

Experiences and Perceptions of Medical Discrimination Among a Multiethnic Sample of Breast Cancer Patients in the Greater San Francisco Bay Area, California

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Breast cancer is the cancer most commonly diagnosed among women in the United States.¹ Racial/ethnic disparities in the survivorship experience, including diagnosis, treatment, quality-of-life, and survival, have been documented.²⁻⁵ For example, breast cancer survival differences between African Americans and non-Hispanic Whites are among the most striking and consistent of health disparities.¹ Research also suggests that certain racial/ethnic groups like African Americans, Latinas, and Asians are more likely to be diagnosed with late-stage disease.⁶⁻⁹ However, prognostic factors including socioeconomic status, access to care, and biological factors, to the extent that they have been examined, do not fully explain the observed differences.¹⁰ Research frameworks encompassing a multilevel framework that considers the interactions among social and biological factors, within a historical and ecological perspective (i.e., a socio-ecological framework¹¹) are needed to examine underlying institutional and societal forces that contribute to health disparities.¹²

There has been a growing interest in examining health impacts from discrimination,¹³ the process by which members of a defined social group are treated unfairly because of their membership in that group.¹⁴ For example, studies have suggested that racial minorities receive fewer referrals for specialty services and poorer quality health care than Whites, after controlling for a number of confounders including socioeconomic status, gender, age, health insurance, and stage of illness.¹⁵⁻¹⁷ Studies suggest that some of this may be the result of provider prejudice and medical mistrust on the part of the patient.^{15,16,18}

At least 3 pathways have been proposed by which discrimination may impact health. First, discrimination can lead to socioeconomic inequities, which can affect health (e.g.,

Objectives. We conducted qualitative interviews with breast cancer survivors to identify themes related to institutional, personally mediated, and internalized discrimination in the medical setting.

Methods. We conducted 7 focus groups and 23 one-on-one interviews with a multiethnic sample of breast cancer survivors randomly selected from a population-based registry covering the Greater San Francisco Bay Area, California.

Results. Participants reported experiencing different forms of medical discrimination related to class, race, and language. Among African Americans, participants reported experiencing internalized discrimination and personal or group discrimination discrepancy—perceiving discrimination against them as a racial/ethnic group, yet not perceiving or discussing personal experiences of discrimination. Among Asian immigrants, participants reported experiencing institutional and personally mediated overt types of discrimination, including lack of access to quality and readily available translation services. Our results also indicated well-established coping mechanisms in response to discrimination experiences in both groups.

Conclusions. Participants reported experiencing medical discrimination at all 3 levels, which may have deleterious health effects through the biopsychosocial stress pathway and through active coping mechanisms that could lead to delayed- or underutilization of the health care system to avoid discrimination. (*Am J Public Health.* 2012;102:1027–1034. doi:10.2105/AJPH.2011.300554)

compromising access to care and quality of care and causing disproportionate environmental exposures to toxins). Second, discrimination can increase chronic stress. Chronic and severe social stress trigger the stress-response system, activating adaptive physiologic mechanisms, which, over time, degrades the body's ability to properly regulate biological systems, resulting in adverse health consequences.^{19,20} Increasingly, studies have shown that exposure to racial discrimination is associated with numerous physiological disturbances,²¹ including overcirculation of stress hormones,²² which, among other outcomes, is linked to an uninhibited inflammatory response.²³ Chronic inflammation has been associated with breast cancer recurrence and mortality.²⁴

Third, discrimination can restrict access to goods and services. Discrimination experienced

in health care settings may inadvertently influence individuals to avoid using needed health care.²⁵ The psychological model of stigma-induced identity threat posits that an individual who has experienced discrimination that threatens his or her identity will have involuntary responses (e.g., anxiety and vigilance).²⁶ In turn, the individual may engage in a variety of voluntary coping mechanisms, including engagement (i.e., fight) or disengagement (i.e., flight) strategies. In accordance with the disengagement strategy, an individual who has experienced discrimination may avoid mainstream institutions, such as the health care system, where they fear they may be discriminated against. African Americans, Latinas, and Asians have been found to report more medical mistrust²⁷ and provider discrimination, which is associated with lower satisfaction with

care^{28,29} and delayed health utilization.³⁰ Some studies have found an association among perceived discrimination, screening mammography,^{31,32} and health care utilization.^{33,34} As mentioned previously, discrimination may also restrict health care services because of provider bias and differences in referral for specialty services.^{16,18}

Whereas there is growing research on the subject of whether discrimination influences health,^{21,35–42} few studies have investigated the link between discrimination and breast cancer,⁴³ although plausible links are evident. To our knowledge, no studies have investigated the extent of medical discrimination among breast cancer patients.

We applied a multilevel concept of discrimination based on Jones⁴⁴ 3-level framework for understanding racism, in which *institutionalized racism* is defined as the structural and differential access to goods, services, and opportunities within a society; *personally mediated racism* encompasses differential assumptions about and actions toward others on the basis of race; and *internalized racism* is the acceptance of negative assumptions about their own abilities and worth by members of the stigmatized group. The intent of this qualitative research was to explore experiences of medical discrimination among breast cancer patients that would inform future research aimed at understanding the impact of discrimination on breast cancer outcomes.

METHODS

We examined qualitative data from one component of a larger, mixed-methods study of breast cancer patients. With the purpose of generating hypotheses about how racial/ethnic discrimination might impact breast cancer experience, we conducted 7 focus groups and 23 one-on-one interviews with a multiethnic sample of breast cancer patients to derive themes on medical discrimination in the context of their diagnoses, treatments, and follow-up examinations. We conducted both types of interviews because we wanted to take into consideration the fact that some patients might feel more comfortable relaying information in a one-on-one setting, whereas others would be more comfortable in a group context. Furthermore, data from one-on-one interviews

generally provide more depth, whereas data from focus groups typically provide more breadth. Focus groups explicitly use group interaction to elicit information sharing.⁴⁵

Samples and Data

We randomly selected female patients through the population-based Greater Bay Area Cancer Registry (which covers the Greater San Francisco Bay Area in Northern California) who were diagnosed with first histologically confirmed primary breast cancer (*International Classification of Disease for Oncology, third edition [ICD-O-3]* site codes C50.0–50.9) between January 1, 2006, and December 31, 2008; who were older than 20 years at diagnosis; and who resided in San Francisco, Contra Costa, Alameda, San Mateo, or Santa Clara county. These patients were contacted for study participation by mail. The overall participation rate was 20.7% for focus groups and 31.3% for one-on-one interviews, with African Americans having the highest participation rates for focus groups (66.7%) and one-on-one interviews (75.0%). Filipinas had the lowest participation rate for focus groups (10.3%), and Japanese had the lowest for one-on-one interviews (21.4%). We conducted 7 focus groups (n = 37 participants) and 23 one-on-one interviews from July 21, 2008, through March 13, 2009. A total of 60 breast cancer patients participated, including 9 African Americans, 9 non-Hispanic Whites, 8 Latinas, 17 Chinese (Cantonese and Mandarin speakers), 9 Japanese, and 8 other Asians (Filipinas, Vietnamese, and Asian Indians).

Eligible cases who were selected from the registry and who agreed to participate were randomly assigned to a focus group or one-on-one interview pool. Cases were recruited from these separate pools until the study population recruitment goal was met (3 one-on-one interviews and 1 focus group of 6–8 participants per racial/ethnic group). With the exception of the Chinese and Latina groups, whose interviews were conducted in their respective languages, all interviews were conducted in English. Interviews were 2 hours, audio-recorded, transcribed in-language, and translated into English, as applicable. Participants were compensated \$30 for their time and an additional \$15 for any travel required.

A female interviewer was racially/ethnically matched to participants in African American, Chinese, and Latina groups. Interviewers were not ethnically/racially matched to the other groups because of resource constraints. However, we observed no differences in depth or length of answers between those interviews where the interviewer and interviewee were matched and those that were not matched. Furthermore, our topic guide for the one-on-one interviews and focus groups contained essentially the same format and interview questions. Having observed congruent response depth, breadth, and quality, as well as similar themes across interview methods, we report pooled results for one-on-one and focus group interviews.

The study protocol was approved by the institutional review boards of the Cancer Prevention Institute of California and the California Health and Human Services Agency.

Analysis

A semistructured interview guide was used (Table 1). We used a combined grounded theory and phenomenological process for our qualitative analysis, applying comparative analysis to identify themes across different levels of discrimination and across racial or ethnic groups while also being open to the identification of additional levels or forms of discrimination that might not have been captured by Jones' 3-level framework.⁴⁶

The goal of the analysis was to identify core concepts or themes related to participants' experience with medical discrimination. We used Jones' framework to provide structure for organizing our results and to confirm whether medical discrimination existed across the 3 levels and what themes emerged within each of the levels. At the same time, we applied a more exploratory approach to identify themes emerging from the data through a phenomenological process. A team of 5 research staff independently conducted manual coding of each interview transcript. We developed a codebook through an iterative and interactive coding and consensus building process and used it to identify emergent themes. We also obtained input for the emergent themes from the bilingual and bicultural interviewers.

TABLE 1—Content of Semistructured Interview Topic Guide for One-On-One Interviews and Focus Group Sessions with Breast Cancer Survivors: Greater San Francisco Bay Area, CA, July 21, 2008–March 13, 2009

Topics	Category
Diagnosis	Diagnosis process Experience with medical team during the diagnosis process
Treatment	Communication between provider and patient regarding treatment options Perceived choice in treatment options Adherence to treatment Side effects from treatment Other sources of information on treatment options
Discrimination—medical setting	Perceived discrimination experiences during the course of breast cancer diagnosis and treatment Possible reasons for discrimination experiences (e.g., race/ethnicity, age, English proficiency, height, weight, education, and economic status)
Discrimination—other setting	General perceived discrimination experiences (nonmedical setting) Physical and emotional responses to discrimination experiences Perceptions of discrimination
Coping and social support	Knowledge and participation in support groups Coping strategies and experiences Neighborhood characteristics
Immigrant stress	Immigration history Acculturative stress

RESULTS

Characteristics of the participants are presented in Table 2. Approximately half of the participants were born outside of the United States, all of whom were Latinas or Asians. Most participants had higher educational levels, with 75% reporting at least some college education. Nearly all participants reported having some form of health insurance, ranging from private insurance to public assistance. A total of 90% of participants were diagnosed with early stage (I or II) breast cancer. Emergent themes are summarized in Table 3 and discussed in the following sections.

Institutionalized Discrimination

Institutionalized discrimination “represents the processes built into social entities—governments, bureaucracies, and culture—that reinforce . . . hierarchy.”⁴⁷ This level of discrimination may not be obvious to individuals because it requires knowledge about certain systems or institutions and how members of other groups are treated.³⁷

Economic inequities. Participants across racial/ethnic groups perceived a link between their income status and the quality of care they

received during their diagnosis and treatment. Participants from different income levels reasoned that their economic status influenced the type of insurance they had and their ability to pay out-of-pocket expenses, which in turn affected their quality of care. Examples of subpar quality of care included limited number of medical visits, the amount of personal contact with their providers, and access to (perceived) prestigious medical facilities.

I find a huge discrimination in what healthcare you have. That’s the first thing they want to know. If your healthcare is going to pay 100% of this then you are likely going to get better care, more frequent visits and care. If you have out-of-pocket expense that you can’t afford then you are going to get a minimum of their time.

—African American participant

We don’t have money to get treated in Stanford or other places. Good service definitely requires good price.

—Chinese–Cantonese speaker

You can choose better doctor, expensive medical care, but if you just have HMO, you have less money because HMO, you know, sometimes, it’s good only when . . . you are . . . you are healthy, but when you are sick, they don’t care for you.

—Filipina participant

Language barriers. A number of immigrant participants discussed how their limited

English proficiency hindered communication with their providers and affected their care. Language barriers were most commonly reported among Asian immigrant participants, primarily Chinese, Vietnamese, and Filipinas, and less so with Latina immigrants.

In American [sic], the people who speak English . . . for sure will get very good care or assistance. . . . I am an immigrant. I am more like a foreign [sic]. If I am a native, and my mother language is English, I would get even better care for sure.

—Chinese–Mandarin speaker

My . . . English is not well. They, the doctors, mostly speak English. . . the communication was really bad. . . I felt the interpretation and communication were really bad in the entire process.

—Chinese–Mandarin speaker

Personally Mediated Discrimination

Personally mediated discrimination refers to direct interpersonal experiences with discrimination. Specifically, it is discrimination mediated through a person or group of people rather than an institution, or even oneself, as in the case of internalized racism. It can be intentional or unintentional and can include acts of commission and omission.⁴⁴ The predominant emergent theme related to personally mediated racism was provider prejudice.

Provider prejudice. Prejudice among providers emerged as a theme among African Americans, Filipinas, and Chinese participants. These participants described experiences in which they felt their providers made assumptions based on the participants’ race/ethnicity, education, and immigrant status that compromised their quality of care. The following quote illustrates the belief that providers may underestimate a patient’s ability to understand, based on an assumption about the individual’s educational level, and thus limit the information they provide to patients.

I think the assumption that doctors sometimes give is that “they won’t understand.” They think they need to limit what they tell us because we wouldn’t understand. So back to that question you asked about education. Yes, they feel that we don’t have that much education to understand what’s going on, so they limit what they tell us.

—African American participant

Some immigrant participants described feeling that they were treated with less respect because of the provider’s assumption about their educational level. They also described feeling that they were regarded as “outsiders”

TABLE 2—Sociodemographic and Other Characteristics of Breast Cancer Participants: Greater San Francisco Bay Area, CA, July 21, 2008–March 13, 2009

Category	No. (%) or Mean (Range)
Data collection method	
One-on-one interviews	23 (38.3)
Focus group	37 (61.7)
Nativity	
Foreign-born	31 (51.7)
US-born	29 (48.3)
Marital status	
Married	45 (75.0)
Not married (separate, divorced, widowed, and never married) ^a	15 (25.0)
Educational level	
≤ 12 y or vocational or technical school ^a	15 (25.0)
Some college	32 (53.3)
Postcollege	13 (21.7)
Current employment	
Employed	19 (31.7)
Unemployed (student, homemaker and unemployed) ^a	16 (26.7)
Retired	25 (41.7)
Insurance status	
Medicare, MediCal, or uninsured ^a	12 (20.3)
Medigap	19 (31.7)
Private	32 (53.3)
Years since diagnosis	
1	18 (30.0)
2–3	42 (70.0)
Household annual income, \$	
< 30 000	15 (25.0)
30 000–59 999	9 (15.0)
60 000–79 999	5 (8.3)
≥ 80 000	18 (30.0)
Don't know or refused	13 (21.6)
Stage at diagnosis	
I	34 (56.7)
II	20 (33.3)
III and IV	6 (10.0)
Race/ethnicity	
African American	9 (15.0)
Latina	8 (13.3)
Non-Hispanic White	9 (15.0)
Chinese–Cantonese speaker	8 (13.3)
Chinese–Mandarin speaker	9 (15.0)
Japanese	9 (15.0)
Other Asians (Filipina, Asian Indian, and Vietnamese) ^a	8 (13.3)
Age at diagnosis, y	
African American	63.2 (51–73)
Latina	63.6 (41–81)
Non-Hispanic White	65.6 (42–79)

Continued

because of their immigrant status and that may also have compromised their care.

You are different. Some [providers] might treat you as an outsider. Maybe... or they might ignore you because of the poor communication.
—Chinese–Mandarin speaker

Internalized Discrimination

When people are discriminated against, they may make these discriminatory beliefs part of their self-image. In our study, we found that participants internalized their medical discrimination experiences as being the result of their own inadequacies, such as limited education, low English proficiency, and non-compliance. These perceptions placed the responsibility of receiving quality care on the participants themselves, and these internalized beliefs were found across racial/ethnic groups. The following quotes suggest self-blame. Rather than expecting providers to provide relevant information about their condition, participants cited their own perceived inadequacies.

If you don't have enough education, you don't even know what to ask. Right? He also doesn't know what to tell you. So maybe in his mind he would think, "You wouldn't understand. Even if I tell you, you wouldn't know. Even if I explain to you, you wouldn't understand. So why telling you so much?"
—Chinese–Cantonese speaker

I think what happens with a lot of African Americans, minorities, is the lack of social communication and therefore afraid to ask the questions.
—African American participant

Still putting the onus of doctor-patient communication on themselves, others cited limited English language proficiency as a barrier to receiving medical information.

My English is not good enough. And I don't communicate with them.
—Chinese–Cantonese speaker

Personal or Group Discrimination Discrepancy

In addition to themes fitting into Jones' 3-level framework, additional themes unrelated to the framework also emerged. Our qualitative data suggest that participants seldom reported discrimination directed at them personally, yet they readily reported discrimination directed toward their racial/ethnic group as a whole. This personal or group discrimination

TABLE 2—Continued

Chinese—Cantonese speaker	61.3 (36–78)
Chinese—Mandarin speaker	54.3 (45–71)
Japanese	56.1 (36–84)
Other Asians (Filipina, Asian Indian, and Vietnamese) ^a	57.8 (40–74)

^aData were merged in accordance with cancer registry guidelines requiring that all cells have at least 5 counts.

discrepancy⁴⁸ was most commonly referenced among our African American participants.

I was able with this binder of his to gather information as to what this was and how it works. So, I think he respected the fact that I could perhaps understand. But I do know people who have told me whom have gone through the treatment and they say to me, “Wow, your doctors told you all kinds of things. My doctor didn’t tell me any of this.” So I do know and these are African Americans.’

—African American participant

Being Black I am always going to know people not treated right.

—African American participant

Some explanations for this discrepancy may include denial of personal discrimination, self-blame, protection of self-esteem, or an unwillingness to identify a perpetrator, particularly medical providers.^{39,49}

Active Coping Behavior

Another theme, unrelated to Jones’ framework, was active coping behavior as a management strategy. Several participants stated that they believed minority groups must work harder to achieve success or cope with everyday challenges.

I believe that as an individual, you make your own success. You may have more hoops that you have to jump through to be successful, but I don’t think because you’re Black, Chinese, Spanish, that you’re stopped because you’re of a different ethnic background.

—African American participant

Although the participant indicates that she believed that people are responsible for their own outcomes in life, she also acknowledged that being “Black, Chinese, Spanish” may require one to work harder. On the one hand, she acknowledges discrimination, albeit subtly, but on the other hand, she minimizes the role of discrimination in favor of a personal responsibility argument.

Awareness of even subtle discrimination in the medical setting can lead to an ongoing form of vigilance where the expectation of discrimination can lead to active coping behaviors, such as impression management, a process whereby one attempts to manage the impression others have of oneself to avoid the consequences of stereotypes and discriminatory treatment.^{50–52} The following quote from an African American illustrates

positive self-presentation, a form of impression management.

My education made a vast difference in my care. I am very educated, and I take great care of myself. Of course it made a difference. When you can speak their language, well-dressed so they see that you have pride in yourself, you are treated with a higher level of respect. I am just being open and honest. It’s society and that’s how it works. I do my homework.

—African American participant

DISCUSSION

Our study explored the qualitative experience of discrimination in the medical setting among breast cancer survivors in the Greater San Francisco Bay Area. Participants reported experiencing both implicit and explicit discrimination consistent with Jones’ multilevel framework.⁴⁴ Themes that we identified as consistent with this framework were reported across racial/ethnic groups, although the extent to which they were reported varied across groups. We also identified additional themes that did not fit neatly within Jones’ framework.

Reported medical discrimination experiences were fairly subtle, yet participants reported awareness of these more implicit discrimination experiences. It was not unusual for our study participants to deny that they were treated unequally and then to describe experiences that were unequivocally consistent with poor quality of care.

TABLE 3—Emergent Medical Discrimination Themes From Interviews and Focus Groups with Breast Cancer Survivors: Greater San Francisco Bay Area, CA, July 21, 2008–March 13, 2009

Type of Discrimination	Theme
Institutionalized	Economic inequities: Income is positively associated with quality of care. Language barriers: English language proficiency influenced patient-provider communication and subsequently quality of care.
Personally mediated	Provider prejudice: Providers may make assumptions about patients based on their personal prejudice regarding race/ethnicity, education, and immigrant status. Patients believe that providers withheld information from them based on their assumptions about the patient’s limited ability to comprehend all the information. Immigrant participants believed they were treated with less respect by providers because of their immigrant status.
Internalized	Self-blame: Patients may attribute poorer quality of care or problems with their providers to their own inadequacies (e.g., language proficiency or educational level).
Other	Personal and group discrimination discrepancy: Patients tend to report less on discrimination directed at the individual level yet more on discrimination directed toward their own racial/ethnic group. Active coping behavior: African American and Asian patients apply active coping mechanisms in which they believe they must work harder to receive optimal health care. This behavior includes impression management strategies to present positive images of themselves to receive better care.

The predominant forms of medical discrimination themes in our study sample were related to class, race, and language. Our findings also showed striking themes that were more predominant among African Americans and Asian immigrants related to blame attribution and coping behavior. Previous studies have shown that African Americans perceive racial discrimination from medical providers, often associated with feelings of disrespect and cultural incompetence.^{53,54} However, we also found that whereas African Americans perceive medical discrimination against them as a group, they tended to not perceive or discuss personal experiences of discrimination.^{48,49} Additionally, themes of well-established coping mechanisms, such as accepting the idea that one must work harder and use positive self-presentation to obtain optimal health care, emerged from the data.

Our findings showed that immigrants, mainly Asians, are exposed to multiple and often overt forms of medical discrimination, including lack of access and readily available translation services. Although Asians are often acutely aware of being the target of differential treatment, many believe they are “outsiders,” and this belief results in their passive attitude and acceptance of such mistreatment. By contrast, we did not observe strong evidence of language discrimination in Latinas. One possible reason is there is a greater availability of Spanish-speaking medical staff. A study of physicians in California found that 26% of primary care physicians and 22% of specialists reported being fluent in Spanish.⁵⁵

There were a number of common themes across racial/ethnic groups. Class-based discrimination at the institution level was reported across racial/ethnic groups. The concept of needing to work harder to cope with unlevel playing fields, referred to in the literature as “John Henryism” and typically found in men,⁵⁶ emerged in our samples of both African American and Asian women. Additionally, impression management strategies were used more by African American patients and those of low socioeconomic status.⁵⁷ Our qualitative data also suggested

personally mediated discrimination in the form of provider prejudice among African Americans and Asian immigrants. Perceived provider discrimination has been shown to affect self-reported quality of care across racial/ethnic populations.²⁹ One study showed that perceived medical discrimination can affect adherence to recommended health behavior, such as obtaining mammography and colorectal cancer screening, in women.³² Experiences with provider discrimination can lead to future avoidance of the overall health care system as part of a disengagement coping strategy.²⁵

Limitations

Our findings should be interpreted in light of several considerations. Although this qualitative analysis included many of the major racial/ethnic groups in the region, it is limited by its small sample size within each group. One novel aspect of this study’s design is its rigorous random sampling method of recruiting participants from a population-based cancer registry, although participation rates were generally low, resulting in part from the length of the interviews, lack of language concordance for all groups (e.g., Filipinas), generally older age of cases, and the added difficulty of scheduling focus groups.

Therefore, study participants may not be representative of all newly diagnosed breast cancer patients in the San Francisco Bay Area with respect to socioeconomic status, insurance status, and cancer stage. As individuals of lower socioeconomic status are more likely to be diagnosed with advanced stage cancer, which in turn requires more intensive medical care, our results likely under-represent the true extent of discrimination that exists in the general patient population.

Conclusions

Our qualitative findings of self-reported medical discrimination experiences underscore a need for further research into how discrimination can impact breast cancer patients. Overall, the impact of discrimination in the medical setting on the coordination of breast cancer care and long-term

surveillance and management warrants further study.

The unique aspect of this study is its use of a conceptual multilevel discrimination framework and focus on the medical setting. Our qualitative findings highlight the need to incorporate both implicit and explicit discrimination experiences in quantitative surveys to better characterize their prevalence in the medical setting and their impact on breast cancer outcomes. ■

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Contributors

T. Quach led the analysis and writing of the article. P. Morris, L. Allen, S.J. Shema, and J.K. Winters worked on the coding of qualitative data. All authors were involved in the identification of emergent themes and results interpretation. G.M. Le helped in the literature review for the emergent themes. A. Nuru-Jeter and S.L. Gomez provided guidance on the overall qualitative analysis and results interpretation. All authors contributed to the writing of the article.

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Human Participant Protection

This study was reviewed and approved by institutional review board of the Cancer Prevention Institute of California and the California Health and Human Services Agency.

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