place at all levels of community education, medical access, and medical intervention, to enable corrective action that will begin to amend this trend of disparities in healthcare experienced by racial and ethnic minorities. To do so effectively, one will require collaborative efforts between local, state, and federal health agencies, professional medical societies, and all concerned constituents. A greater diversity in leadership of these groups will boost the efforts ti eliminate health disparity in general.

ACKNOWLEDGMENTS

Special mention must be made of the consistent and valuable political support received from County Commissioner *Norman Mitchell*, Chairman of the Board of Mecklenburg County Commissioners Community Health & Safety Committee, North Carolina State Representative *Beverly Earle*, Chairman of the House Select Committee on HealthCare, and Sub Committee on Medicaid, and North Carolina State Senator *Charlie Dannelly*, Deputy President Pro Tem of the North Carolina State Senate.

V

CONCLUDING RECOMMENDATIONS

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Principles for Eliminating Racial and Ethnic Disparities in Healthcare

John Z. Ayanian, MD, MPP
and Richard Allen Williams, MD

INTRODUCTION

The elimination of racial and ethnic disparities in *health* has become a national priority in the United States *(1)*. 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 healthcare as an important factor contributing to disparities in health outcomes *(2)*. 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 *(3)*, 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 *(4)*.

In this chapter, five principles are presented (Table 1) to guide policymakers, healthcare leaders, and healthcare professionals seeking to reduce and ultimately eliminate racial and ethnic disparities in healthcare. These principles are based on clinical and policy experience, review of the research literature on healthcare disparities, and findings and recommendations of key reports from the Institute of Medicine *(2)* and the American College of Physicians *(5)*. The principles have been refined with input from an advisory

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Table 1
Principles for Eliminating Racial and Ethnic Disparities in Healthcare

1. Provide insurance coverage and access to high-quality care for all Americans
2. Promote a diverse health-care workforce
3. Deliver patient-centered care
4. Maintain accurate and complete race/ethnicity data to monitor disparities in care
5. Set measurable goals for improving quality and ensure that goals are achieved equitably for all racial and ethnic groups

committee of clinical and academic leaders in minority healthcare 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.

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. 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 Alaska Natives are approx 3 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 *(6)*.

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 *(7–10)*. 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 *(11–13)* 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 *(13–15)*. Approximately 80% of uninsured Americans are members of working families *(7)*. However, the proportion of people with no insurance are 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

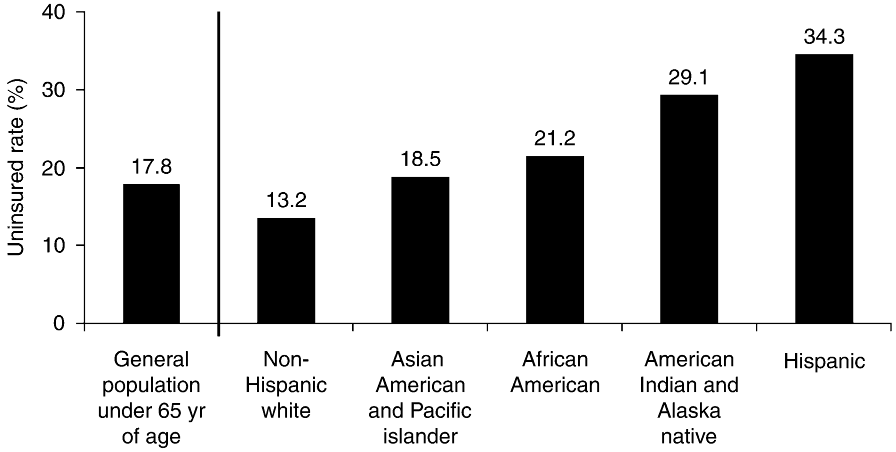

Fig. 1. Probability of being uninsured by race and ethnicity, US nonelderly population, 2004 *(59)*.

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. Expanding eligibility for these programs to cover a larger proportion of people with low incomes would be particularly beneficial for minority Americans, especially if such expansions were coupled with more effective efforts to enroll those who are eligible for these programs.

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, approx 20% of primary care physicians in the United States treat approx 80% of African American patients *(16)*. 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 universal insurance coverage would provide financial access to a broader range of healthcare providers for minority Americans who are currently uninsured, many of these individuals 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 healthcare.

Safety-net organizations such as community health centers and public hospitals play a substantial role in caring for minority patients, particularly those with low incomes and immigrants. Many of these organizations rely on federal, state, or local government funding to support healthcare 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 *(17)*.

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 compromised 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 *[18]*). In 1980, 5.1% of all US medical school graduates were African Americans, and 3.1% of graduates were Latino. By 2004, these proportions have risen modestly to 6.5 and 6.4%, respectively *(18)*, but they still represented 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, primary, secondary, and university educational systems serving minority students must ensure that their 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, for example, that minority patients rate the quality of their communication with racially concordant physicians more highly *(19,20)*. 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 *(21)*.

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 *(22,23)*. 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 healthcare 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 were 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 healthcare as defined by the Institute of Medicine in its *Crossing the Quality Chasm* report *(24)*. 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 *(25,26)*. 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 have reported significantly higher rates of problems with coordination of care, the strongest correlate of lower ratings of quality of care for all racial and ethnic groups *(26,27)*. 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 healthcare *(28)*. 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 school, residency programs, and continuing education for health professionals *(2)*, but evidence for the effectiveness of such programs to improve care for minority patients and reduce disparities is not well developed *(29–31)*. 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 *(32,33)*. 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 *(34–36)*, 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 *(32)*. 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 *(37)*. 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 *(38)*. 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 *(39)*.

Healthcare providers, hospitals, and health plans have a crucial role to play in consistently collecting self-reported race and ethnicity directly from patients *(17,32)*. Recent evidence indicates that 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 *(40)*. Public and private agencies that accredit healthcare organizations, such as state health departments and the Joint Commission on Accreditation of Healthcare Organizations, have the potential to accelerate the collection of race and ethnicity 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 *(41)*. Such geocoding is most useful to identify African Americans who live in predominantly African American neighborhoods *(42)*. For Asian American and Latino patients, analyses of surnames are another method for determining race and ethnicity with reasonable accuracy *(42,43)*.

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 *(24)*. 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 cross-cutting 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 healthcare over the past decade, most quality monitoring and improvement programs have not included an explicit focus on disparities or equity. Addressing inequalities in quality as a central theme of quality improvement has the potential to move the elimination of healthcare disparities from a peripheral position on the health policy agenda to a much more central position *(32,44)*.

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 in process measures have included hemodialysis dosing *(45)*, diabetes testing *(46,47)*, use of β-blockers after acute myocardial infarction *(46)*, assessments of ventricular function, and use of angiotensin-converting enzyme inhibitors or angiotensin receptor blockers for congestive heart failure *(48)*, and adjuvant chemotherapy for colon cancer *(49)*.

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 compared with white patients with diabetes mellitus, hypertension, or heart disease *(46,47,50)*. Similarly, among patients with end-stage renal disease, hematocrit, and serum albumin levels have remained significantly lower for African Americans than for whites *(45)*. These and other differences in clinical outcome measures likely contribute to the substantial racial disparities in life expectancy for African Americans relative to white Americans *(51,52)*. Racial disparities in mortality related to hypertension, diabetes, ischemic heart disease, and HIV infection—conditions that have highly effective therapies—together account for 40% of the disparity between African Americans and whites in life-years lost before age 75 *(53)*.

Distinguishing differences in quality and outcomes by race and ethnicity between and within healthcare organizations is an important priority for disparities research *(54)*. 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.

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 treatment and outcomes for hospital-based services, such as acute myocardial infarction care or major cardiovascular or cancer procedures *(55–58)*. In contrast, racial 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 across both higher and lower quality health plans and medical groups *(46,47)*. 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.

Numerous publicly and privately funded organizations in the United States have interrelated mandates to develop evidence-based quality measures, monitor the quality of healthcare organizations and providers, and promote quality improvement in healthcare. Examples of these organizations include the National Quality Forum (www.qualityforum.org), National Committee for Quality Assurance (www.ncqa.org), and state and regional Quality Improvement Organizations (www.medqic.org) funded by the Centers for Medicare and Medicaid Services to evaluate and promote the quality of healthcare for Medicare beneficiaries. With their well-established focus on quality of care, these organizations could play a substantial role in reducing healthcare disparities by embracing and explicitly linking these two issues in their efforts to improve care.

CONCLUSION

The five principles presented to eliminate racial and ethnic disparities in healthcare 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. Healthcare professionals can begin to redress these disparities in health by ensuring that high-quality healthcare is provided equitably regardless of patients' race or ethnicity.

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