eHealth Solutions for Healthcare Disparities
eHealth Solutions for Healthcare Disparities

Edited by

Michael Christopher Gibbons, MD, MPH
Associate Director, Johns Hopkins Urban Health Institute (UHI)
Director, Center for Community HEALTH (CCH)
Assistant Professor of Public Health and Medicine,
Johns Hopkins Medical Institutions
Baltimore, Maryland
Preface

Over the past decade a rapidly expanding body of literature has demonstrated the existence of healthcare disparities. While consensus has not emerged regarding the causes of disparities, they are generally thought to be related to provider, patient, and healthcare system factors. On the one hand, the current US healthcare system is oriented toward individualized acute care. Yet healthcare disparities by definition are a population level phenomenon. Individuals do not have disparities, groups and populations do. Thus population level data alone will not enable us to develop individualized interventions. Similarly, biologic, cellular, or molecular level data that is not informed by sociocultural realities has limited ability to help us craft the most appropriate interventions to address healthcare disparities. Rather knowledge from each of these levels of analysis must be sought, integrated, and evaluated. In so doing we will gain a far more relevant and informed understanding of healthcare disparities and have a better foundation from which to build clinical and behavioral interventions.

To develop the best interventions, several authorities have suggested the need for greater information technology research and investments. eHealth researchers may be able to make significant contributions in this area through research and its applications. Not surprisingly though, most individuals concerned about healthcare disparities have little knowledge of the fields of health information technologies or eHealth. Similarly, many working in the technology fields have only a cursory understanding of healthcare disparities. As such, the intent of this book is to draw together two unlikely bedfellows; the information technology fields and the sociobehavioral and population sciences, and to challenge readers to consider new possibilities and opportunities across the two disciplines.

In order to successfully accomplish this task the first section of this book contains several chapters discussing the field of healthcare disparities and current consensus on factors considered important in their causation. Because any serious consideration of computer technologies is not complete without a discussion of the role of the Internet, the second section of the book contains several chapters discussing the role of the Internet in society and emerging disparities in access and utilization of this technology. The third section of this book focuses on three computer- and technology-based themes most relevant to healthcare disparities, namely eHealth,
Medical Informatics, and Public Health Informatics. Finally, the last section of this book has several chapters pulling it all together. These chapters discuss future innovations in research that will be needed to foster a more informed and comprehensive understanding of healthcare disparities as well as policy opportunities for moving forward. The book ends with a chapter suggesting several ways in which technology may help us achieve the goal of reducing and eliminating healthcare disparities, some perhaps not previously considered. It is our hope that you find this book not only interesting, but also intellectually provocative to the point that you challenge old notions and conventions related to healthcare disparities and develop new technology-based collaborations to make the promise and the potential of technology strategies to address healthcare disparities, a reality.

M. Chris Gibbons
Editor
Contents

Preface ................................................................. v
Contributors............................................................... ix

Section I

1. An Overview of Healthcare Disparities ......................... 3
2. Provider Factors in Healthcare Disparities ..................... 11
3. Patient Factors in Healthcare Disparities ....................... 19
5. The Social “Nonmedical” Determinants of Health .............. 39

Section II

6. The Role of the Internet in American Life ....................... 51
7. The iHealth Revolution.............................................. 60
8. Digital Disparities................................................... 66

Section III

9. The Role of eHealth in Patient Engagement
   and Quality Improvement......................................... 75
10. Medical Informatics............................................... 93
11. Public Health Informatics........................................ 109
Section IV

12. Beyond Traditional Paradigms in Disparities Research ............... 129
13. Health Information Technology Policy Perspectives and Healthcare Disparities ....................... 145
14. Disparities and eHealth: Achieving the Promise and the Potential ....................... 154

Author Index ................................................................. 165

Subject Index ............................................................... 173
Contributors

Michael Christopher Gibbons, MD, MPH, Associate Director, Johns Hopkins Urban Health Institute (UHI); Director, Center for Community HEALTH (CCH); Assistant Professor of Public Health and Medicine, Johns Hopkins Medical Institutions, Baltimore, MD

Anthony J Alberg, PhD, Johns Hopkins Bloomberg School of Public Health, Johns Hopkins Oncology Center, Baltimore, MD

David Ahern, PhD, National Program Director, Health e-Technologies Initiative, Brigham and Women’s Hospital; Assistant Professor of Psychology (Psychiatry), Harvard Medical School, Boston, MA

Stephen Baylin, MD, Johns Hopkins School of Medicine, Johns Hopkins Oncology Center, Baltimore, MD

Malcolm Brock, MD, Johns Hopkins School of Medicine, Johns Hopkins Oncology Center, Baltimore, MD

Stephanie Chang, MD, MPH, Department of Medicine, Johns Hopkins School of Medicine, Baltimore, MD

Charles B. Eaton, MD, MS, Professor of Family Medicine, The Warren Alpert Medical School of Brown University; Director, Center for Primary Care and Prevention, Memorial Hospital of Rhode Island, Pawtucket, RI

Patricia Flatley Brennan, RN, PhD, FAAN, Moehlman Bascom Professor, School of Nursing and College of Engineering, University of Wisconsin-Madison, Madison, WI

C. Earl Fox, MD, MPH, Johns Hopkins Urban Health Institute, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Thomas Glass, PhD, Johns Hopkins Bloomberg School of Public Health, Johns Hopkins Bloomberg School of Public Health Center on Aging and Health, Baltimore, MD

Bradford W. Hesse, PhD, National Cancer Institute, Bethesda, MD
Thomas A LaVeist, PhD, Johns Hopkins Bloomberg School of Public Health, Johns Hopkins Center for Health Disparities Solutions, Baltimore, MD

David Levine, MD, MPH, ScD, Johns Hopkins School of Medicine, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Ruth Perot, MAT, Executive Director, Summit Health Institute for Research and Education, Washington, DC

Judith M. Phalen, MPH, Deputy Director, Health e-Technologies Initiative, Brigham and Women’s Hospital, Boston, MA

Nadra Tyus, PhD, Post Doctoral Fellow, Johns Hopkins Urban Health Institute, Baltimore, MD

Rupa S Valdez, PhD.(candidate), Predoctoral Fellow, College of Engineering, University of Wisconsin-Madison, Madison, WI
Section I
An Overview of Healthcare Disparities

Michael Christopher Gibbons

Recognition of a Problem

By the early 1980s, Wennberg et al., using small area analysis and geographic information systems analytic techniques, demonstrated that a significant amount of nonrandom medical practice variability existed between clinical practices in different geographic locales, despite treating clinically similar patients (Barnes, O’Brien, Comstock, D’Arpa, & Donahue, 1985; McPherson, Wennberg, Hovind, & Clifford, 1982). In their study they examined the incidence of several common surgical procedures in seven hospital service areas in southern Norway, 21 sites in the United Kingdom, and 18 sites in the northeastern US. Although overall surgical rates were higher in the US than in the United Kingdom or Norway, there was significant variability in surgical rates among sites. In addition the variability was similar across all the three countries. In fact there was surprising consistency among countries in the rank order of variability for most procedures: tonsillectomy, hemorrhoidectomy, hysterectomy, and prostatectomy varied more from area to area than did appendectomy, hernia repair, or cholecystectomy. Thus this variation appeared to be nonrandom and not related to the organization or financing of care across the three countries (McPherson et al.).

A large analysis by Barnes seemed to corroborate Weinberg’s findings of differential healthcare delivery in relation to geography. In this study Barnes et al. examined over 140,000 surgical procedures performed in Massachusetts in 1980. The location of the facilities where these procedures occurred was mapped and subdivided into more than 150 geographically defined areas across the state. The resulting analysis revealed that per capita surgical rates across geographic areas were significantly (two-to threefold) different and seemingly unrelated to clinical characteristics of patients served. Some surgical procedures were even being provided at rates substantially different from the statewide rate (Barnes et al., 1985).

By the early 1990s the evidence of disparate care provision in the US healthcare system continued to mount with the emergence of data from the Harvard Medical Practice Study (Brennan, Leape, Laird, Localio, & Hiatt, 1990; Brennan, Leape, et al., 1991; Leape et al., 1991; Leape et al., 1991). This study was undertaken, in part, to evaluate risk factors related to injury caused by the healthcare system. This comprehensive study was
Based on more than 30,000 medical records from 51 randomly chosen hospitals in New York (Brennan, Hebert, et al., 1991), and revealed that a significant amount of injury to patients from medical practice occurred in this sample of the healthcare system. It also found that these adverse events were not randomly distributed with many injuries being the result of substandard care (Brennan, Leape, et al., 1991; Brennan et al., 1990; Leape et al.). An examination of hospital characteristics associated with these adverse events revealed that in addition to other factors, a significantly higher risk of adverse events was found among hospitals serving large proportions of minority patients. In fact in multivariate analysis, the only factor that remained significantly associated with an increased risk of adverse events due to negligence was treatment of a large proportion of minority patients (Brennan, Hebert, et al.). Although the authors could not explain the cause of these findings they suggested that they reflected the quality of care delivered in hospitals, not patient behavioral factors or other clinical factors related to the natural history of patient disease (Brennan, Hebert, et al.).

Thus by the late 1990s, growing evidence suggested that issues of racial and ethnic healthcare differences, practice variation, and substandard care, may all be related to the quality of health care experienced by patients. About this time Fiscella published his paper entitled “Inequality in Quality,” in which he called attention to issues of healthcare quality and healthcare disparities as related issues of healthcare organizational capacity. He further contended that national efforts to eliminate racial and ethnic disparities in health care and national health-care quality improvement initiatives represented two inseparable components of providing high-quality health care for all citizens (Fiscella, Franks, Gold, & Clancy, 2000). Thus for the first time in the US, it was suggested that health care should not be considered high quality as long as significant quality gaps and healthcare disparities remained.

Synthesizing the Scientific Evidence on Healthcare Disparities

To help bring clarity to these issues, the Institute of Medicine released the first of several reports highlighting and summarizing the scientific evidence concerning issues of differential health status, culture, behavior, communication, substandard care/medical errors, and healthcare quality (Haynes & Smedley, 1999; Institute of Medicine, 2001, 2002, 2003; IOM Committee on Quality of Healthcare in America, 2001; Kohn, Corrigan, & Donaldson, 2000; Smedley, Stith, & Nelson, 2003). The first report entitled “To Err is Human; Building a safer healthcare system” helped quantify the magnitude of the quality problem in the eyes of the public. This report suggested that the number of people who die each year from medical errors may be as high as 98,000 (Kohn et al.). With this assertion, no longer could poor outcomes or healthcare quality issues be seen as limited to the poor, to those patients who make poor health decisions or to the uninsured. This report suggested that providers and the healthcare system themselves played a role in the ultimate healthcare outcomes of patients.
Two reports followed that were released the following year in 2001. The first entitled “Envisioning the National Health Care Quality Report” (Institute of Medicine, 2001) laid the groundwork for a National Healthcare Quality Report. This would be national systematic annual evaluation of healthcare quality in the US. The second entitled “Crossing the quality chasm: A new health system for the 21st century” (IOM Committee on Quality of Healthcare in America, 2001) advocated a new vision for the future of health care. This vision was based not only on the growing realization of the existence of significant health quality gaps in the US healthcare system, but also on the notion that working harder within the context of the then current system, would not likely yield significant improvement. Rather, fundamental changes in the healthcare system would be needed (IOM Committee on Quality of Healthcare in America). The authors argued that although science and medical technology had advanced rapidly in recent years, the healthcare system in its then current capacity was lagging in its ability to communicate effectively with patients and to adequately coordinate care among patients suffering from chronic diseases who are in need of nonhospital-based care (IOM Committee on Quality of Healthcare in America). In the view of this committee, health care in the future should be of high quality in each of six critical dimensions. These include (1) Safety – providing health care that does not cause patient injuries, (2) Effective – providing evidence-based healthcare services to all who need them at the needed level/amount, (3) Patient centered – providing health care that is responsive to individual patient preferences, needs, and values, (4) Timely – providing health care without harmful delays, (5) Efficient – providing health care in a way that minimizes waste of resources, and (6) Equitable – providing health care of a consistent quality to all patients at all times, in any location or setting. Although it was not explicitly stated, this committee appeared to feel strongly that a healthcare system that achieved these goals among all patients would be a system that would also have successfully addressed healthcare disparities among racial and ethnic minorities.

Unfortunately, achieving these goals would not come easily. The growing diversity of the US population along with the quality problems in the US healthcare system strongly suggested that prevailing notions of health communication, patient behavior, and patient–provider interaction needed to be reexamined, particularly among minority populations. There was a growing realization that the recent advances in diagnostic testing and medical treatment along with quantum leaps in our understanding of disease at the cellular, molecular, and genetic levels were not sufficient to guarantee optimal health. The widespread documentation of healthcare disparities suggested that psychological factors, human behaviors, social ties as well as family and community life might also be important determinants of healthcare outcomes which should be considered more closely and integrated better into the context of US health care (Singer & Ryff, 2001). In short, the social and behavioral sciences which traditionally had not been considered within the domain of health care were perhaps linked to illness, health, and healthcare outcomes (Singer & Ryff).

This represented new ground for US health care. As such the IOM commissioned a report entitled “Speaking of health: Assessing health communication strategies for diverse populations.” This study explored the dynamics
and challenges of effective cross-cultural communication. It examined the need for more science-based communication interventions, and the role of sociocultural factors on patient beliefs and behaviors in health care (Institute of Medicine, 2002). While the committee was unable to determine, from the then existing literature, if socioculturally determined knowledge could improve healthcare communications or enhance efforts to address health disparities, they were able to recommend that (1) underserved individuals and communities should be encouraged to participate actively in the construction of health communication campaigns in their communities, (2) practitioners should employ evidence-based, multicomponent programs that integrate communication with access to services, and (3) novel technology-based communication strategies to improve the health of diverse populations should be explored (Institute of Medicine, 2002).

Because, as the report highlighted, the precise nature and impact of the association between the sociobehavioral sciences and the medicoclinical sciences could not be definitively characterized, medical research conducted and supported via the National Institutes of Health should begin to focus on elucidating this knowledge in addition to understanding the biology of disease. To this end, the director of the Office of Behavioral and Social Science Research at the National Institutes of Health requested assistance from the National Research Council (NRC) to develop a research plan to guide the NIH in supporting an integrative approach to health research (Singer & Ryff, 2001). The report entitled “New Horizons in Health: An Integrative Approach” articulated ten priority areas for research investment that would integrate the behavioral, social, and biomedical sciences into healthcare research. In their report the NRC recommended a focus on predis ease pathways or the identification of early and long-term biological, behavioral, psychological, and social precursors to disease. It was also recommended that a focus on the identification of biological, behavioral, psychological, and social factors that contribute to health and resilience, not just disease, morbidity and mortality would likely yield insights not possible using a deficit model of health. It was recommended that there should be an emphasis on environmentally induced gene expression. Such a focus carried the promise of significantly enhancing our understanding of the links between recently derived molecular genetic processes and biological, behavioral, psychological, and social realities. Finally, the NRC recommended a distinct focus on the impact of aggregate neighborhood, community-level, and larger population-level factors on health and healthcare outcomes.

Due to the significant scope of each of these recommendations, there existed the potential to lose focus on the healthcare disparities issue. Thus the NRC recommended that a specific focus on inequalities in health and specifically on interventions to address these inequalities be maintained in healthcare research. Also, because many of these recommendations represented fairly radical departures from the status quo in health care and biomedical research, the NRC recommended a focus on new multilevel, integrative evaluative methodologies, and study designs as well as a focus on the development of a new type of clinical researcher, one who
possesses the necessary skills and aptitude to conduct this type of integrative and transdisciplinary work (Singer & Ryff, 2001).

The culmination of work on quality and healthcare disparities came with the 2003 release of a report entitled “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care” (Smedley et al., 2003). In this report, the IOM Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care was specifically charged with assessing the extent and potential sources of racial and ethnic disparities in health care that are not otherwise attributable to access to care, ability to pay, or insurance coverage. The committee was also to provide recommendations regarding potential interventions to eliminate these healthcare disparities (Smedley et al.). The committee found evidence that, within the US, even among the middle class and individuals with access to health care, racial and ethnic disparities indeed existed. In some cases these disparities were increasing and were likely related to patient factors, provider factors, socio-economic factors, and broader factors related to historic and contemporary race-based bias (Smedley et al.). These disparities were, with few exceptions, remarkably consistent across a wide range of illnesses and healthcare services including cardiovascular disease, cancer, end stage renal disease, diabetes care, kidney transplantation, pediatric care, maternal and child health, mental health, rehabilitative and nursing home services, and many surgical services (Smedley et al.). In a few cases the committee found that minorities were actually more likely than Whites to experience certain procedures (bilateral orchiectomy, leg amputations) and that there was little evidence that these disparities were the result of patient preferences (Smedley et al.).

**Time Trends and Recent Data**

Even before the release of the IOM reports, the US congress became involved by passing the Healthcare Research and Quality Act of 1999 which directed the Agency for Healthcare Research and Quality (AHRQ) to develop an annual National Healthcare Quality Report and an Annual National Healthcare Disparities Report. Building on the IOM’s Quality Chasm report which outlined six dimensions of high-quality health care, AHRQ developed a disparities conceptual framework that incorporated these quality dimensions with special emphasis on the equity domain (Agency for Healthcare Research and Quality, 2003).

To date, four annual reports have been released, with the first becoming available in 2004. The initial report provided the baseline information needed for prospective evaluation of progress toward reducing healthcare disparities and for the first time measured the magnitude of these disparities from a national perspective (Agency for Healthcare Research and Quality, 2003). The major findings and conclusions of this first report include the demonstration that racial and ethnic healthcare disparities are a pervasive national problem affecting all parts of the healthcare continuum, across all diseases and medical conditions (Agency for Healthcare Research and
Quality, 2003). The report also found that healthcare disparities were associated with poorly managed care, avoidable complications, significant morbidity, disability, access to care barriers, and excessive personal and societal costs (Agency for Healthcare Research and Quality, 2003). The second report, released in 2004 largely echoed these findings, but also suggested that some areas appeared to have been improving including late stage breast cancer diagnoses and childhood immunization rates between Whites and African-Americans (Agency for Healthcare Research and Quality, 2004). In contrast, the 2005 report found that many of the gains outlined in the 2004 report were no longer improving while others were in fact getting worse. It also showed that low income individuals regardless of race or ethnicity often experienced the largest disparities in healthcare quality (Agency for Healthcare Research and Quality, 2005). Finally this report also suggested a need for a shift in national focus from merely documenting disparities to finding ways to reduce or eliminate the gaps (Agency for Healthcare Research and Quality, 2005). Not surprisingly the 2006 report also documented inconsistent improvements and some worsening in US healthcare disparities (Agency for Healthcare Research and Quality, 2006).

Summary

Over the last two decades research from several distinct lines of investigation have coalesced to underscore the relationship between medical care, biophysiological processes, sociocultural, and other environmental influences on healthcare outcomes generally and healthcare disparities specifically. In the early 1980s researchers examining variability in clinical practice patterns found nonrandom distributions in care across geographic locations. In the mid 1980s the report of the Secretary’s Task Forces on Black and Minority Health (Department of Health and Human Services, 1985) highlighted the fact that the health of Blacks and minorities significantly lagged behind that of Whites in the US. By the early 1990s large scale epidemiologic studies confirmed earlier findings of nonrandom distribution of clinical practice patterns and the association between substandard care and low income and minority patients. These early findings encouraged a focus on healthcare quality problems within the US healthcare system. Upon closer examination it was revealed that problems associated with quality and healthcare disparities were in fact linked and should be considered together. In the case of healthcare disparities, the recent clinical and technological advances that had been achieved appeared insufficient to guarantee the reduction of healthcare disparities. As such, efforts were undertaken to better clarify the impact of “nonmedical” communications and social factors on healthcare outcomes. These investigations highlighted the need to better integrate the biomedical and sociobehavioral disciplines in current health care and clinical practice to improve quality and address disparities among an increasingly diverse population. In addition, national efforts to document and quantify both the magnitude of the healthcare disparities and healthcare quality problems.
were needed. These evaluations documented the pervasiveness of healthcare disparities at all levels of health care. They also suggested that close to 100,000 people may die each year from healthcare quality related issues and medical errors. This spurred a significant amount of planning to develop interventions and monitor progress at the national level. To date, much has been accomplished to improve overall healthcare quality and healthcare disparities. While some quality indicators and healthcare disparities have improved several others have not and some even worsened. As such, while progress is occurring, more work needs to be done.

References


Several factors related to healthcare providers may be associated with healthcare disparities. Communication is fundamental to the healthcare process. Patient–provider communication is a multidimensional concept relating in part to both providers and patients. This chapter will discuss those aspects of patient–provider communication more closely related to the provider. Chapter 3 will discuss those patient–provider communication issues more closely related to patients.

Provider Communication

Most of the research being conducted prior to 1990 on the relationship between communication and healthcare outcomes came from European (British, Dutch, and American) studies with relatively little work conducted on other populations. In addition, the medical and communication models originating with these ethnic traditions considered the ideal doctor–patient relationship as somewhat paternalistic with the patients receiving and obeying medical instructions (Ong, de Haes, Hoos, & Lammes, 1995; Roter & Hall, 1993). Early investigators studied the technical or medical competency aspects of the doctor–patient visit, the degree to which the physicians responded to nonsomatic or psychosomatic issues and the degree to which open, secure, and workable relationships were established (Roter & Hall).

The motives underlying physician communication have also been studied. Provider motives have been defined as instrumental or socioemotional. Instrumental communication is communication that is focused on the so-called “cure” aspects of treatment (i.e., signs, symptoms, tests, treatments, side effects). Socioemotional communication is that communication that is focused on the so-called “care”-oriented behaviors (i.e., feelings, emotions, daily functioning, coping) (Ong et al., 1995). Most of the communications and health quality literature have focused on instrumental communication and particularly the information giving and seeking behaviors of doctors. These studies suggest that the amount of information given during the medical visit appears to increase as patient expressions of questioning and concern