


Discerning Disparities: The Data Gap

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Abstract

Health disparities that focus on gender and on the ancillary dependent variables of race and ethnicity reflect continually early illness, compromised quality of life, and often premature and preventable deaths. The inability of the nation to eliminate disparities also track along race and gender in communities where a limited number of health-care providers and policymakers identify as being from these traditionally underserved and marginalized population groups. Epidemiologists and other researchers and analysts have traditionally failed to integrate the social determinants of health and other variables known to support upward mobility in their predictive analyses of health status. The poor, and poor men of color particularly, begin a descent to invisibility and separation that has been witnessed since the early days of this nation. This history has the majority of men of color mired in poverty or near poverty and has more substantively and explicitly affected both American Indians and Africans forced into immigration into the United States and into slavery. Other racial and ethnic groups including large distinct ethnic groups of Asian Americans and Hispanics/Latinx do not have their treatment by systems fully reported from a health and social justice perspective simply because the systems do not disaggregate by race and ethnicity. It is axiomatic that examining disparities through the lens of race, ethnicity, and gender provides a unique opportunity to reflect upon what is known about boys' and men's health, particularly men from communities of color, and about payment systems. Integration of all populations into the enumeration of morbidity, mortality, and disparity indices is a dynamic reflection of the vision and exclusive actions of decision makers.

Keywords

marginalization, gender issues and sexual orientation, health inequality/disparity, health-care issues, health policy issues, men of color, special populations, quantitative research

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The nation first formally acknowledged that racial disparities existed in health status, a tacit admission that race, ethnicity, and poverty have a bearing on health status in this nation in 1985, with the release by the U.S. Department of Health and Human Services, under the leadership of Secretary Margaret Heckler, the Report of the Secretary's Task Force on Black and Minority Health (U.S. Department of Health and Human Services, 1985). The report gave urgency to the imperative for a fundamental shift in how health needs were determined, and services delivered. Even that report while vast in content, could not include the complete picture of gender-related health status because data sets from across all sectors that collect statistical information, particularly by race, ethnicity, and gender, were then and still are not now compiled into a complete portrait of health by race, ethnicity,

class, and significantly, gender. Consequently, decision making is not fully informed and inclusive of the needs of all, but upon who is counted, and by implication who is not. Yet, those not counted leave an indelible imprint on policy and practice.

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In this article, we provide an overview of data systems and their gaps as a fundamental flaw in assuring the health of men, particularly poor men and men of color. We discuss opportunities to assure more inclusive and comprehensive data collection including a potential tool that could be used. We end with a call for inclusive, comprehensive data collection as a critical step toward achieving equity.

Historical Parallel in Determining Who and What Counts

Concomitant with the release of the Heckler Report in 1985, the Public Health Service Task Force on Women's Health Issues concluded that the historical lack of research on women's health concerns compromised the quality of health information available to women as well as the health care they receive. Since the publication of that report, there has been a transformation in women's health research—including changes in government support of research, in policies, in regulations, and in infrastructure—that has resulted in the generation of new scientific knowledge about women's health. Offices of women's health have been established in a number of government agencies (Institute of Medicine, 2010). Government reports and reports from other organizations, including the Institute of Medicine (IOM), have highlighted the need for, and tracked the progress of, the inclusion of women in health research (Institute of Medicine, 2010). A number of nongovernment organizations have also provided leadership in research in women's health. And women as advocates, research subjects, researchers, clinicians, administrators, and U.S. representatives and senators have played a major role in building a women's health movement.

During the preparation of the Institute of Medicine report, the Patient Protection and Affordable Care Act of 2010 (Public Law 111-148) was passed, which formally codified the Offices of Women's Health within the Department of Health and Human Services (HHS). The Act also formally established an Office of Women's Health in the Directors' Office of the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the Food and Drug Administration, the Health Resources and Services Administration, the Substance Abuse and Mental Health Services Administration; an HHS Coordinating Committee on Women's Health; and the National Women's Health Information Center. Notably, many of the conditions that the IOM committee reviewed are more common or have poorer outcomes in women who are socially disadvantaged than in women who are not. The conditions reviewed include three diseases on which there has been major

progress—breast cancer, cardiovascular disease, and cervical cancer (Institute of Medicine, 2010). The fact that subgroups of women are not benefiting from the progress that has been made could indicate that the most relevant groups, the groups that have the greatest burden of disease, are not being adequately studied and research results are not being translated into practice and policies germane to them. While women's health is not a focus of this examination of epidemiological practices, this may be a further example of who is counted and who is not, with no rationale other than historical exclusion based on race and ethnicity.

Correcting a False Narrative of Progress: African American Boys and Men as Proxy

In 2018, 33 years later after the release of the Heckler Report, though much has been published describing disparities, little has occurred to improve the health of poor boys and men and specifically the health of poor boys and men of color. Data methodology and systems used to assess and address disparities have not evolved in a manner that supports comprehensive inclusive policymaking. The imperfect processes and tools have continued to separate and segregate poor, underserved boys and men as no comprehensive portrait of their health and well-being exists. The potential for systems reform that will improve the health of all may well lie in finding solutions to the health-care needs of those most marginalized historically and contemporarily.

Major Data Gathering Agencies and Processes: The Bureau of Census

The most relied upon source for information on the health of the U.S. population is produced by the United States Bureau of the Census (<https://www.census.gov/topics/health/about.html>). The Census Bureau processes are often politicized and critiqued due to: who is excluded from their data products, which definitions of race and ethnicity are used, and the lack of data on individuals who have no stable residence. Current efforts to add questions relating to citizenship will likely further compromise data collection, particularly in families with mixed status. Since revenue allocation is often based on geographic population size, some communities (often located in rural areas) benefit disproportionately because of large prisons or jails which serve as de facto economic development schemes. This diverts resources that could otherwise be made available to develop an equitable health system or deploy resources that may reduce those variables that contribute inordinately to risk-taking behaviors, if other factors or measures were taken into account.

The Trouble With the Numbers That Guide Policy: One Example

The sociologist Becky Pettit reports that at any given time between 1925 and the mid-1970s, about 100 per 100,000 Americans were in state and federal prisons (Pettit & Western, 2004). Since then the imprisonment rate has jumped to 512 per 100,000 if inmates in local jails are included in the count. Some 2.3 million Americans are currently incarcerated and the nation's incarceration rate is 768 per 100,000, the highest in the world. The probability of incarceration varies strikingly by sex, race, age, and education level (Pettit & Western, 2004). Pettit, a sociologist trained in demographic methods, calculates that in 2008 an astonishing 37% of Black men aged 20–34 with less than a high school education were incarcerated, as were over 11% of all Black men in that age group (Pettit & Western, 2004). During the recession year of 2008, Black male high school dropouts were more likely to be in jail or prison than employed.

Pettit & Western, 2004, opcit notes that statistical portraits of the American population beyond those derived from census data trace their origins to 1939 when the Division of Research of the Work Projects Administration conducted its first monthly “Sample Survey of Unemployment” (Frankel & Stock, 1942). Individuals living in households were sampled for this survey, and a decision was made to exclude those living in institutions such as hospitals, prisons, and jails. In 1947, this monthly survey was renamed the Current Population Survey, and its exclusive focus on individuals living in households continues to this day. In fact, nearly all federal sample surveys of the population use a similar household sampling frame, including the American Community Survey. Social scientists commonly have portrayed the social, economic, political, and health conditions of the U.S. population largely on the basis of such household data, a process that made “invisible” the aforementioned 37% of young Black men with less than a high school education who were incarcerated.

Pettit contends that most contemporary accounts of the educational attainment, economic well-being, political participation, and social integration of African American men are inaccurate and present a false illusion of Black progress. For instance, Pettit calculates that Black men's wages as a percentage of White men's wages fell from 52% in 1980 to 28% in 2008 if one includes all men in the base, including the unemployed and the incarcerated. When analysts use standard social survey data that exclude the incarcerated, Black men (especially young Black men) appear to be improving their economic position compared to White men. Pettit highlights how mass incarceration has reached such high levels that it no longer allows social scientists to rely on standard household survey data to

produce accurate descriptions of national sociodemographic trends.

Other Taxpayer Data Sources That Should Guide Policy

Multiple other agencies and systems are taxpayer supported to assess and report health status. The Centers for Disease Control produces vital statistics through the National Vital Statistics system, and other health measures based upon the National Health and Nutrition Examination Survey (NHANES), the National Health Interview Survey (NHIS), and the Behavioral Risk Factor Surveillance Survey (BRFSS). The Agency for Health Research and Quality (AHRQ) measures health system performance, but does not include prison health systems as a part of its mandate. Another significant data source that tracks the quality of care is the Healthcare Effectiveness Data and Information Set (HEDIS), though the lack of application to prison health care restricts its findings as it is not inclusive of all systems that deliver health care to the American public.

Significant information is collected by the Center for Medicare and Medicaid Services (CMS) that is used to drive performance and quality for those beneficiaries. However, many poor men do not have Medicaid coverage and there are significant disparities in Medicaid coverage by race and ethnicity. System-wide data do not contain information to guide service design and delivery for poor men or men of color. For poor men, the exception is the Supplemental Security Disability Insurance (DI) program. African Americans have higher rates of disability and consequently are more likely to receive benefits from the Social Security Disability Insurance (DI) program. African Americans comprise approximately 12% of the American population but represent 20% of DI beneficiaries (National Committee to Preserve Social Security & Medicare, 2018).

Rejecting Exclusion: Designing Meaningful Comprehensive Fact-Finding Instruments

There exists a unique opportunity to focus on select populations that demonstrate high morbidity, mortality, and general lack of access to preventive primary health care. Race, ethnicity, and gender coalesce in the African American male population to produce high levels of chronic disease as well as the highest rates of preventable mortality. These individuals have their best chance to receive health care, if they are poor, in the criminal justice system. The Eight Amendment to the U.S. Constitution does guarantee access to care though Makrides and Shulman (2017) report that “little is known about the

health status of inmates as few nationally representative data sets available.”

The National Academy of Medicine's Vital Directions for Health and Health Care Priorities report uses the words “disparities” and “equity” once (Dzau et al., 2017). This report proposes a transformation of the nation's health system, but does not articulate or describe a clear path forward to address “hidden populations” that are missing due to the lack of information on our entire population. The report specifically does not recognize individuals who are homeless, unable or not permitted to work, or who live in the margins of society. Current population and systems analytic approaches sum make invisible the demographic divides that are imposed by race, poverty, personal circumstance including years of incarceration or legal status in the United States, homelessness, those exiting foster care with no adult guidance or family, and other variables.

The Others: Major Reservoirs of Data That Do Not Inform the Whole

The office of veterans affairs. The Office of Veterans Affairs (VA) is a reservoir of data that can contribute to the portrait of disparity among those returning to family and community. Racial/ethnic minorities are nearly 25% of all veterans (VA Office of Health Equity, 2016). Compared to the general population, veterans are older, sicker, and more likely to suffer from mental and behavioral illness (Ibrahim, 2018). The VA, despite its focus on preventive care and access to a patient-centered health-care home, has not eliminated disparities in chronic conditions such as diabetes or strokes (Peterson et al., 2018). According to Petersen et al. (2018), the inability to draw strong conclusions about disparities among veterans by race, gender, and condition is limited by single studies with imprecise findings. There are no cumulative studies that assess by race and gender the complete health profile of an individual.

The vast systems for collecting data span states, private and philanthropic organizations, health delivery agencies, and others. All of these contribute to the development and measurement of health system performance and to efforts such as Healthy People 2020 and other massive reports (<https://www.healthypeople.gov/2020/data-search/Data-Sources>) designed to illustrate the health of our nation's populations. Regardless of these efforts, nowhere is there a cogent portrait of the health status of poor men by race and ethnicity; more specifically, there is no cogent portrait of poor men (and boys) of color, despite the additional impact of race and racism on their general social and health status (Krieger, 2014; Morales, Lara, Kington, Valdez, & Escarce, 2002) all of which are compounded by their lack of trust in health

systems (Richardson, Allen, Xiao, & Vallone, 2012). Trust is a metaphor for fear of being discriminated against based on many things including the infamous Tuskegee Study (<https://www.cdc.gov/tuskegee/timeline.htm>). The data that we do have isolate the physical status and physiological factors from the social status and sociological assaults on health and sense of well-being. Poverty breeds illness. To cure illness, the social determinants of health that include interpersonal interactions must also be addressed (Krieger, 2007; Treadwell & Ro, 2003).

In their article “Causes and Causes of Causes of Population Health: A Public Health of Consequence,” Galea and Vaughn state that “social conditions may be the cause of causes and that more attention must be given to those when summarizing and integrating data that frame policy and practice” (Galea & Vaughan, 2018). Their research highlights the importance of counting not only the apparent health disparity but of also examining qualitatively and quantitatively the individual holistically in his or her environmental niche and context to determine appropriate interventions.

The criminal justice system. The absence of data integrated into other systems to foster a complete profile of health and wellness, morbidity, and mortality is most apparent among individuals who are incarcerated in jails, prisons, and other detention centers in the United States. This data segregated from other population data discussed above eliminate from policy deliberation the health and well-being of hundreds of thousands of individuals who are captured by the criminal justice system. These captured individuals are predominantly poor men of color in numbers disproportionate to their representation in the overall population. The Bureau of Justice does collect information on the health status and health-care needs of those in federal and state prisons and in jails using the National Inmate Survey, as a part of the Prison Rape Elimination Act (Public Law 108-79) when funding permits. These data primarily focus on sexual harassment or assaults in incarceration and do not probe beyond educational level and marital status, other social factors that may be important when case managers seek sustainable outplacement into home, neighborhood, and community (Maruschak, Berzofsky, & Unangst, 2015). These significant, though incomplete, data capture and reflect primarily the sexual history of poor men (and women) which are not integrated with the data on the rest of the U.S. population. The majority of those incarcerated are released back into their communities without health insurance and become dependent on local health systems that have not factored their needs into service and payment programs (The National Reentry Resource Center, 2018). While federal, state, county, and city entities all wall off data of those in prison, there appears to be lack of recognition is that the

“wall” of the prison is really a porous membrane and individuals filter back and forth, taking their illnesses with them back into their families and community or conversely, back into detention and incarceration. This movement, mobility of individuals and illnesses, indicates that integration (versus segregation) of data is mandatory.

What is not embedded within the fractious and fragmented purportedly nationally representative data collection systems, portrait of America’s health and well-being, are facts and figures that are collected from the criminal justice system that houses well over 2 million individuals per year in federal, state, and county prisons, and in jails and youth detention centers operated by cities and counties across the nation per year. Even the total numbers of those incarcerated is not known, though much is known about the racial and ethnic disparity among those behind the fence. Adding to the numbers are those incarcerated for reported violations of the nation’s immigration policies. These detainees are protected, in theory, from cruel and unusual punishment under the 8th Amendment to the U.S. Constitution. Many of these individuals have poor health and have had limited health care before incarceration and detention. Systems external to the criminal justice system have no mandate that compels that they pay attention to and provide gender-based health care to boys (over 18) and men in this nation. Further, the systems overall are ill-informed by the very data collection systems that provide the data upon which policy is promulgated.

Potential Opportunity Through the Lens of Population Health

Regardless of the source or agency reporting data, reports silo illnesses as if these may not be connected to or are a result of interactive physiological issues or issues in the socioeconomic context that may be more endemic in some racial, ethnic, gender categories. Data reports also often obscure the differences that are vested in race, ethnicity, and most importantly gender. Population-based medicine that assesses by discrete population is not manifest or embraced as an integral value in documents that guide policy dialogue and formulation. The conundrum is that the current egalitarian systems separate by virtue of lack of inclusion, populations that are not equal in opportunity or access to care.

Traction may be building at the federal level for supporting the transformation of health and human services, at two levels: first connecting the head back to the body by focusing on the integration of physical and mental health (they seem to leave out for unexplained reasons teeth/oral); and second, building linkages and bridges

between health care and the social determinants of health. An example of a sense of new directions can be found in the Center for Medicare and Medicaid Services (CMS) funding of the Accountable Health Communities which puts screening, referral, and outreach systems in place. At the core of each of these efforts is the need for linked integrated data. From a prevention perspective, a linked integrated data system that captures both risk and protective factors would present a better chance of eliminating disparities. At issue is who should comprise a population health panel? One could reasonably argue that those experiencing the greatest disparities represent the greatest opportunity to achieve the triple aim of improved care resulting in better health outcomes at reduced cost (Berwick, Nolan, & Whittington, 2008). Hence the focus on men of color and more so, particularly on young men of color is prescient..

Underutilized Resources That Could Make a Difference

Healthy People 2020 provides numerous indicators that can be analyzed, but one can surmise correctly that men of color are likely to experience the greatest disparities. Despite the goals of having a national health agenda, we are overlooking the obvious and continue to be inextricably linked to discriminatory practices when we fail to collect and examine data by race and gender.

The Office of Minority Health that is embedded in each federal agency potentially has the ability to guide a course correction with regard to data collection and perhaps providing funding to reshape what and how data are collected and analyzed. The guidance with regard to addressing disparities and developing information via modification of the numerous surveys that are already administered each year, at great expense to taxpayers, continues to produce exclusionary reports.

Why We Can’t Wait: The Compelling Demographic Shift

Racial and ethnic minorities, some of whom are soon to be majority in some areas, have historically experienced marginalization in the United States (American Psychological Association, 2018). Immigration has played a key role in these racial/ethnic changes, putting the United States on a path to become “majority minority” by 2043. And, as the Kaiser Family Foundation notes, “As the population becomes more diverse, with people of color projected to account for over half of the population in 2045, it is increasingly important to address health disparities as these drive unnecessary costs” (Ubri & Artiga, 2016).

What Should We Ask to Support Change Making and Improved Health?

A major challenge is the absence of standard data collection and reporting formats that can be used across institutions and jurisdiction to insure compatibility of data collected to facilitate analysis and report generation. The Morehouse School of Medicine, in collaboration with Correct Care Solutions, a for-profit public health-care system, has developed an instrument for the collection of comprehensive information that can guide integrated whole-person care (see Supplemental Exhibit 1). The instrument development was informed by case workers from the Office of the Public Defender and others in Fulton County Criminal Justice system. Data collected through this instrument are meant to be an integral component of the health record so that both health and social service needs can be identified, and issues simultaneously addressed. In addition, information on family status, including numbers of children, is included as child support issues impact both incarceration due to lack of payment the need for legal services and income.

The instrument includes an assessment of housing and homelessness, mental health, substance abuse including types of drugs involved, job training/educational needs, source of regular health care, oral health needs, employment, medication (if any), and any other items that the individual might identify. Also included are conditions including self-reported diabetes, hearing problem, hepatitis, HIV, respiratory problems, among others. The overarching commitment is to assess an individual consistent with his or her total reality. By having standardized profiles, it is possible to intuit courses of interventions that incorporate all aspects of health, healing, and well-being.

Discussion

The case for placing a spotlight on gender differences in health care, status, and use has been made by the Kaiser Family Foundation (The Henry J. Kaiser Family Foundation, 2015). The report affirms that uninsured and low-income men face cost-related barriers to care and have difficulties paying the health-care-related bills. The report addresses disparity issues related to access to care by oversampling African Americans and Hispanics; however, it does not include institutionalized populations without access to landlines or cell phones. Epidemiology that does not depict the plight of poor boys and men as being constrained in health-seeking behaviors due to poverty or low-income is misleading and contributes to the invisibility of this very vulnerable population (Krieger, 2014).

It is evident that there is a lack of comprehensive transformative data that can guide the framing of future research, service design, interventions, and inclusive public policy. Establishing an Office of Men's Health may

well be an idea whose time has come. The success of the NAM/IOM study that resulted in the formation of an Office of Women's Health provides a template for performing similar work in the interest of boys and men, particularly poor men and boys. Deliberate effort must be made to ensure that those most at risk of poor health and poor health outcomes are intentionally included and sampled, perhaps over-sampled, given the lack of current knowledge.

The absence of a study of men's health along racial and ethnic lines may be embedded in a lack of political will and commitment by public policymakers to address health disparities and the lack of gender health equity. There may also be a perception by some that males are already the major beneficiaries of societal benefits. Those perspectives, perhaps embedded in feminist discussions, fail to take into account the devastating impact of race and racism on boys and men of color. It is time to rethink and seriously consider an Office of Men's Health as all men are not equal in this nation with regard to income and opportunity.

A Catalyst for Change is Focused Funding

Nothing happens without special focus and funding. An effort to reform epidemiological practice that will produce what needs to be known in order to protect the nation's health is an idea whose time has come. The traditional and current analytic practices have not produced health equity and health justice. It is time for a change. Some attempts to utilize de novo methods of data collection and analysis are extant. For example, Washington's Department of Social and Human Services has developed an integrated data hub that is designed to link medical, social service, housing, criminal justice, and other data so that reports can be generated on specific populations, such as youth exiting foster care or individuals with behavioral health conditions (Washington State Department of Social and Health Services, 2018).

Philanthropy has been engaged to a degree in addressing the data gaps, as exemplified through the Robert Wood Johnson Foundation's Data Across Sectors for Health (DASH) program. More is needed and funding for a pilot statewide initiative that includes public and private funding may assist. Clearly, several steps can be taken to rethink what data should be collected and integrated in order to identify disparities with respect to social context and to design comprehensive wrap-around interventions to improve health. What may need to occur a priori is a firm commitment to inclusion and to illuminating the role of the social determinants on gender-based health disparities. Finally, federal agencies must develop performance measures to eliminate disparities that necessitate uniform data collection across sectors and reporting findings by race, ethnicity, and gender.

Conclusion

Addressing racial disparities is a persistent challenge for the health care system. Without reformed data collection processes and analysis, it will be difficult both to pinpoint the issues, identify those populations at greatest risk for disparities, and remove the drivers of poor health among poor men and poor men of color. Most of what is known is about the African American population as it has been studied, to a degree, for the longest period of time though not across sectors. While many small studies examine issues that appear to be endemic to underserved populations (namely, HIV, diabetes, prostate cancer), the approaches to solutions are still predominantly siloed by disease and/or profession. Collecting information on the individual within the context of his environment will enable implementation of strategies that not only eliminate disparities but that simultaneously foster in an age of health equity and health and social justice.

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