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Not Separate but Still Unequal: Disparities, Invisibility and Bias in Access and Quality of Health Care in Michigan



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ABSTRACT

Current research points to race and ethnicity as predictive of disparities in access and quality of health care. A 2002 Institute of Medicine Study found that African-American patients tend not to receive the same type of care as White patients, even when controlling for socioeconomic status. Self-reported perceptions of racial bias within the patient provider relationship, from the patient's perspective, are analyzed to uncover the subtle ways perceptions of differential treatment based on racial bias work to create barriers or perpetuate disparities in health outcomes for African-American breast cancer survivors in Michigan.

Introduction

Breast cancer, like other forms of cancer, is an equal opportunity killer. Cancer cells pay no attention to the race or ethnicity of the body in which they reside. Cancer cells do not care about the biology or genetics of the body they inhabit. They go about their divisions, invisible to detection, until they have created a critical mass identifiable with current diagnostic tools. When it comes to mortality from breast cancer, despite 40 years of civil rights struggles in America, this equal opportunity killer may take an unwittingly given advantage, cloaked in the guise of racial bias, and thereby ravage African-American women's lives unequally.

This study seeks to discover if perceptions of racial bias directed towards African-American breast cancer survivors by health care providers is contributing to the measured disparities in health outcomes. While it is likely that racial bias is not the only factor contributing to higher mortality rates for African-American women diagnosed with breast cancer as compared to White women, current evidence points to race and ethnicity as predictive of disparities in access and quality of health care despite socioeconomic status (Smedley, Stith, & Nelson, 2003). A 2002 Institute of Medicine Study found that African-American patients of similar socioeconomic status tend to receive lower quality treatments than White patients (Dept. of Health and Human Services, 2003, p.4). The American Cancer Society states, "additional factors that contribute to the survival differential include unequal access to medical care and a higher prevalence of coexisting medical conditions" (American Cancer Society, 2004, p. 20). Other studies, however, point to additional persistent barriers even in the absence of financial constraints (Arbelaez, Cooper, & Saha, 2003, p. 1713). According to National Cancer



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Institute data, death rates for African-American women are higher than for White women at all age ranges (National Cancer Institute, 2000). Disparities in outcomes, with deadly consequences for African-American women, can be seen in the five-year survival rates of the disease. Data from the Surveillance, Epidemiological, and End Results (SEER) cancer registries, between the years 1992-1998, document five-year survival rates for White women at 87.6 per 100,000 and African-American women's five-year survival rate at 72.5 per 100,000 for the same span of time. During the years 1979 to 1996, the rates of breast cancer actually declined for White women, but African-American women and other women of color did not experience any decline in the rate of the disease during the same period of time (Layde & Marabella, 2001, p. 120).

Despite these significant disparities in health outcomes for African-American breast cancer survivors, many White Americans are unaware of the inequalities in access to health care. Researchers conducting a recent poll commissioned by Harvard Forums on Health found that African Americans and Hispanics living in the United States are much more likely to recognize that minorities do not always have an equal level of health care (Late, 2003, p. 1). The same poll found that many White Americans are unaware that such disparities exist. In fact, the researchers found that 57 percent of African Americans and 49 percent of Hispanics felt health care providers treated minorities differently (Late, p.1)

Context for Proposed Study

This study hopes to contribute to the ongoing dialogue between researchers looking at ameliorating disparate health outcomes for African-American breast cancer survivors. Allowing women to speak in their own words of their experiences during treatment may

elucidate patterns in healthcare delivery that may be negatively influencing outcomes. Perceptions matter.

Perceptions of bias, aside from adding to the cognitive load women need to manage, may compound the unequal brunt of disease borne by women who are already fighting for their lives.

This study addressed issues that are difficult for some to talk about: breast cancer and racial bias. Breast cancer was not mentioned publicly until the 1980s, and racism is a topic that is often unaddressed, despite its harmful mental and physical consequences. Racism is not a subject that is discussed dispassionately, nor should it be. This study hopes to help break the silence and push for an ongoing, thoughtful dialogue about how intentional or unintentional racism may be contributing to the disparities in outcomes for African-American breast cancer survivors. Perhaps, because there is no intent, White providers may be unable to "see" racism and the biased assumptions and actions that may flow from this mindset. People of color, however, are aware of the bias because they experience its effects. This racism invisible—intentional or not—may have deadly implications for delivery of quality care. This study does not seek to castigate healthcare providers; this study asks these questions to raise awareness and start a dialogue about how this racism may be telegraphed, intended or not, to African-American women who are being treated for breast cancer.

According to Dr. Lisa Ikemoto (2003), "provider bias can directly translate into less effective health care for patients of color" (p. 96). A study conducted by Kevin Schulman in 1999 (Schulman as cited in Ikemoto, p. 96) surveyed seven hundred and twenty primary care physicians who took part in video interviews with actors portraying male and female, black and white patients. Physicians referred African-American

women at the lowest overall rates. The critical race theorist Paul Kivel argues that we should assume that racism is at least a part of the picture in self-reports of racial bias, and "in light of this assumption, we should look for the patterns involved rather than treating most events as isolated occurrences" (Kivel as cited in Rothenberg, 2002, p.128). Ikemoto maintains that health care providers trumpeting of the values of "objectivity and universalism do not shield them from the racism, nativism, and ethnocentrism inherent in dominate culture" (Ikemoto, p. 97).

Scope

The lifetime, national risk for breast cancer in women is one in seven (American Cancer Society, 2004, p.19). The lifetime risk of breast cancer in Michigan is similar to national rates. Each year over 7,000 women are diagnosed with breast cancer and 1,400 women die of the disease (Olszewski & Wisdom, 2004, p. 20). Breast cancer is second to heart disease as the leading causes of death and, on average, results in a loss of 18.4 years of life to women (Olszewski & Wisdom, p. 20). African-American women have a lower incident rate of breast cancer compared to White women; however, African-American women have a significantly higher mortality rate from the disease (Olszewski & Wisdom, p. 20). African-American women have a 36.9 per 100,000 rate of mortality nationally and 35.9 per 100,000 rate of mortality in Michigan, as compared to White women who have a 27.2 per 100,000 national death rate and a 27.3 per 100,000 death rate in Michigan (CDC, 2003, p. 2).

Breast cancer is not preventable; but, if it is detected and treated early, outcomes improve significantly, which leads to reduced mortality and increased survival time (Olszewski & Wisdom, 2004, p. 20). One of the most deadly outcomes for African-American women

with breast cancer is the fact that African-American women are diagnosed at distant or later stages of the disease 42.3 percent of the time, compared to White women at 29 percent (Olszewski & Wisdom p. 20). A late diagnosis of breast cancer not only subjects women to longer and more toxic treatment regimens, late diagnoses rob women of years of life. The overall survival rate for African-American women is 73.5 percent compared to 88 percent for Whites (Olszewski & Wisdom, p. 21). Another disparity in health care, which may contribute to poorer outcomes for African-American breast cancer survivors, is the fact that African-American women are under-represented in clinical trials of cancer drugs and treatment regimens. Another alarming trend, according to a recent study, found that “the proportion of trial participants who are black has declined in recent years” (Murthy, Krumholz, Cary, & Gross, 2004, p. 2726).

Other than age, more than 80 percent of breast cancers have no known risk factors (Olszewski & Wisdom, 2004, p. 20). Less than 10 percent of breast cancer is due to inherited genes (Burstein, Miller, & Mocharnuk, 2002, p. 3). The remaining 90 to 95 percent of breast cancers happen randomly (Burstein, Miller, & Mocharnuk, p. 3).

Hypotheses

While the factors contributing to disparities for African-American women’s experiences with this disease are likely to be multifaceted, this study seeks to examine only a small piece of the puzzle. This study seeks to uncover how perceptions of bias operating within the patient provider relationship may be contributing to the late diagnosis and poor prognosis for African-American women with breast cancer. While most healthcare providers believe prejudice and discrimination to be “morally abhorrent and at odds with their

professional values, healthcare providers, like other members of society, may not recognize manifestations of prejudice in their own behavior” (Smedley, Stith & Nelson, 2002, p. 162). Therefore, with the idea that subtle perceptions of bias could be contributing to poor health outcomes for African-American women with breast cancer, this proposed study seeks to ask the following:

- Does the perception of provider bias change the care seeking behavior of African-American women or influence the importance the women place on preventative mammogram screening in the first place?
- Does racial bias work to limit physician recommendations for follow-up screening or further investigation such as biopsy of African-American women?
- Do perceptions of bias create barriers for African-American women in access or compliance with appropriate adjuvant therapy?

Methods

My research project began by identifying African-American breast cancer survivors who were diagnosed and treated for cancer while living in Michigan. Several phone calls were made to network with women to identify survivors willing to either take part in an interview or complete a questionnaire for this study. Two breast cancer survivor support groups were contacted to solicit volunteers.

Seventy questionnaires were mailed or emailed to breast cancer survivors, and four completed questionnaires were returned to me. Four women took part in face-to-face interviews. The same questionnaire was used for both the survey and the interviews.

The questionnaire included a series of open and closed questions to explore the women’s perceptions of bias while undergoing care. Questions were asked to determine if perceptions of bias limited care seeking, compliance, or other health-related behaviors. To control for lack of insurance coverage, only women with some insurance coverage were included in the sample. The age ranges were confined to women who are between 35 to 65 years old, and socioeconomic status information was gathered using questions addressing yearly income, occupation, and number of years of educational attainment. The women must have received medical treatment for breast cancer in Michigan within the last ten years. Confidentiality was assured to each woman through a randomly assigned number. Questions were asked to identify and control for racial concordance between patients and providers. The sample was gathered using a snowball method, which is a way of gathering names of potential interviewees from the women who have already been contacted. Initially, the women will likely have been treated while living in similar geographical regions, but as the snowball expands, it will lead to women from various locales, which will control for regional differences in health care service providers.

While this is a qualitative study, insightful gleanings could serve as a guide to better conceptualized and tightly measured future studies. The purpose is to probe survivors for how perceptions of bias within the patient provider relationship may compound their diagnosis of cancer in ways that White survivors do not experience. Patterns within the reports of the women’s experiences will be identified to understand if subtle, verbal and nonverbal cues, are working to alter behavior, which may directly or indirectly be contributing to poor outcomes. The questionnaire probes for

knowledge of common age appropriate preventative screening services and unintended barriers of access to appropriate evidenced-based health care for these women. Questions probe for inappropriate comments, “gut feelings,” and personal experiences that the women perceive were in response to, or resulting from, their race.

Definitions

For the purpose of this proposal, disparities will be defined as “differences in time spent trying to get healthcare, information about healthcare not being available in the same ways to different groups, quality or availability of insurance, transportation, and other factors that act as deterrents” (Casanas, Coello, Parsons, & Rocco, 2003, p. 39). Prejudice is defined in the realm of psychology as “an unjustified negative attitude based on a person’s group membership” (Smedley, Stith, & Nelson, 2002, p. 162). When prejudice is reasoned to be a valid individual worldview it is likely to become normative for that individual (Smedley, Stith, & Nelson, p. 162). For the purposes of this study, healthcare providers could be physicians, physician assistants, nurses, or other allied healthcare workers.

History of Health Care Inequality

Dr. Martin Luther King Jr. once said, “of all the forms of inequalities, injustice in health is the most shocking and the most inhumane” (cited in Farmer, 2003, p. 173). Despite the gains made for people of color since the start of the civil rights movement, disparities in health outcomes continue to this day. This issue is important from moral, personal, and economic perspectives. Disparities in health outcomes exact costs in dollars for all of us; however, people of color disproportionately pay with their lives. Disparities cause avoidable disabilities and escalations of poorly managed

chronic conditions result in expensive, avoidable complications, and may lead to increases in hospitalizations. This downward loop of worsening health leads to increased costs for the individual and for the public health programs many people depend on for health care (National Health Disparities Report, 2003. p. 6).

The idea of overt discrimination may seem alien to most people born after the civil rights struggles of the 1960s in the United States. Books and films shape knowledge of life in pre-civil rights America for many citizens. For others who lived it, the first-hand accounts are woven into familial history, shaped with each retelling of the day-to-day struggles for the basic human rights each American holds dear. Feagin and Sikes (1994, p. 204) report that one historic study of overt discrimination is the Tuskegee Study, which began in 1932. According to Feagin and Sikes, the American government promised 400 African-American men free treatment for “Bad Blood” a euphemism for syphilis. However, they report that medical treatment was withheld, and the study allowed the men to go untreated for syphilis four decades. No new drugs were tested and no effort was made to establish the benefits of any of the older forms of treatment.

A more recent study, conducted in 2000, found that doctors rated African-American patients as less intelligent, less educated, and less likely to comply with medical advice than White patients, even after income and education levels were controlled for (Smedley, Stith, & Nelson, 2002, p. 11). Another study found that African-American respondents were less likely to trust their doctors and more likely to trust their insurance plans (Boulware, Cooper, LaViest, & Ratner, 2003, p. 1). Additionally, studies show that African-American patients rank their doctor visits less participatory

when there is lack of racial concordance between patients and providers despite provider gender (Cooper-Patrick, et al. 1999, p. 588). Research does suggest, “provider’s diagnostic and treatment decisions, as well as feelings about patients, are influenced by patients’ race and ethnicity” (Smedley, Stith, & Nelson p. 11).

Support for the hypotheses of this proposal can be found in a study done in 2002, which suggests three possible mechanisms working to create disparate health outcomes as measured in minority patients. These mechanisms are located within the provider side of the exchange and include: “bias against minorities, greater clinical uncertainty when working with minority patients, and beliefs or stereotypes held by the provider about the behavior or health of minorities” (Smedley, Stith, & Nelson, 2002, p. 9). Studies show that minority patients are aware of the bias held by providers towards them, and recent studies report that minority patients feel they have lower quality interactions with their doctors (Arbelaez, Cooper, & Saha, 2003, p. 1713). The hypotheses of this proposal ask if patients’ awareness of provider bias holds implications for their health outcomes. A study that lends credence to the hypotheses of this proposal presents evidence that even “small numeric differences on perceptual measures can have important effects on health and health care” (Doescher, Fiscella, Franks, & Saver, 2000, p. 1161). This study found that a “1-point change in the medical skepticism score (range 1-5) was associated with an 11 percent increase in total mortality” (Doescher, Fiscella, Franks, & Saver, p. 1161).

Bias may be communicated in ways from providers to patients without the providers’ awareness that such attitudes are being projected. Bias may be overt and conscious, or may be unconscious, and due to origins which

“arise from virtually universal social categorization processes, bias may exist, often unconsciously, among people who strongly endorse egalitarian principles” (Smedley, Stith, & Nelson, 2002, p. 10). These same researchers have found that “socially conditioned implicit prejudice may be manifested in healthcare providers’ nonverbal behaviors reflecting anxiety (e.g., increased rate of blinking), aversion (e.g., reduced eye contact) or avoidance (e.g., more closed postures) when interacting with minority rather than white patients” (Smedley, Stith & Nelson, p. 162). This awareness of provider bias may perpetuate disparate health outcomes by working to alienate patients from the treatment decision-making process.

Racism is present in every day life and is obvious in popular culture (Hall, Harrell, & Taliaferro, 2003, p. 243). Racism is not only present in individual acts of bias and interpersonal discrimination, it is also present in the relationship between health and health outcomes (Hall, Harrell, & Taliaferro, p. 243). These acts of discrimination and interpersonal bias act as “salt in the wounds previously inflicted by a host of negative life events whose relationship to racism is often cloaked” (Hall, Harrell, & Taliaferro, p. 243).

Social cognition theorists study how people make sense of other people and the “processes that underlie social perception, social interaction, and social influence” (Fu & van Ryn, 2003, p. 248). Psychologists have focused on social cognition for several decades, which has resulted in a “massive body of evidence with significant implications for understanding how race/ethnicity influences provider behavior” (Fu & van Ryn, p. 248). Studies show that patient perceptions are important and do recognize that communication, both verbal and nonverbal, influence patient’s behavior (Cooper-Patrick, et al., 1999, p. 588).

With the knowledge of race and ethnicity as an influence of provider behavior, this study suggests that further investigation of how intentional or unintentional bias of providers works to create poorer health outcomes for African-American women. Studies show that African-American women are less likely to receive recommendations for mammography at age appropriate intervals (Fu & van Ryn, 2003, p. 252). Women who are less likely to receive recommendations for mammograms are more likely to be diagnosed at a later, less treatable stage of disease. Literature shows “that to a large extent, racial/ethnic bias differentials seen in staging are the result of lower screening rates” (Cutter & Jacobellis, 2002, p. 1148). According to the Physicians Insurers Association of America (as cited in Steyksal, 1996, p. 1), “the most expensive and common medico legal claim against physicians is delay in the diagnosis of breast cancer.”

There are many confounding factors within the study of disparities, including racial and gender patient/provider concordance, type of hospital or clinic or geographic variations, co-morbidities, and compliance with medical recommendations (Smedley, Stith, & Nelson, 2002, p. 42). Yet studies show that despite adjusting for all of these confounding factors, disparities in outcomes for African-Americans continue to predominate in cardiovascular care (Smedley, Stith, & Nelson, p. 42). Though most studies have examined racism and its contributions to disparities in cardiac care, fewer studies have examined the role of bias in relation to breast cancer. It is a logical question to ask if the same sort of mechanisms documented in disparate outcomes in heart disease could be contributing to disparate breast cancer outcomes.

Critical Race Theory, Social Constructs and Access to Quality Health Care

The impetus for this study is grounded in critical race theory. The disparities minorities face in access to quality health care, as compared to people in the majority population, grow out of historic and contemporary inequities (Smedley, Stith, & Nelson, 2004, p. 1). The complex tangle of health systems, administrative and bureaucratic processes and policies, as well as individual healthcare providers and patients they treat, coupled with the patient provider interactions, weave together to create a complex matrix that contribute to inequalities in treatment for minorities in the United States (Smedley, Stith, & Nelson, p. 1). This complex matrix also includes racial and ethnic stereotyping, bias, socioeconomic status, language, and cultural barriers, which work to limit access and quality of health care (Smedley, Stith, & Nelson, p. 1)

Critical race theory has grown out of examinations of the legal system of the 1970s in America. Legal scholars Derrick Bell and Richard Delgado began to challenge the slow pace of racial reform since the Civil Rights Movement of the 1960s (Jeris & McDowell, 2004, p. 82). The advances of the Civil Rights Movement have been legally challenged to this day in an attempt to disregard race for a “color-blind meritocracy” (Jeris & McDowell, p. 82). Critical race theory offers a broad social perspective for assessing the speed and direction of this country’s policies in relationship to race and has been used in education, law, and the social sciences as a lens with which to analyze historical power relationships between groups of people in this country (Jeris & McDowell, p. 82). Critical race theory recognizes the ongoing implications for people that have grown out of the legal history of this country’s racist past.

Dr. Harold Freeman, 1997 Chair of the President's Cancer Panel, quoting Albert Einstein, said, "What you see depends on where you stand" (Einstein as cited in Freeman, 1997, p. 2). Einstein made his remarks to describe the point of view from which scientists approach scientific investigation of race, which he knew all too well, are often shaped by social and political thought.

Because there is no language to describe the experience of racism or of growing up a minority in America, critical race theorists "attempt to inject the cultural viewpoints of people of color, derived from a common history of oppression" (Casanas, Coello, Parsons, & Rocco, 2003, p. 39).

The assumption that underlies critical race theory is the idea that many interactions of privilege that Whites take for granted happen without any conscious thought. In everyday interactions, the privileges and power of invisibility happen with no awareness of how these interactions might be different for those who do not share the same physical features. These privileges, apart from their intentions or conscious choices, influence lives in large and small ways. Whites do not often face racial profiling which affects, for example, the ability to move freely through a store without security people following, or driving a car without worrying if skin color will single the driver out for undue harassment by law enforcement.

Discussion

The women who took part in interviews (n=4) and responded to the questionnaire (n=4) reported experiencing no perceptions of racial bias during their treatment for cancer. Every woman reported being treated by healthcare providers of a race different from her own, and each woman responded that her relationships with healthcare providers were excellent. None of the women said they would be

more likely to talk about their health issues with a provider of the same race; this was true both in the questionnaire and within the interviews. The women all responded that they did not know how their care might improve if their healthcare providers were of the same race. The questionnaire respondents (QR) and the interviewees reported that the healthcare personnel they encountered always treated them with dignity and respect. They all responded that racism has not influenced the care they received.

All of the women reported that they were able to take all of the medications and follow all of the guidelines and recommendations for their illness. They all reported they were given ample time for questions, and they all felt they were well informed by their healthcare providers. Every woman reported having a primary caregiver and reported having trust in this person. The follow-up cycles varied for each woman, and they reported being seen by surgeons and oncologists. The QRs and interviewees were all in their early fifties when diagnosed, and none of the women reported any recurrences of disease.

It is interesting to note that the women who took part were at Stage I when diagnosed with cancer. The women were of similar socioeconomic backgrounds, worked in white-collar occupations, and all reported having some college education.

Limitations

The study design may have contributed to the non-findings. Perhaps women who have had negative experiences with healthcare providers are less likely to take part in the first place. Perhaps it is too frightening for women to consider perceptions of bias while being treated for a potentially life threatening disease. The questionnaire and interview question design was not pre-tested, and the questions chosen could be

altered to probe more deeply into the subtle interactions between patients and providers. Gender bias is likely to be a confounding issue and difficult to tease out within this study of perceptions of bias and health outcomes. All of the women who took part in this study were from similar education and socioeconomic backgrounds. Each woman was Stage I at diagnosis. It is important to note there is little regional variability among the women in the current sample. The small sample size offers a narrow snapshot of the range of interactions expected to be analyzed for this study.

In response to concerns about the bias that can occur when measures of health status are based on self-reports, Williams, Neighbors, and Jackson (2003) conducted a longitudinal study of African Americans which revealed that "no association between baseline measures of major depression or psychological distress and subsequent reports of racial discrimination" (p. 204). Researcher bias is another limitation, especially for the face-to-face interviews. A more robust study design is planned for winter 2005, which will include ethnographies of African-American and White survivor group meetings, to better capture the essence of patient provider relationship.

Conclusion

The data collected from the women who took part in this study does not uncover perceptions of bias within the patient provider relationship. This is more likely to be due to the study design than a conclusive finding. Researchers who conducted a study on discrimination in health outcomes recently concluded that, "one of the critically important issues for future research is to improve the assessment of discrimination in health studies" (Williams, Neighbors, & Jackson, 2003, p. 202). These researchers also acknowledge the serious

methodological issues and inadequate assessment of discrimination in health status in many studies, but states that “nonetheless, the consistency of the finding that discrimination is associated with higher rates of disease is quite robust” (Williams, Neighbors, & Jackson, p. 202).

As Dr. Sandra Harding (cited in National Cancer Institute, 1997, p. 14) said, “individual scientists can best avoid racist bias in their work by identifying their own values and studying the history, philosophy, and sociology of science; and since human values change slowly, the lessons of the past remain of great relevance.” Future research must strive to measure the way perceptions of discrimination adversely affect health behaviors and create negative emotional states, which may contribute to physiological responses and their subsequent impact on health (Williams, Neighbors, & Jackson, 2003, p. 205).

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