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TITLE: **Impact of Institutional - and Individual – Level Discrimination on Medical Care & Quality of Life among Breast Cancer Survivors**

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14. ABSTRACT

This study used mixed-methods to develop a survey to measure discrimination among a diverse sample of breast cancer survivors, and to measure the prevalence of discrimination and association with breast cancer outcomes, including stage at diagnosis, treatment, and quality of life. Through the qualitative component of the study, we have gleaned invaluable perspectives regarding the subtle but important aspects of discrimination and its potential impacts on breast cancer outcomes. We encountered challenges with regards to recruitment, but did complete epidemiologic interviews with 523 respondents, with balanced representation across our target racial/ethnic groups (non-Hispanic Whites, African Americans, Hispanics, Chinese, Filipinas). Our results showed that interpersonal and institutional discrimination varied across racial/ethnic groups and were associated with most of the outcomes of interest; these results warrant further evaluation with more focused data analyses and in larger study populations. Our results also inform future research efforts on survey development.

15. SUBJECT TERMS
Discrimination, race, ethnicity, breast cancer, institution, quality of life, medical care, treatment, qualitative analysis, focus group, cognitive interview, instrument development, multi-lingual

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INTRODUCTION

The objective of this study was to measure the prevalence and impacts of discrimination at the institutional- and individual- level to identify the underlying factors contributing to disparities in breast cancer diagnosis, treatment, and quality of life. The specific aims were to: 1) develop a survey tool tailored towards cancer patients for assessing discrimination in health care settings; 2) quantify the prevalence of individual- and contextual-level discrimination across racial/ethnic groups; and 3) assess the effects of individual- and contextual-level discrimination on disparities in: a) late stage diagnosis, b) cancer treatment (including breast conserving surgery (BCS) and adjuvant radiation), and c) quality of life (QOL). This study comprised two components: developmental (Aim 1) and application (Aims 2-3). The developmental component used qualitative research to develop an instrument tailored for breast cancer patients. Because tools have not been developed for cancer patients nor for different races/ethnicities, we conducted focus groups and qualitative (one-on-one) interviews to discern relevant discrimination topics. The topics, together with existing instruments, were used to develop an instrument to be cognitive-tested in a small sample of patients. In the application component, we conducted a cross-sectional epidemiologic study using a multilevel approach by incorporating individual- and neighborhood-level information including: 1) previously collected geographic information systems (GIS) data about the social and built environment; and 2) telephone interviews with a population-based cohort of breast cancer patients. The application component also included a test-retest of selected survey items for a random 10% of participants.

BODY

The Statement of Work, including approved modifications and one-year no-cost extension, and associated report of progress, is shown below:

> ***Task 1*** Obtain IRB approvals, design and obtain approvals on focus group and qualitative interview instruments, translate and back-translate instruments, develop study tracking system and training materials, Months 1-6
> > a. Prepare and submit IRB applications for DOD and CPIC.
> > b. Apply for cancer registry data from the Greater Bay Area Cancer Registry (GBACR).
> > c. Develop MS Access tracking system.
> > d. Develop interviewer training manual.
> > e. Translate, back-translate, convene meeting(s) to decenter instruments.
> > f. Hire staff.
> > g. Obtain first case listing data from the GBACR, download into tracking system.
> > h. Organize community advisory committee meeting to introduce study and obtain feedback about general research strategy.
>
> Deliverables: IRB approvals, finalized instruments for focus group and qualitative interviews, community advisory committee feedback

> During this time, we did all of the specific tasks listed above to prepare for the study. All survey instruments were translated and independently back-translated into Spanish, Chinese, and Tagalog. In addition to DOD and CPIC, we also had to obtain IRB approval from the California state IRB, or the California Protection of Human Subjects (CPHS). From the start, the multiple IRBs and multi-phasic nature of our study presented considerable unforeseen delays.

> ***Task 2*** Conduct focus group and qualitative interviews, Months 7-18
> > a.   Select breast cancer patients for contacting regarding focus group and qualitative interviews.
> > b.   Recruit breast cancer patients for fulfilling the numbers of required focus group and qualitative participants for each racial/ethnic group.
> > c.   Conduct focus group and qualitative interviews.
> > d.   Transcribe interviews.
>
> Deliverables: completed focus group and qualitative interviews, transcripts of completed interviews

> For this task and all subsequent phases of the study, breast cancer survivors were identified from the Greater Bay Area Cancer Registry (GBACR), which releases cancer case information to one approved study at a time. The eligibility criteria was: residence (at time of diagnosis (2006-

2009) and interview) in one of the Greater San Francisco Bay Area counties (San Francisco, Contra Costa, Alameda, San Mateo, and Santa Clara), age 20 or older at diagnosis, diagnosis with first-primary invasive stage I-IV breast cancer, and alive at the time of interview. Listings of eligible cases were received from the GBACR on a quarterly basis and cases were tracked in an Access database. For recruitment, an introductory package was mailed out to randomly selected cases. Two weeks upon mailing the introductory package, trained interviewers called and recruited study subjects by telephone. As described in prior annual reports, this task, or the qualitative phases, took longer than expected. Recruitment was unexpectedly difficult as we experienced considerably lower response rates than in previous studies.

Task 3 Conduct qualitative data analysis, design epidemiologic survey instrument, Months 19-34
a. Code the transcribed interviews.
b. Conduct thematic-driven qualitative data analysis.
c. Design epidemiologic survey instrument.
d. Translate epidemiologic survey instrument.
e. Develop and obtain IRB approval for recruitment materials and procedures for cognitive interviews.
Deliverables: completed qualitative data analysis, epidemiologic survey instrument and recruitment materials for cognitive interviews

We had not originally expected nor proposed to conduct <u>full</u> qualitative analysis, but reviewing the transcripts had shown that such an analysis was necessary since indications of medical and institutional discrimination were not explicitly evident from reading the transcripts. Our qualitative results were published in a special issue of the American Journal of Public Health on Discrimination (Quach et al., AJPH, May 2012 (Appendix B)). The results were also presented as a poster at the NIH Science of Discrimination conference (February 2011) and the DOD BCRP Era of Hope meeting (August 2011) (Appendix C). Our abstract reporting on the social support, social burden, and social networks qualitative findings will be presented at the 2012 American Public Health Association (APHA) meeting in October. We have also given several educational seminars on the value of mixed methods in improving epidemiologic surveys, and used our experiences from this project as an example. Several more manuscripts are in progress, one describing the mixed-methods process and experience, and a second focusing on the qualitative results related to social support and social burden.

Developing the survey items for the epidemiologic survey instrument was also a more extensive process than expected, as we wanted to operationalize some of the important themes that were derived from the qualitative analysis, such as John Henryism, cultural health capital, impression management, personal-group discrepancy, social burden, etc., and so we conducted an extensive search of literature from various disciplines to look for survey items that had already been developed, and in some cases, such as for cultural health capital, developed items de-novo.

Task 4 Conduct cognitive interviews, revise epidemiologic survey instrument as necessary, Months 35-48
a. Select breast cancer patients for contacting regarding cognitive interviews.
b. Recruit breast cancer patients for fulfilling the numbers of required cognitive interviews for each racial/ethnic group.
c. Conduct cognitive interviews.
d. Convene study staff meetings to discuss results from cognitive interviews and to revise instrument as necessary.
Deliverables: completed cognitive interviews, refined epidemiologic survey instrument based on cognitive testing

We held several group (study team) meetings to select the final survey items to be cognitive tested, to review and discuss cognitive testing results, and to decide on the final epidemiologic survey (Appendix A). Participants for this phase were recruited as described above in Task 2. We learned that it is difficult to quantitatively capture the depth of issues related to general and medical discrimination. Several items were dropped due to poor results from cognitive testing, and extensive revisions to items were made based on cognitive testing results. We ended up conducting two phases of cognitive interviews so that we could test changes to study items.

Task 5 Conduct epidemiologic interviews, GIS analysis to create neighborhood variables, Months 49-60
a.   Select breast cancer patients for contacting regarding epidemiologic interviews.
b.   Recruit breast cancer patients for the epidemiologic interviews.
c.   Conduct epidemiologic interviews.
d.   Randomly select 10% of participants from each racial/ethnic group to conduct 15-minute retest.
e.   Conduct test-retest reliability sub-analysis.
f.   Design data entry system in MS Access.
g.   Edit questionnaire, conduct double data entry.
h.   Conduct quarterly, interim data analysis to look for unusual data patterns.
i.   Clean and prepare epidemiologic interview data for analysis.
j.   Conduct GIS analysis to create study-specific neighborhood measures and merge to interview dataset.
k.   Create statistical program to conduct multilevel modeling analysis.
l.   Conduct test-runs of multilevel modeling analysis.
Deliverables: completed epidemiologic interviews, epidemiologic analytic dataset, multilevel modeling analysis program, prepare manuscript on test-retest reliability results

The main challenges we encountered in the study overall were related to recruitment, and particularly important concerns for Task 5 were low response rates, described further below, and not having received a sufficient number of cases from the GBACR, particularly for most of the minority groups, due to these cases being released to another study. We also encountered several challenges with regards to coordinating IRB reviews between the state of California and CPIC, and were continually delayed by slow reviews at the California IRB. We also experienced some staff turn-over, as our study coordinator, African-American interviewer, and multiple Filipina interviewers left for other jobs, and we had to hire and re-train new staff to fill these roles. Secondary to issues in hiring, training, and retaining qualified Tagalog interviewers, we also experienced issues relating to the Tagalog (Filipino language) version of the survey instrument, with some respondents reporting in the cognitive testing that the translation and words used were too technical, given that most Filipino Americans used a modified version of the Tagalog language, a blend of English and Tagalog. As a result, the Tagalog translation of the final survey instrument has undergone a rigorous process of translation, back-translation, input from outside Tagalog-language consultants, and further refinement.

In addition to not having received enough cases from the GBACR for recruitment, the most limiting challenge was the unexpectedly low response rates (see Table 1 (Appendix D)). Based on our prior studies, we had expected participation rates of 60-70% (among those whom we are able to reach and are eligible), but found that our participation rates in this study were highly variable and substantially lower than in earlier studies. Our response rates in the epidemiologic telephone interviews ranged from a low of 20% among the "Other" race/ethnicity group to a high of 47% among non-Hispanic Whites. The overall response rate in this phase was 34%. Unfortunately, these generally low response rates are consistent with other current studies among breast cancer patients and survivors, and while we don't completely know the reasons, we suspect that it is due to a combination of reasons including overlap with other research studies, study topic being studied, or simply a sign of the times (e.g., greater dis-interest in research, confusion with telemarkers and thus not answering the phone, increasing use of caller-ID to screen callers, etc). The study overlap issue might have resulted in two possible reasons for the unexpectedly lower response rates: 1) the more willing participants had already

been contacted and enrolled into a prior study and their data were not released to this and subsequent studies; this is a very real possibility as a large study that was ongoing at the same time as this study had first priority for the same cases and discussions with the Principal Investigator and field staff of that study reported that although they did also experience lower than usual response rates, their response rates did not seem to be as low as ours and other studies; 2) the multiple ongoing studies of breast cancer in the Bay Area and California (not only from the cancer registries) may have resulted in study fatigue on the part of patients. The topic of this study may have also contributed to the response rates, as we noted that some participants seemed less interested and/or displeased to learn that the survey questions seemingly had nothing to do with their breast cancer diagnosis, despite our explanations for the importance of this research. Indeed, approximately 3% of participants who initially agreed to participate ended up refusing after receiving the "Show Cards" of some of the survey response categories, which were designed to assist in administration of the telephone survey. Table 1 (Appendix D) shows the disposition codes from each phase of the interview, by racial/ethnic group. As a result of these unexpectedly low response rates and not having received sufficient numbers of cases from the GBACR, we were able to recruit a total of 523 participants for the epidemiologic telephone survey.

That said, we did complete the specific items outlined in this Task. We developed an Access database for data entry, and edited and entered the data. We conducted a retest of a selected number of survey items to a randomly selected 15% of the sample. We obtained geocodes on the participants and extracted relevant contextual variables of interest from our California Neighborhoods Data System. Our biostatistician explored multi-level analysis procedures but given the sparse clustering of participants by geography (i.e., nearly all block groups had only one participant), determined that multi-level analysis was not necessary.

Task 6 Conduct data analysis, Months 55-60
a.   Conduct preliminary descriptive analysis, determine variable cut-points, create composite variables.
b.   Conduct multilevel modeling analyses.
Deliverables: completed data analysis, final data results tables

Table 2 shows selected sociodemographic and clinical characteristics (based on cancer registry data) among the 523 epidemiologic telephone survey respondents compared to the general population of eligible cases from the GBACR. In comparison to the registry eligible cases from the GBACR (n=11,925), the EBCC responders (n=523) were slightly younger at diagnosis (except for African Americans, among whom responders were slightly older, and Hispanics, among whom there was no statistically significant difference in age), have a higher proportion of cases diagnosed in 2006 and 2008, and were more likely to be married (among non-Hispanic Whites and Chinese). There generally were no differences in disease characteristics (stage, histologic subtype, grade), nor socioeconomic status (based on block-group level composite index of Census socioeconomic measures on education, income, poverty).

Table 3 compares the sociodemographic and clinical characteristics of the epidemiologic telephone survey responders (N=523) versus non-responders (N=1900) by race/ethnicity. Overall, in comparison to non-responders, the EBCC responders were younger at diagnosis, and have a higher proportion of US-born cases (only among non-Hispanic Whites and "Other" race/ethnicity group), cases from Contra Costa and Santa Clara, cases diagnosed in 2006 (lower proportion for 2007 and similar for 2008+2009), married, AJCC stage I cases, cases with lobular breast cancer tumors, and cases from block groups with high SES; however, many of these comparisons were not statistically significant within racial/ethnic groups. The following are statistically significant differences within each racial/ethnic group:
o   Among non-Hispanic Whites, EBCC responders had a higher proportion of cases from Contra Costa county, married cases, and cases with lobular breast cancer tumors, as well as a lower proportion of foreign-born (although based on small numbers).

- Among African Americans, EBCC responders were older at diagnosis, and had a higher proportion of cases diagnosed in 2008 & 2009, and cases with grade II disease.
- Among Chinese, EBCC responders had a higher proportion of married cases.
- Among Filipinas, EBCC responders were younger at diagnosis, and had a higher proportion of cases from Santa Clara (relatively fewer from Alameda and San Mateo counties).
- Among "Other" race/ethnicity cases, EBCC responders were younger at diagnosis, and had a higher proportion of US born cases.

Table 4 shows sociodemographic and clinical characteristics among the EBCC epidemiologic telephone survey responders. At the time of this report, data for N=513 respondents had been entered and cleaned, and thus the remaining tables based on the survey data are for these 513 respondents. On average, respondents were interviewed four years after diagnosis (range from 2-6 years). The majority of Hispanic, Asian, and "Other" race/ethnicity cases were foreign-born. All non-Hispanic Whites, African Americans, "Other" race/ethnicity cases, half of Filipinas (98%) did their interviews in English; 34% of Chinese and 50% of Hispanic cases did their interviews in English. In general, sociodemographic and clinical characteristics for EBCC participants varied by race/ethnicity, except for insurance types, Medicare Part A and/or B, Part D prescription drug coverage, extra insurance for Medicare, military health care, and other types of insurance; SEER summary stage; AJCC stage, grade, and hormone (endocrine) treatment use. Marginally significant differences were detected for surgical treatment, and insurance type—other government health program. Selected findings are highlighted below:

- Chinese, Filipina, and "Other" race/ethnicity cases were younger at diagnosis, while non-Hispanic Whites, African Americans and Hispanics were older.
- African Americans, Hispanics and "Other" cases had relatively lower proportions of married cases, while non-Hispanic White, Chinese, and Filipina had higher proportions.
- Non-Hispanic Whites (9%) and "Others" (13%) had relatively lower proportion of cases that had ≤ HS graduation, while Hispanic (48%) and Chinese (27%) cases had relatively higher proportions that had ≤ HS graduation; non-Hispanic Whites (63%), Chinese (59%), Filipino (61%), and "Others" (59%) cases had a higher proportion of at least completing college, while African Americans (32%) and Hispanics (25%) had lower proportions compared to the total sample.
- African Americans, Hispanics, and Chinese had relatively higher proportion of cases with ≤$55,000 annual household income compared to the total sample; however, the proportion of unknown/missing data varied from 8.1% among African Americans to 32.5% among Hispanics.
- Hispanic and Chinese cases has lower proportions of cases reporting health insurance coverage through their job/spouse's job, while Filipinas and "Others" had higher proportion compared to total sample. Non-Hispanic Whites had higher proportion of cases with individual health insurance not via employment, and African Americans, Filipinas and "Others" had lower proportions compared to the total sample. Hispanic (22.5%) and Chinese (19.6%) had higher proportions with Medi-Cal (California's Medicaid program) insurance.
- In this sample, stage at diagnosis was not statistically different across the racial/ethnic groups, but Filipinas did have a relatively lower proportion of stage I and higher proportion of stage III disease than the other racial/ethnic groups.
- Non-Hispanic Whites had high proportion of lobular tumors, while Chinese, Filipina and "Other" cases had higher proportions of ductal tumors.
- African Americans and Hispanics had higher proportions of BCS (breast conserving surgery) without radiation compared to the total sample, while Chinese and Filipinas had higher proportions of mastectomy compared to the total sample.

- 53% of the total sample lived in a block group that was in the highest SES quintile. Non-Hispanic Whites (69%) and Filipinas (59%) had higher proportions of cases living in the highest SES quintile, while African Americans (21%) and Hispanics (30%) had lower proportions.

Table 5 shows the percent reporting discrimination experiences by race/ethnicity. With regards to the medical discrimination items, overall, 47% of EBCC participants reported having experienced medical discrimination while getting breast cancer treatment. This varied by racial/ethnic groups: 37% of Filipinos, 39% of African Americans, 44% of non-Hispanic Whites and Others, 48% of Hispanics, and 63% of Chinese cases reporting discrimination. Among those who reported discrimination, 12% attributed it to race/ethnicity and 11% to immigration, which also varied by race/ethnicity. African Americans (42%) and Hispanic (32%) had higher proportions attributing their medical discrimination experiences to race/ethnicity, while non-Hispanic Whites (2%) and the "Other" racial/ethnic group (4%) had lower proportions attributing to race/ethnicity. Hispanics (21%), Chinese (22%), Filipinas (24%) and the "Other" racial/ethnic group (18%) were more likely than the other groups to attribute discrimination to immigration. Overall, 7% of those reporting medical discrimination did not attribute the experiences to any specific reason. Many respondents provided unique responses to the attribution question, which we reviewed as a group and upcoded to one of the existing attribution categories, if appropriate. Those that were not upcoded are listed in Appendix E.

We were interested to test how often respondents reported medical discrimination using a single global measure of medical discrimination due to race/ethnicity. Using this single global measure, 11% of the total sample reported having discrimination experiences, and reports varied by racial/ethnic groups (with similar ranking as summary measure, except for non-Hispanic Whites, who now report the least). Overall, using this single global measure, a higher proportion of respondents reported racial/ethnic medical discrimination compared to using the experiences of discrimination question followed by the attribution question.

By Approach	NH White	African American	Hispanic	Chinese	Filipino	Other	Total
M1 and M2	2 (1%)	10 (16.1%)	6 (15%)	8 (7.8%)	2 (4.3%)	1 (1.6%)	29 (5.7%)
M3 (global)	4 (2%)	11 (17.7%)	5 (12.5%)	21 (20.6%)	6 (13.0%)	7 (11.1%)	54 (10.5%)

Reports of medical discrimination, at the item level, were as follows (those with asterisks varied by racial/ethnic groups):
- 10% for denied test/treatment
- 13% for inappropriate comments to you /about you
- 14% for act as if he/she thinks you are not smart
- 17% for less respect*
    - Chinese reported in higher proportions than total (and African Americans)
- 17% for act as if he/she is better than you
- 17% for insist on receiving a test/treatment*
    - Chinese and "Others" reported in higher proportions than total
- 21% for poorer service
- 25% for wait longer*
    - Hispanics, Chinese and "Others" reported in higher proportions than total (and African Americans)
- 30% for not listening

Overall, 16% of the sample reported being concerned for themselves with being treated unfairly due to their race/ethnicity in the future. Reports varied by race/ethnicity: 31% of African Americans, followed by Hispanics (30%), Chinese (28%), Filipina (22%), "Others" (13%) and non-Hispanic Whites (2%),

reported being concerned about future racial/ethnic discrimination. When asked about being concerned for members of their same racial/ethnic group, 32% reported being concerned overall, and this varied by race/ethnicity: 66% of African Americans, followed by Hispanics (58%), Chinese (45%), Other (38%), Filipina (37%), and non-Hispanic Whites (8%), reported being concerned for a member of their racial/ethnic group.

For provider mistrust, overall reports ranged from 4% (doctor made references to your race/ethnicity or skin color when it did not seem important) to 48% (because of your insurance status, you are happy to receive any medical treatment you can get). The only item that varied by racial/ethnic group is "doctor made references to your race/ethnicity or skin color when it did not seem important" with the highest proportion being reported by Chinese (11%), followed by African-Americans (7%), Hispanics and "Others" (5%), and non-Hispanic Whites and Filipinas (<1%).

With regard to the general discrimination questions, respondents were asked about major lifetime discrimination experiences across 8 domains, e.g., school, work, housing, medical care, police courts, etc. We summed reports of discrimination across these items and report on any lifetime discrimination. Any lifetime discrimination experiences were reported by 84% of the total sample, with reports varying by race/ethnicity: 92% of African Americans, followed by non-Hispanic Whites (87%), Chinese (85%), "Others" (84%), Hispanics (75%), and Filipinas (67%). Among those who reported having experienced lifetime discrimination, 39% attributed their experiences to race/ethnicity, 22% to immigration, 84% to other reasons, and 4% did not report a specific attribution. Reports of racial/ethnic, immigration and other attributions varied by race/ethnicity, with non-Hispanic Whites reporting the lowest proportion of racial/ethnic attribution and non-Hispanic Whites and African Americans for immigration.

Respondents were asked about recent everyday discrimination experiences (adapting questions from the Everyday Discrimination Scale). We defined recent as the past 12 months and asked 9 items about day-to-day experiences of unfair treatment, e.g., treated with less respect, received poorer service, people act as if they are afraid of you, been called names/insulted, etc. We summed reports of discrimination across these items and report on any recent everyday discrimination in the report. Recent everyday discrimination experiences were reported by 64% of the total sample. Interestingly, the reports did not vary significantly by racial/ethnic group (58%-68%).

Among those who reported having experienced recent everyday discrimination, 27% attributed their experiences to race/ethnicity, 15% to immigration, 68% to other reasons, and 21% did not provide a specific attribution for their experiences. Reports of attribution varied across racial/ethnic groups. For racial/ethnic attributions, 74% of African-Americans said yes, followed by Filipinas (47%), "Others" (32%), Chinese (31%), Hispanics (17%), and non-Hispanic Whites (5%). For immigration, 37% of Filipinas said yes, followed by Chinese (34%), "Others" (22%), Hispanics (13%), and 2% of African Americans and non-Hispanic Whites. 48% of Hispanics did not report an attribution for their discrimination experiences, followed by 30% of non-Hispanic Whites, 20% of Filipinas, and 14% of African Americans.

Among those who reported recent everyday discrimination experiences, we asked about their usual responses to these experiences. Reports were as follows (those with asterisks varied by racial/ethnic groups):

- 38% reported try to do something (marginally significant)
  - 45% of non-Hispanic Whites; 22% of Hispanics
- 60% reported accept it as a fact of life
- 34% reported work harder to prove them wrong
- 11% reported believe that you brought it on yourself*
  - 25% among Chinese, 22% among "Others", 7% among Filipinas, 6% among non-Hispanic Whites, 4% among Hispanics, and 2% among African Americans
- 63% reported talk to someone (marginally significant)

- 73% of "Others", 39% of Hispanics
- 46% reported express anger or get mad
- 39% reported pray about the situation*
  - 67% of African Americans, 63% of Filipinas, 39% of "Others", 37% of Chinese, 29% of non-Hispanic Whites, and 17% of Hispanics

With a single global measure of recent everyday discrimination due to race/ethnicity, 23% of the total sample reported having discrimination experiences, and reports varied by racial/ethnic groups. There were some differences in the reports of everyday racial/ethnic discrimination between the multi-item and single global item approach. Asking directly about racial/ethnic discrimination yielded higher reports for Chinese and "Other" racial/ethnic groups, and similar levels of report for non-Hispanic Whites, African Americans, Hispanics, and Filipinas.

By Approach	NH White	African American	Hispanic	Chinese	Filipino	Other	Total
D4 and D5	6 (3.0%)	31 (50.0%)	4 (10.0%)	21 (20.6%)	14 (30.4%)	13 (20.6%)	89 (17.3%)
D8 (global)	9 (4.5%)	32 (51.6%)	5 (12.5%)	40 (39.2%)	13 (28.3%)	18 (28.6%)	117 (22.8%)

With regards to institutional discrimination, we included in the epidemiologic survey measures of hospital mistrust, and also examined secondary (census) data on racial/ethnic residential segregation. Hospital mistrust was measured using 5 items that ask about hospitals (e.g., Patients have sometimes been deceived or misled at hospitals, Hospitals give the best care to people with the most money, Hospitals will treat you differently depending on what insurance you have). We report on both percent agreement with any item in the subset and a summary score. The summary score has sufficient inter-item reliability at 0.70 or greater for African Americans, Hispanics, Filipinas and "Others", and less sufficient for non-Hispanic Whites. Overall 80% of participants agreed with at least 1 of these 5 items (average 2.2 items), indicating some level of hospital mistrust. Both agreement with any single hospital mistrust item and the summary score varied by racial/ethnic groups, with non-Hispanic Whites, African Americans, and Hispanics having higher hospital mistrust scores and Chinese, Filipinas, and "Other" participants having lower medical mistrust scores.

Study participants' residential addresses at diagnosis were geocoded to Census 2000 street files (Census 2010 not yet available). We used measures of racial/ethnic residential segregation at the participant's block group. The measures are hybrid measures of a higher-level area (MSA/PMSA) at which residential segregation indices are available via the US Census Bureau in combination with % racial/ethnic composition at the block group level. We chose to examine two dimensions of residential segregation – Dissimilarity Index and Isolation Index - as these measures are more sensitive for some racial/ethnic groups. Dissimilarity is a measure of evenness and measures the degree to which each neighborhood (block group) has the same distribution of the minority group to the dominant group (non-Hispanic Whites) as the metropolitan (MSA/PMSA) area overall. The Isolation Index is a measure of exposure and measures the average probability of contact between the minority group and non-Hispanic Whites at the neighborhood level. Measures were not available for non-Hispanic Whites and "Others". For the Dissimilarity Index measure, among African American participants, 47% lived in neighborhoods at the time of diagnosis that were highly segregated (high segregation, high African-American composition at the block group). 35% of Hispanics lived in highly segregated neighborhoods as did 34% of Chinese and 22% of Filipinas. For the Isolation Index measure, 47% of African Americans, 75% of Chinese, and 70% of Filipinas lived in highly segregated neighborhoods. While the two measures provided the same estimate of racial/ethnic residential segregation for African Americans, their sensitivity varied for Hispanics and Asians.

Table 6 shows the distributions of resources/coping styles by race/ethnicity. Based on results from our qualitative phase, we included three distinct measures of resources/coping styles, including

John Henryism active coping, stress via the Perceived Stress Scale, and neighborhood cohesion/collective efficacy. The John Henryism Scale was used to measure active coping among EBCC participants. Overall, participants had a summary score of 22.2 with a possible range of 12-48 and higher scores indicating more active coping. Scores varied by racial/ethnic group with African Americans, Hispanics, and Filipinas having lower mean scores and Chinese having higher mean scores compared to the total sample. The internal reliability (Cronbach's alpha) was strong for this scale, overall and by racial/ethnic group (0.82 for the total sample, range from 0.76-0.85).

The Perceived Stress Scale was used to measure general perceived stress among EBCC participants; higher scores indicate greater stress. Overall the summary score was 15.5, and there was no statistically significant variation in mean scores by racial/ethnic group, although Chinese had slightly higher scores than all other racial/ethnic groups. The internal reliability (Cronbach's alpha) was strong for this scale, overall and by racial/ethnic group (0.82 for the total sample, range from 0.76-0.85).

Neighborhood cohesion/collective efficacy was measured using 5 questions asking about interactions and level of engagement with neighbors; higher scores indicate more collective efficacy. For the total sample, the mean summary score was 8.7 with a possible range of 5-20. Scores varied by racial/ethnic group with non-Hispanic Whites and African Americans reporting higher cohesion than the total sample, and Hispanics, Chinese and Filipinas reporting lower cohesion among their neighbors.

Table 7 shows the distribution of one of our major outcomes of interest, quality of life (QOL) variables, and internal consistency reliability of QOL scales by race/ethnicity. To assess QOL, we used selected measures from the Patient Reported Outcomes Measurement Information System (PROMIS) item bank, which were developed by NIH towards the goal of providing highly reliable and valid standardized tools for studies that measure patient–reported health status. Across the ten domains of QOL, there were significant racial/ethnic differences in seven of ten domains, including general health, quality of life, physical health, mental health, social satisfaction, social activities, fatigue, and pain. QOL scores for each PROMIS global item ranged from 1 to 5 for each item, with lower scores indicating better QOL and higher scores indicating worse QOL. The mean overall PROMIS summary score combining all ten items was significantly different across racial/ethnic groups, with non-Hispanic White women reporting the highest overall QOL (summary score=22.2) and African American and Chinese women reporting the worst overall QOL (summary scores=26.3 and 26.0, respectively). The internal consistency reliability of the PROMIS scale indicate that the scale performed considerably well, with Cronbach's alphas ranging from .88 to .91 across racial/ethnic groups.

Because EBCC participants were generally on average 4 years out since diagnosis, we sought to examine the psychosocial impact of breast cancer before and after diagnosis, using the PROMIS cancer-specific items for psychosocial illness impact. Results showed that there were significant differences across racial/ethnic groups for each psychosocial statement before and after diagnosis. The psychosocial summary scores (higher scores mean better psychosocial positive impact) indicate that African American and Hispanic women were most likely to agree with these positive statements before diagnosis (summary scores = 17.3 and 17.1, respectively), while Chinese women were least likely to agree with these positive statements (summary score = 15.0). Overall, most racial/ethnic groups tended to agree more strongly with these statements after diagnosis, particularly in non-Hispanic white, Hispanic, Chinese, and "Other" women. The internal consistency reliability of the PROMIS psychosocial positive illness impact scale indicate that the scales performed moderately well, with Cronbach's alphas ranging from .45 to .76 for pre-diagnostic scale measures and .41 to .87 for post-diagnostic scale measures.

We assessed breast cancer-specific quality of life items using selected measures from the standardized FACT-B scale (Functional Assessment of Cancer Therapies – Breast). These measures included six statements assessing the extent to which participants agreed with each item, which primarily measured side effects, body image, and worry about cancer in family members. Significant racial/ethnic differences were found for four of the six items, including feeling self-conscious about the way you dress, swollen/tender arms, feeling sexually attractive, and worrying about risk of cancer in other family members. The overall summary scores for this scale revealed that non-Hispanic White women were least affected by these items, suggesting better QOL (summary score = 11.7) and Filipina women were most affected by these items (summary score = 13.5). The Cronbach's alphas for the FACT-B scales were lowest of all QOL scales, with alphas ranging from .21 to .63.

Table 8 shows the QOL subscale scores by type of discrimination experience. Participants reporting any medical discrimination had lower quality of life across the four scales. While all four QOL scales performed consistently in assessing QOL, we focus here on results from the main PROMIS QOL scale in the first column of the table for ease of interpretation and simplicity. Among participants who reported any medical discrimination, those who attributed their discrimination experience to race/ethnicity had poorer QOL than participants who attributed discrimination to non-race/ethnicity reasons (PROMIS summary scores = 29.8 for race/ethnicity and 24.6 for non-race/ethnicity attributions (higher PROMIS summary scores indicate worse QOL, while lower scores indicate better QOL)). Similarly, participants who attributed their discrimination experience to immigration had poorer QOL than those who attributed it to non-immigration reasons (PROMIS summary scores = 29.6 for immigration and 24.7 for non-immigration attributions).

Results were similar with the global racial/ethnic discrimination single item. Participants who reported any medical discrimination had poorer QOL than those who did not report any medical discrimination based on the global measure (PROMIS summary scores = 29.1 vs. 23.6, respectively).

Lifetime discrimination did not appear to be associated with QOL, while participants reporting any recent everyday discrimination had slightly worse QOL than those who did not report any recent discrimination (PROMIS summary scores = 23.0 vs. 24.8, respectively).

To assess institutional-level discrimination, we included measurements for hospital mistrust and the two segregation indices. Those reporting any hospital mistrust had a marginally lower mean PROMIS QOL score (better QOL) relative to those reporting no mistrust. There were no differences in mean QOL scores by levels of segregation x racial/ethnic composition, with the exception of pre-diagnostic psychological illness positive impact, which showed lower scores (lower QOL) among those living in neighborhoods with higher proportions of residents with the same race/ethnicity as the respondent, regardless of level of dissimilarity. These QOL scores were lowest, however, among respondents living in neighborhoods with high isolation index and high same-race/ethnicity composition, relative to the other neighborhoods.

Table 9 shows the bivariate associations between discrimination experiences and surgical treatment outcomes (breast conserving surgery (BCS) no radiation (non-guideline treatment), BCS, and mastectomy) among early-stage (SEER summary stage = localized) breast cancer patients. Participants who received BCS without radiation were more likely to report any medical discrimination experiences (62.5%) compared with those who received mastectomy (49.5%) and BCS with radiation (41%) (global p=0.02). For lifetime discrimination experiences, there did not appear to be any significant differences in the type of surgical treatment received. However, for recent everyday discrimination using both the item-based measure and global measures of racial/ethnic discrimination, patients who received BCS without radiation were more likely to report any discrimination that those who received BCS with radiation or mastectomy, although this comparison was statistically significant only for the global measure.

Patients who received mastectomy were less likely to report any hospital mistrust compared to those who received BCS without radiation or BCS with radiation. Patients who received BCS without radiation (40%) and those who received BCS with radiation were more likely to live in high dissimilarity and high same-race/ethnicity composition neighborhoods, while patients who received mastectomy were more likely to live in low segregation neighborhoods. There were no differences for the isolation index.

Table 10 shows the bivariate associations between discrimination experiences and receipt of hormone (endocrine) therapy among participants who were diagnosed with estrogen receptor positive (ER+) and/or progesterone receptor positive (PR+) tumors (n=435), for whom the guideline-recommended treatment is endocrine therapy (Tamoxifen or aromatase inhibitors) for five years. There did not appear to be any significant associations between discrimination experiences and receipt of hormone therapy. Overall, the proportion of participants reporting any type of discrimination was similar in both women who had never hormone therapy and women who ever received hormone therapy.

Table 11 shows the bivariate association between stage at diagnosis and type of discrimination experience. Among EBCC participants who completed the epidemiologic telephone survey, 71% were diagnosed with early stage breast cancer, while 29% were diagnosed with late stage. As expected and shown in Table 2, participants were slightly over-represented in terms of earlier stage at diagnosis compared to the general population of study-eligible breast cancer patients from the cancer registry. Overall, there was no statistically significant association between stage at diagnosis and type of discrimination experience.

Table 12 shows the agreement statistics for the survey items selected for test-retest. Responders to the epidemiologic telephone survey were randomly sampled to be re-contacted after 2 weeks for a retest of these selected survey items. The mean number of days between the initial epidemiologic telephone interview and re-test was 20.1 days, and ranged from a minimum of 5 to a maximum of 193 days. The mean, minimum, and maximum numbers of days by racial/ethnic group is shown below.

Race/Ethnicity	Mean	Minimum	Maximum
NH White	15.7	6	37
African American	26.9	7	96
Hispanic	9.39	7	14
Chinese	20.2	5	193
Filipino	29.6	14	81
Other	23.1	13	65
Total	20.1	5	193

Of 144 respondents selected for a retest, 102 participated and 42 declined. African Americans were considerably more likely than other racial/ethnic groups to decline the retest. Absolute agreement statistics, not chance-adjusted, were calculated. In general, agreement on the medical discrimination items were moderately high to high, ranging from 76.5 (did you have to wait longer…) to 90.2 (did someone make inappropriate comments…), and agreements for most measures were in the 80s range. Agreements for the attribution items, however, were lower, in the 50's range. Agreement for the concern about unfair treatment due to race/ethnicity item was 82.4% and agreement for the personal-group discrepancy question was 70.6%. Agreement for the provider medical mistrust questions ranged from 50% (because of your

insurance status…) to 72.5% (in general, you find it difficult to trust doctors). Again, while test-retest agreements for the general recent everyday discrimination items were generally high, agreements for the attribution items were moderately low. These results, in addition to the large number of participants who reported a variety of types of attribution (see Appendix E), indicate that further research is needed in survey research on the optimal ways to meaningfully capture discrimination attribution.

Test-retest agreement for the PROMIS general health and psychosocial impact items were moderate, generally in the 50s range. Self-assessment of breast cancer surgery was exceedingly high. Provider preference was also high, but reasons for preference, among small sample of patients who reported preferring their own race/ethnicity, were moderately low on agreement. Support network questions were moderately high on agreement.

Although the results presented in this final report are primarily descriptive, we are in the process of reviewing these results to determine specific areas/topic for which we will conduct more focused and detailed analyses. We are also in the process of seeking additional funding to support more detailed data analysis and manuscript preparation.

Task 7 Prepare final reports, finalize manuscripts, and disseminate study findings, Months 59-60
a. Prepare final report for the community advisory committee.
b. Organize community advisory committee meeting to review final results, obtain feedback about implication of results and develop strategic plan for dissemination of results.
c. Present study findings at scientific and community forums.
Deliverables: initial manuscript of study results

Our qualitative results were published in a special issue of the American Journal of Public Health on Discrimination (Quach et al., AJPH, May 2012 (Appendix B)). The results were also presented as a poster at the NIH Science of Discrimination conference (February 2011) and the DOD BCRP Era of Hope meeting (August 2011) (Appendix C). Our abstract reporting on the social support, social burden, and social networks qualitative findings will be presented at the 2012 American Public Health Association (APHA) meeting in October. We have also given several educational seminars on the value of mixed methods in improving epidemiologic surveys, and used our experiences from this project as an example. Several more manuscripts are in progress, one describing the mixed-methods process and experience, and a second focusing on the qualitative results related to social support and social burden.

KEY RESEARCH ACCOMPLISHMENTS

- Used rigorous mixed-methods process to identify relevant themes related to discrimination and breast cancer outcomes in diverse population of breast cancer survivors, developed survey instrument based on comprehensive literature review and tailoring of survey instruments, as well as de-novo development of new items, and cognitive testing of items. Translated epidemiologic survey instrument in three languages (Spanish, Chinese, and Tagalog).
- Provided contributions to the value of the mixed-methods process to improving epidemiologic surveys – our team has given several seminars to various audiences on this topic, using this study as an example, and are in the process of writing a process manuscript.
- Provided valuable contributions to the discrimination, especially survey development, literature on measurement of types of and responses to discrimination in a diverse cancer survivor population.
- Translated and provided pilot test results on the PROMIS items (and will be shared with PROMIS investigators) on patient-reported outcome survey instrument.
- Manuscript reporting on qualitative results on medical discrimination selected for inclusion in a special theme issue on discrimination for the American Journal of Public Health.

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- Two additional manuscripts are currently under preparation, including manuscripts reporting on: 1) qualitative results on social support, social burden, and social networks; 2) process paper on the benefits of integrating mixed-methods research in epidemiologic studies.
- Presented research findings at several scientific meetings.
- Submitted 8 grant applications to leverage infrastructure developed through this study; one grant was funded, 3 are currently pending, and more are planned. The funded grant from the CBCRP is using the Asian cases recruited as part of the epidemiologic phase for a pilot case-control study.
- Provided innovative preliminary results demonstrating the importance of discrimination on cancer outcomes for larger-scale studies.

REPORTABLE OUTCOMES

Manuscripts

Quach T, Nuru-Jeter A, Morris P, Allen L, Shema SJ, Winters JK, Le GM, Gomez SL. Experiences and perceptions of medical discrimination among a multi-ethnic sample of breast cancer patients in the San Francisco Bay Area. American Journal of Public Health 2012;102(5):1027-34.

Le G, et al. Combining qualitative and quantitative methods to improve measurement in epidemiologic research. Manuscript in preparation.

Le G, et al. A re-appraisal of social support networks among breast cancer survivors: A qualitative study among multi-ethnic women in the San Francisco Bay Area. Manuscript in preparation.

Presentations

Gomez SL, Le GM, Quach T, Allen L, Morris P, Shema SJ, Winters JK, Nuru-Jeter A. Using a mixed-methods approach to develop self-reported measures of health care discrimination in a multiethnic sample of breast cancer patients in the San Francisco Bay Area (poster). NIH Science of Discrimination Meeting, Bethesda, MD, February 2011.

Gomez SL, Le GM, Quach T, Allen L, Morris P, Shema SJ, Winters JK, Nuru-Jeter A. Using a mixed-methods approach to develop self-reported measures of health care discrimination in a multiethnic sample of breast cancer patients in the San Francisco Bay Area (poster). DOD BCRP Era of Hope Meeting, Orlando, FL, August 2011.

Gomez SL. Le GM, Shariff-Marco S. Mixed methods: A promising approach for improving surveys in epidemiologic research. Departmental Seminar. Health Research and Policy, School of Medicine, November 1, 2011, Stanford, CA.

Le G, Morris P, Allen L, Quach T, Shariff-Marco S, Chen H, Winters JK, Shema SJ, Gomez SL. Negative aspects of social support networks among a diverse sample of breast cancer survivors in the San Francisco Bay Area (abstract accepted for poster presentation for session "Innovations in Cancer Survivorship Research"). American Public Health Association Annual Meeting, San Francisco, CA, October 31, 2012.

Funding applied for based on work supported by this award

Le, GM. Social Networks and Breast Cancer Outcomes in Diverse Communities. R21 grant submitted to the National Cancer Institute. Pending.

Le GM. Use and Influence of Social Networking Sites in Breast Cancer Survivors from Diverse Communities. Pilot grant submitted to the Stanford Cancer Institute. Pending.

Gomez SL. Multi-level Social and Cultural Predictors of Disparities in Breast Cancer Care. R01 submitted to the National Institute of Minority Health Disparities. Pending.

Gomez SL. The Immigrant Experience and Breast Cancer Risk in Asians. SRI (Special Research Initiative) grant submitted to the California Breast Cancer Research Program. Funded.

Gomez SL. Pathways to Disparities in Breast Cancer Care. R01 submitted to the National Institute of Minority Health Disparities. Not funded.

Gomez, SL. Social Networks and Breast Cancer Outcomes in Diverse Communities. IDEA grant submitted to the California Breast Cancer Research Program. Not funded.

Gomez SL. Discrimination and Disparities in Breast Cancer Care: Elucidating Pathways and Focus on Treatments. IDEA Expansion grant submitted to the DOD BCRP. Not funded.

Gomez SL. Reaching Toward Equality in Breast Cancer Care: Multilevel Influences of Neighborhoods and Institutions. IDEA grant submitted to the DOD BCRP. Not funded.

CONCLUSIONS

This study sought to use mixed-methods to develop a survey to measure discrimination among a diverse sample of breast cancer survivors, and to use the survey to measure the prevalence of discrimination and association of discrimination with breast cancer outcomes, including stage at diagnosis, treatment, and quality of life. Through the qualitative component of the study, we have gleaned invaluable perspectives regarding the subtle but important aspects of discrimination and its potential impacts on breast cancer outcomes. We aimed to develop an epidemiologic survey, drawing upon concepts and tools developed in other sociological disciplines, to quantify these aspects of discrimination and related themes. We encountered challenges with regards to recruitment, but did complete interviews with 523 respondents, with balanced representation across our target racial/ethnic groups (non-Hispanic Whites, African Americans, Hispanics, Chinese, Filipinas) to enable analyses specific to these groups. Our results showed that certain measures of interpersonal and institutional discrimination varied across racial/ethnic groups and were associated with most of the outcomes of interest. For example, interpersonal measures of medical and recent everyday discrimination varied by racial/ethnic groups and were associated with QOL (PROMIS global measure) and type of surgical treatment. Hospital mistrust and segregation measures also varied by racial/ethnic groups and were associated with QOL and treatment. These results warrant further evaluation with more focused data analyses and in larger study populations, for which we are actively seeking additional funding to support. Our results also inform future research efforts on survey development, in general (i.e., the value of mixed methods) and specific to discrimination measurement.

REFERENCES

None.

APPENDICES

A. Epidemiologic survey

B. Manuscript: Quach T, Nuru-Jeter A, Morris P, Allen L, Shema SJ, Winters JK, Le GM, Gomez SL. Experiences and perceptions of medical discrimination among a multi-ethnic sample of breast cancer patients in the San Francisco Bay Area. American Journal of Public Health 2012;102(5):1027-34.

C. Poster presented at the NIH Science of Discrimination Meeting (February 2011) and DOD BCRP Era of Hope Meeting (August 2011): Gomez SL, Le GM, Quach T, Allen L, Morris P, Shema SJ, Winters JK, Nuru-Jeter A. Using a mixed-methods approach to develop self-reported measures of health care discrimination in a multiethnic sample of breast cancer patients in the San Francisco Bay Area.

D. Tables

E. Open-ended responses to discrimination attribution survey items

List of personnel receiving pay from the research effort.

Scarlett Lin Gomez, Principal Investigator
Bang Nguyen, Co-Investigator
Thu Quach, Co-Investigator
Minh-Tram (Gem) Le, Co-investigator
David Nelson, Biostatistician
Preety Kalra, Project Director
Laura Allen, Program Manager
Pagan Morris, Project Coordinator
Helen Chen, Project Coordinator
Daisy Lubag, Project Coordinator
Sarah Aroner, Research Assistant
Regina Lagman, Filipina Interviewer
Alene Pham, Interviewer
Sonja Godfrey, African-American Interviewer
Mei-Chin Kuo, Mandarin Interviewer
Kathie Lau, Cantonese Interviewer
Zinnia Loya, Hispanic Interviewer
Lavetta Cross, African-American Interviewer
Shyanne Reese, African-American Interviewer
Regina Dela Cruz, Filipina Interviewer
Karen Llagas, Filipina Interviewer
Rowena Aseo, Filipina Interviewer
Josie Pasucal, Tagalog Translator
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June Kristine Winters, Research Assistant
Laura McClure, Epidemiologist
Christine Lieu, Intern
Sarah Shema, Biostatistical Programmer

Appendix A

Epidemiologic Survey

EQUALITY IN BREAST CANCER CARE

Epidemiologic Survey

07/19/2011

DATE:_____   TIME START:_____

STUDY ID:_____   TIME END:_____

                                        RETEST: _____ Y

INTERVIEWER:_____   _____ N

➢ GENERAL INSTRUCTIONS TO INTERVIEWER:

IT IS EXTREMELY IMPORTANT TO <u>READ EACH QUESTION VERBATIM</u>. All participants need to hear each question in the exact same way in order for us to ensure that the responses they provide are not biased.

*Read all **BOLD black** type. The questions are in **BOLD black** type, as well as some instructions and introductions to various sections. Do not read choices that are in ALL CAPS. The choice "I don't know" is indicated by "D/K," and if the participant refuses to answer a question, select "REF" or "REFUSED." You are not to give "D/K" as an answer choice, but if, after probing, the participant says that they do not know, you would then circle that choice. **Instructions that begin with BLUE BOLD fonts indicate that there are optional, additional explanations or probes you can read to the participant—they are not required to be read.** **The fonts in red are instructions to guide you to the next question or skip pattern.** Instructions in* yellow text boxes *indicate you need to either enter an answer response on the Reference Sheet, or check the Reference Sheet response for skip pattern. If there are no skip pattern instructions, proceed to the next question.*

➢ READ THESE INSTRUCTIONS TO PARTICIPANT:

Thank you again for agreeing to participate in the Equality in Breast Cancer Care or "EBCC" study.

During this interview, we will be asking you a variety of questions, some will be specific to your breast cancer treatment and others will be broader questions about your life experiences. You may skip any questions that you do not feel comfortable answering. You may also stop answering questions at any time. You can decide not to participate simply by telling me that you do not want to answer any questions at all.

We appreciate your time and effort in helping us with this research study.

SECTION 1: INTRODUCTION (INTRO)

INTRO1.   **Do you have any questions before we begin?**

   1   Yes → *Address participant's questions as applicable, and then go to **INTRO2***

   2   No → *Go to **INTRO2***

INTRO2.   **May I start with the questions?**

   1   Yes → *Begin Survey*

   2   No → *Comments regarding refusal:*

   _____

   _____

   _____

SECTION 2: GENERAL QUESTIONS (G)

We would like to gather some basic information about you.

G1. **What is your date of birth?** _____/_____/_____
                                                Month   Day   Year

G2. **Are you Latina or Hispanic?**
(Circle one)

1. Yes → *Go to G3*
2. No → *Go to G4*
88. REFUSED
99. D/K

> If **Yes,** check box here and on Reference Sheet box **G2.**

G3. **Please look at Show Card #1. What is your Latina or Hispanic ancestry or origin? You may choose all that apply.** *(Circle all that apply)*

1. Argentinean	13. Paraguayan
2. Bolivian	14. Panamanian
3. Chicana	15. Peruvian
4. Chilean	16. Puerto Rican
5. Costa Rican	17. Salvadoran
6. Cuban	18. Spanish (from Spain)
7. Ecuadoran	19. Uruguayan
8. Guatemalan	20. Venezuela
9. Honduran	87. Other Latina (please specify):
10. Mexican American	
11. Mexican/ Mexicana	88. REFUSED
12. Nicaraguan	99. D/K

> If **more than one** response selected, check box here and on Reference Sheet box **G3.**

G4. **Please look at Show Card #2. Which of the races/ethnicities would you use to describe yourself? You may choose all that apply.**
(Circle all that apply)

1. American Indian or Alaskan Native
2. Asian
3. Black/African-American
4. Native Hawaiian
5. Other Pacific Islander
6. White
87. Other (please specify): _____
88. REFUSED
99. D/K

> Circle responses here and on Reference Sheet item **G4.**

> If **more than one** response selected, check box here and on Reference Sheet box **G4.**

G5.　[If R is American Indian or Alaska Native] **Please look at Show Card #3. Which of the listed tribes is your tribal heritage? You may choose all that apply.** *(Circle all that apply)*

1. Athabascan	11. Navajo	
2. Cahuilla	12. Pomo	If **more than one** response selected, check box here and Reference Sheet box **G5.**
3. Cherokee	13. Pueblo	
4. Choctaw	14. Sioux	
5. Chumash	15. Tlingit	
6. Karuk	16. Yurok	
7. Kumeyaay	87. Other tribe (please specify):	
8. Luiseno		
9. Maidu	88. REFUSED	
10. Miwok	99. D/K	

G6.　[If R is American Indian or Alaska Native] – **Are you enrolled in a state or federally recognized tribe?** *(Circle one)*

1. Yes → *Go to G7*
2. No → *Check Reference Page response to item G4, Go to appropriate ethnic group question (if more apply), based on response to G4.*
88. REFUSED
99. D/K

G7.　**Please look at Show Card #3. In which of the listed tribes are you enrolled?** *(Circle all that apply)*

1. Athabascan	11. Navajo
2. Cahuilla	12. Pomo
3. Cherokee	13. Pueblo
4. Choctaw	14. Sioux
5. Chumash	15. Tlingit
6. Karuk	16. Yurok
7. Kumeyaay	87. Other tribe (please specify):
8. Luiseno	
9. Maidu	88. REFUSED
10. Miwok	99. D/K

G8.   [If R is Asian] – **Please look at Show Card #4. Which of the listed ethnic groups best describe you (such as Chinese, Filipina)? You may choose all that apply.**
        (Circle all that apply)

1.	Bangladeshi	11.	Laotian
2.	Burmese	12.	Malaysian
3.	Cambodian (Kampuchean)	13.	Pakistani
4.	Chinese	14.	Sri Lankan
5.	Filipina	15.	Taiwanese
6.	Hmong	16.	Thai
7.	Indian (India)	17.	Vietnamese
8.	Indonesian	87.	Other Asian (please specify): _____
9.	Japanese	88.	REFUSED
10.	Korean	99.	D/K

If **more than one** response selected, check box here and on Reference Sheet box **G8**.

G9.   [If R is Pacific Islander] – **Please look at Show Card #5. Which of the listed ethnic groups best describe you (such as Samoan, Tongan)? You may choose all that apply.** *(Circle all that apply)*

1.	Fijian
2.	Guamanian/Chamorro
3.	Samoan
4.	Tongan
87.	Other Pacific Islander (please specify): _____
88.	REFUSED
99.	D/K

If **more than one** response selected, check box here and on Reference Sheet box **G9**.

G10. **[If R is White] – Please look at Show Card #6. Which of the listed ethnic groups best describe you? You may choose all that apply.** *(Circle all that apply)*

1. Arab Middle Eastern
2. Non-Arab Middle Eastern
3. English
4. Eastern European
5. French
6. German
7. Irish
8. Italian
9. Russian
10. Scandinavian
11. Mixed European descent
87. Other (please specify): _____
88. REFUSED
99. D/K

> If **more than one** response selected, check box here and on Reference Sheet box **G10**.

G11. **[If R is Black/African-American] – Please look at Show Card #7. Which of the listed ethnic groups best describe you? You may choose all that apply.** *(Circle all that apply)*

1. African American
2. Cape Verdean
3. Ethiopian
4. Ghanaian
5. Nigerian
6. Somali
7. Jamaican
8. Haitian
9. Brazilian
85. Other African (please specify): _____
86. Other West Indian/Caribbean (please specify): _____
87. Other Central/South American (please specify): _____
88. REFUSED
99. D/K

> If **more than one** response selected, check box here and on Reference Sheet box **G11**.

> ➢ *Check Reference Sheet boxes **G2 – G11**. If any boxes checked, Go to **G12**. If all boxes blank, Go to **G14**, page 8.*

G12. **Do you identify with any one race or ethnic group in particular?** *(Circle one)*

1. Yes → *Go to **G13***
2. No
88. REFUSED   } *Go to **G14**, page 8.*
99. D/K

G13. **Please look at Show Card #8. Which of the listed racial or ethnic groups do you most identify with? Please choose only one.** *(Circle one)*

1. African American/ Black
2. American Indian or Alaska Native
3. Arab Middle Eastern
4. Non-Arab Middle Eastern
5. Argentinean
6. Asian
7. Bangladeshi
8. Bolivian
9. Brazilian
10. Burmese
11. Cambodian (Kampuchean)
12. Cape Verdean
13. Chicana
14. Chilean
15. Chinese
16. Columbian
17. Costa Rican
18. Cuban
19. Eastern European
20. Ecuadoran
21. English
22. Ethiopian
23. Fijian
24. Filipina
25. French
26. German
27. Ghanaian
28. Guamanian/Chamorro
29. Guatemalan
30. Haitian
31. Hmong
32. Honduran
33. Indian (India)
34. Indonesian
35. Irish
36. Italian
37. Jamaican
38. Japanese
39. Korean
40. Laotian
41. Malaysian
42. Mexican/Mexicana
43. Mixed European descent
44. Native Hawaiian
45. Nicaraguan

46. Nigerian
47. Pakistani
48. Panamanian
49. Paraguayan
50. Peruvian
51. Puerto Rican
52. Russian
53. Salvadoran
54. Samoan
55. Scandinavian
56. Somali
57. Spanish (from Spain)
58. Sri Lankan
59. Taiwanese
60. Thai
61. Tongan
62. Uruguayan
63. Vietnamese
64. White
81. Other African (specify):

_____

82. Other Asian (specify):

_____

83. Other Central/South American (specify):

_____

84. Other Latina (specify):

_____

85. Other Pacific Islander (specify):

_____

86. Other West Indian/Caribbean (specify):

_____

87. Other (specify):

_____

88. REFUSED
99. D/K

G14.   **In what country were you born?**

_____ }

If born outside the US, check box here and on Reference Sheet item **G14**.

SECTION 3: DIAGNOSIS AND TREATMENT (T)

The next section will focus on questions about your breast cancer diagnosis and treatment.

T1. **Have you had a recurrence of your breast cancer since your breast cancer diagnosis in [*dxyr:*_____]?**

(Circle one)

1. Yes
2. No
88. REFUSED
99. D/K

T2. **What was your marital or relationship status at the time of your breast cancer diagnosis?**

(Read responses and circle one)

1. Legally married or registered domestic partner
2. Separated
3. Divorced
4. Widowed
5. Living with a partner to whom you are not married
6. In a relationship but not living with partner
7. Single
87. Other (please specify) _____
88. REFUSED
99. D/K

T3. **Which of the following best describes your <u>current</u> marital or relationship status?**

(Read responses and circle one)

    1.   Legally married or registered domestic partner

    2.   Separated

    3.   Divorced

    4.   Widowed

    5.   Living with a partner to whom you are not married

    6.   In a relationship but not living with partner

    7.   Single

    87.   Other (please specify) _____

    88.   REFUSED

    99.   D/K

T4. **At the time of your breast cancer diagnosis, what was your bra size?**

(Write in number and letter: Ex. 36A)

_____ _____

    88   REFUSED

    99   D/K

T5. **Did you have surgery for your breast cancer? By surgery we mean a procedure in which breast tissue was removed.**

(Circle one)

    1.   Yes → *Go to **T7***

    2.   No → *Go to **T6***

    88.   REFUSED   *Go to **T13**, page 13*

    99.   D/K

T6.   **Please respond 'Yes' or 'No' if any of the following were reasons why you did not have surgery:**

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

1.   You did not feel it was necessary. ....Y   N
2.   You have not had surgery, but are considering doing so. ....Y   N
3.   You didn't want to have surgery. ....Y   N
4.   Your doctor did not recommend it...Y   N

Was it because...

5.   Of your age. ....Y   N
6.   Of side effects...Y   N   *Go to T13*
7.   Of financial or insurance reasons. ....Y   N   *page 13*

Are there any other reasons why you did not have surgery that I have not yet mentioned?

87.   Other reason (specify) _____

87.   Other reason (specify) _____

87.   Other reason (specify) _____

88.   REFUSED

99.   D/K

T7.   **Did you have a lumpectomy or lumpectomies?**
(**Probe:** surgery to remove the lump from your breast?)

(Circle one)

1.   Yes → **How many lumpectomies did you have?** _____

2.   No

88.   REFUSED

99.   D/K

T8.   **Did you have an axillary or sentinel node dissection?**
(**Probe:** surgery to remove lymph nodes from your armpit?)

(Circle one)

1.   Yes

2.   No

88.   REFUSED

99.   D/K

T9. **Did you have a mastectomy?**
(*Probe:* surgery to remove your entire breast?)

(Circle one)

1.   Yes → **Which breast?** *(Circle one)*   Left   Right   Both

2.   No

88.   REFUSED   } *Go to T13, page 13*

99.   D/K

T10. **Was breast reconstruction offered as an option to be done at the same time as your mastectomy?**
(*Provide definition as needed:* Breast reconstruction is surgery to rebuild your breast(s) with some type of tissue or implant. Reconstruction can be done at the time of mastectomy or any time later.)

(Circle one)

1.   Yes

2.   No

88.   REFUSED

99.   D/K

T11. **Did you have breast reconstruction?**

(Circle one)

1.   Yes

2.   No

88.   REFUSED

99.   D/K

T12. **Did you end up getting a mastectomy for any of the following reasons?**

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

1. You did not want to go through radiation treatment ....Y   N

2. You could not (or did not want to) travel everyday to receive radiation treatments............Y   N

3. You believed that someone who gets a mastectomy has a better chance of surviving
    breast cancer than someone who gets a lumpectomy ....Y   N

4. You did not want to worry about a recurrence ....Y   N

Are there any other reasons why you ended up getting a mastectomy that I have not yet mentioned?

87. Other reason (specify) _____

87. Other reason (specify) _____

88. REFUSED

99. D/K

		Yes	No	REF	D/K
T13.	**Did your doctor recommend radiation treatment?** *(Circle one)*	1	2	88	99
T14.	**Did you receive radiation treatment?** *(Circle one)*	1	2	88	99

*Check Reference Sheet, page 2, item **T13** and **T14** for skip pattern instructions*

T15. **Did you stop receiving radiation before completing the recommended number of treatments?**

(Circle one)

1. Yes → *Go to **T16***

2. No

88. REFUSED   *Go to **T19**, page 15*

99. D/K

T16. **Did you end up completing the recommended number of radiation treatments?**

(Circle one)

1. Yes → *Go to T19*

2. No → *Go to T17*

88. REFUSED⎫
             ⎬ *Go to T19, page 15*
99. D/K   ⎭

T17. **Please respond 'Yes' or 'No' if any of the following were reasons why you did not complete radiation:**

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

1. Of side effects ....Y   N

2. Of transportation problems ....Y   N

3. Of financial or insurance reasons..Y   N

Was it because...

4. You did not feel it was necessary to continue ....Y   N

5. You did not want to commit to the length of time required to
    complete treatment...Y   N   *Go to T19, page 15*

6. You were worried about your fertility ....Y   N

Are there any other reasons why you did not complete radiation treatment that I have not yet mentioned?

87. Other reason (specify) _____

87. Other reason (specify) _____

88. REFUSED

99. D/K

T18. **Please respond 'Yes' or 'No' if any of the following were reasons why you did not have radiation:**

(Read each reason and circle 'Y' or 'N' for each)

Was it because...
1. Of financial or insurance reasons ....Y   N

2. Of transportation problems ....Y   N

Was it because...

3. You were worried about side effects ....Y   N

4. You did not feel it was necessary ....Y   N

5. You did not want to commit to the length of time required for treatment.Y   N

6. You were worried it would affect your fertility...Y   N

Are there any other reasons why you did not receive radiation treatment that I have not yet mentioned?

87. Other reason (specify) _____

87. Other reason (specify) _____

88. REFUSED

99. D/K

		Yes	No	REF	D/K
T19.	**Did your doctor recommend chemotherapy?** *(Circle one)*	1	2	88	99
T20.	**Did you receive chemotherapy?** *(Circle one)*	1	2	88	99

*Check Reference Sheet, page 3, item **T19** and **T20** for skip pattern instructions*

T21. **Did you stop receiving chemotherapy before completing the recommended number of treatments?**

(Circle one)

    1.   Yes → *Go to **T22***

    2.   No

    88.   REFUSED   *Go to **T25**, page 17*

    99.   D/K

T22. **Did you end up completing the recommended number of chemotherapy treatments?**
(Circle one)

    1.   Yes → *Go to **T25***

    2.   No → *Go to **T23***

    88.   REFUSED   *Go to **T25**, page 17*

    99.   D/K

T23. **Please respond 'Yes' or 'No' if any of the following were reasons why you did not complete chemotherapy:**

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

1. Of side effects	Y	N
2. Of transportation problems	Y	N
3. Of financial or insurance reasons	Y	N

Was it because...

4. You did not feel it was necessary to continue	Y	N
5. You did not want to commit to the length of time required to complete treatment	Y	N
6. You were worried about your fertility	Y	N

*Go to **T25**, page 17*

Are there any other reasons why you did not complete chemotherapy that I have not yet mentioned?

    87.   Other reason (specify) _____

    87.   Other reason (specify) _____

    88.   REFUSED

    99.   D/K

T24. **Please respond 'Yes' or 'No' if any of the following were reasons why you did not have chemotherapy:**

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

1. Of financial or insurance reasons ....Y   N

2. Of transportation problems ....Y   N

Was it because...

3. You were worried about side effects...Y   N

4. You did not feel it was necessary ....Y   N

5. You did not want to commit to the length of time

   required for treatment ....Y   N

6. You were worried it would affect your fertility....................................Y   N

Are there any other reasons why you did not receive chemotherapy treatment that I have not yet mentioned?

87. Other reason (specify) _____

87. Other reason (specify) _____

88. REFUSED

99. D/K

		Yes	No	REF	D/K
T25.	Did your doctor recommend Tamoxifen, Arimidex, or some other type of hormone treatment for your breast cancer? (*Probe:* The kind of medication that you take for 5 years?) *(Circle one)*	1	2	88	99
T26.	Did you take Tamoxifen, Arimidex, or some other type of hormone treatment for your breast cancer? *(Circle one)*	1	2	88	99

*Check Reference Sheet, page 4, item **T25** and **T26** for skip pattern instructions*

T27. Was there any time you stopped taking hormone treatment?

(Circle one)

1. Yes → *Go to T28*

2. No

88. REFUSED } *Go to T32, page 20*

99. D/K

T28. Are you still taking hormone treatment?

(Circle one)

1. Yes → *Go to T29*

2. No → *Go to T30*

88. REFUSED } *Go to T32, page 20*

99. D/K

T29. Please respond 'Yes' or 'No' if any of the following were reasons why you had temporarily stopped taking hormone treatment:

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

1. Of side effects .... Y   N

2. Of financial or insurance reasons .... Y   N

Was it because...

3. You did not feel it was necessary to continue .... Y   N

4. Your doctor recommended you *stop* temporarily...................... Y   N

5. You were worried it would affect your fertility .... Y   N   *Go to T32, page 20*

Are there any other reasons why you temporarily stopped taking hormone therapy that I have not yet mentioned?

87. Other reason (specify) _____

87. Other reason (specify) _____

88. REFUSED

99. D/K

T30. **Please respond 'Yes' or 'No' if any of the following were reasons why you stopped taking hormone treatment:**

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

1. Of side effects .... Y   N

2. Of financial or insurance reasons .... Y   N

Was it because...

3. You did not feel it was necessary to continue .... Y   N

4. Your doctor recommended you *stop* taking it............................ Y   N

5. You finished treatment... Y   N

6. You were worried it would affect your fertility .... Y   N

Go to T32, page 20

Are there any other reasons why you are no longer taking hormone therapy that I have not yet mentioned?

87. Other reason (specify) _____

87. Other reason (specify) _____

88. REFUSED

99. D/K

T31. **Please respond 'Yes' or 'No' if any of the following were reasons why you did not take hormone treatment:**

(Read each reason and circle 'Y' or 'N' for each)

Was it because...

1. Of financial or insurance reasons .... Y   N

Was it because...

2. You did not feel it was necessary .... Y   N

3. You were worried about side effects .... Y   N

4. You were worried it would affect your fertility................................. Y   N

Are there any other reasons why you did not take hormone therapy that I have not yet mentioned?

87. Other reason (specify) _____

87. Other reason (specify) _____

88. REFUSED

99. D/K

T32. **Which of the following best describes the role your <u>DOCTORS</u> played when making decisions about your treatment? Was the final treatment decision:**

(*Read responses and circle one*)

      1.   Made **on your own**

      2.   Made **after hearing your doctor's input.**

      3.   Made **together with your doctor(s).**

      4.   Made **by your doctor(s) after hearing your input.**

      5.   Made **by your doctor(s) on their own with little input from you.**

   77. N/A (*ex. Family made decision*)

   88. REFUSED

   99. D/K

T33. **Did you seek traditional methods or alternative healing to help with the cancer or side effects from treatment? For example, did you use Chinese or Eastern medicine, vitamins or herbal supplements, massage, yoga, acupuncture, etc?**

(*Circle one*)

      1.   Yes

      2.   No

   88. REFUSED

   99. D/K

T34. **Did you seek spiritual healing such as talking to individuals in your church, praying, meditating, etc?**

(*Circle one*)

      1.   Yes

      2.   No

   88. REFUSED

   99. D/K

SECTION 4: HEALTH INSURANCE (H)

H1. **Did you have health insurance at the time of your breast cancer diagnosis?**

(*Circle one*)

     1. Yes → *Go to H4*

     2. No → *Go to H2*

     88. REFUSED ⎤

                   ⎬ *Go to H2*

     99. D/K ⎦

H2. **Did you get health insurance after you learned of your breast cancer diagnosis?**

(*Circle one*)

     1. Yes → *Go to H4*

     2. No → *Go to H3*

     88. REFUSED ⎤

                   ⎬ *Go to H5*

     99. D/K ⎦

H3. **You said that you had no health insurance from any source for your breast cancer diagnosis and treatment. Is that correct?**

(*Circle one*)

     1. Yes → *Go to H5*

     2. No → *Go to H4*

     88. REFUSED ⎤

                   ⎬ *Go to H5*

     99. D/K ⎦

> Circle response here and enter response number in Reference Sheet, page 5, item **H3**.

H4. **Please look at Show Card #9. What kind of health insurance or health care coverage did you have/get?**

(Circle all that apply)

1. Health insurance through my job or my husband's/wife's/partner's job (such as Blue Cross, HealthNet, Kaiser, etc.)
2. Individual health insurance not provided by my job or my husband's/wife's/partner's job (such as Blue Cross, HealthNet, Kaiser, etc.)
3. MediCare Part A and/or Part B
4. MediCare Part D prescription drug coverage (MediCare drug card)
5. Extra insurance for MediCare (Medi-Gap)
6. Medi-Cal
7. Other government health program (county or state)
8. Military health care (such as TRICARE, VA, CHAMP-VA)
9. Indian Health Service
10. Single-service plan (such as dental, vision, prescriptions)
87. Other: _____
88. REFUSED
99. D/K

> Circle response(s) here and enter response number(s) in Reference Sheet, page 5, item **H4**.

H5. **Did you have any out-of-pocket costs for fertility treatments because of your breast cancer diagnosis? By out-of-pocket, we mean costs that you paid for yourself.**

(Circle one)

1. Yes → *Go to **H6***
2. No
88. REFUSED
99. D/K
} *Go to **H7***

H6. **How much would you estimate your out-of-pocket costs were for these treatments? Your best estimate is fine.**

H7. **Now I'd like you to think about how much money you spent out-of-pocket on breast cancer-related medical care <u>WITHIN THE FIRST YEAR OF YOUR DIAGNOSIS</u>. Again, your best estimate is fine.**

[*If needed, you can offer the definition for out-of-pocket costs:* Include only payments that YOU made, not total bills or charges. Include copayments and deductibles, but do not include health insurance premiums. Do not include health care costs that you were reimbursed for later.]

Did you have any out-of-pocket costs for:	If Yes: How much did you pay out-of-pocket?	No	Didn't rec'v this tx	REF	D/K
a. Did you have any out-of-pocket costs for consultations, including any second opinions?	1 $ _____	2	77	88	99
b. Did you have any out-of-pocket costs for tests, such as blood tests, genetic tests or imaging?	1 $ _____	2	77	88	99
c. Did you have any out-of-pocket costs for surgeries?	1 $ _____	2	77	88	99
d. chemotherapy?	1 $ _____	2	77	88	99
e. radiation?	1 $ _____	2	77	88	99
f. hormonal therapy?	1 $ _____	2	77	88	99
g. any other prescription drugs?	1 $ _____	2	77	88	99
h. any alternative therapies like herbs, Chinese medicine, supplements, and massages?	1 $ _____	2	77	88	99
i. any OTHER out-of-pocket costs related to your breast *cancer care* not mentioned already? [*After the amount is given, ask:*] **Please specify what costs you included.** _____	1 $ _____	2	77	88	99

Section 5: PATIENT-PROVIDER COMMUNICATION (P)

Now we are going to move on to the next Section which is about your doctors and other healthcare providers.

P1 **With which of the following types of doctors did you discuss your breast cancer treatment?**

(Read each doctor type and circle one response for each)

	Yes	No	REF	D/K
a. **Internist/Primary care doctor**	1	2	88	99
a1. [If Yes] **Is your internist/primary care doctor male or female?**	M F			
b. **Surgeon**	1	2	88	99
b1. [If Yes] **Is your surgeon male or female?**	M F			
c. **Plastic Surgeon**	1	2	88	99
c1. [If Yes] **Is your plastic surgeon male or female?**	M F			
d. **Oncologist (doctor who treats cancer with drugs)**	1	2	88	99
d1. [If Yes] **Is your oncologist male or female?**	M F			
e. **Radiation oncologist (radiation doctor)**	1	2	88	99
e1. [If Yes] **Is your radiation oncologist male or female?**	M F			
Are there any other types of doctors that I have not yet mentioned with whom you spoke with about your treatment options?				
f. **Other MD (specify) _____** f1. **Is your [Other MD] male or female?**	1 M F	2	88	99
g. **Other MD (specify) _____** g1. **Is your [Other MD] male or female?**	1 M F	2	88	99

> Circle responses here and also circle doctor types in Reference Sheet, page 5, item **P1.**

P2. How difficult was it for you to reach your [doctor type] when you wanted to? This includes by phone, in-person, or e-mail.	Not at all difficult	Some-what difficult	Very difficult	Refused	Don't Know
a. Internist/Primary care doctor	1	2	3	88	99
b. Surgeon	1	2	3	88	99
c. Plastic Surgeon	1	2	3	88	99
d. Oncologist	1	2	3	88	99
e. Radiation Oncologist	1	2	3	88	99
f. Other MD: _____	1	2	3	88	99
g. Other MD: _____	1	2	3	88	99

P3. How difficult was it for you to understand your [doctor type]?	Not at all difficult	Somewhat difficult	Very difficult	REF	Don't Know	P4. Was this because you and your [doctor type] spoke different languages?	Yes	No	REF	Don't Know
a. Internist/ Primary care doctor	1	2	3	88	99	→ if '2' or '3': Was this because you and your **internist/ primary care doctor** spoke different languages?	1	2	88	99
b. Surgeon	1	2	3	88	99	→ if '2' or '3': Was this because you and your **surgeon** spoke different languages?	1	2	88	99
c. Plastic Surgeon	1	2	3	88	99	→ if '2' or '3': Was this because you and your **plastic surgeon** spoke different languages?	1	2	88	99
d. Oncologist	1	2	3	88	99	→ if '2' or '3': Was this because you and your **oncologist** spoke different languages?	1	2	88	99
e. Radiation Oncologist	1	2	3	88	99	→ if '2' or '3': Was this because you and your **radiation oncologist** spoke different languages?	1	2	88	99
f. Other MD specify: _____ _____	1	2	3	88	99	→ if '2' or '3': Was this because you and your [doctor type] spoke different languages?	1	2	88	99
g. Other MD specify: _____ _____	1	2	3	88	99	→ if '2' or '3': Was this because you and your [doctor type] spoke different languages?	1	2	88	99

If ALL "1", "88," or "99" Go to P7, page 28

If ANY "1" Go to P5, else Go to P7, p 28

P5.   **Did someone else help you understand your doctor(s)?**

(Circle one)

1. Yes → *Go to P6*
2. No
88. REFUSED   } *Go to P7*
99. D/K

P6.   **Please look at Show Card # 10. Who was the <u>main</u> person who helped you understand your doctor(s)?**

(Circle one)

1.   Your husband or partner
2.   Another family member over age 18
3.   A family member under age 18
4.   A friend over age 18
5.   A friend under age 18
6.   A non-medical office staff person
7.   A medical staff person, including nurses or doctors
8.   A professional interpreter
9.   A telephone interpreter service
87. Someone else (specify)

   _____

88. REFUSED
99. D/K

P7. **Please look at Show Card #11. Which of the listed racial/ethnic categories would you use to describe your [doctor type]?**

(Circle all that apply)

a. **Internist/Primary Care doctor**

     1   White

     2   Latino or Hispanic

     3   Black or African American

     4   Asian (specify): _____

     5   American Indian or Alaskan Native

     6   Native Hawaiian or Other Pacific Islander

    87   Other (specify): _____

    88   REFUSED

    99   D/K

b. **Surgeon**

     1   White

     2   Latino or Hispanic

     3   Black or African American

     4   Asian (specify): _____

     5   American Indian or Alaskan Native

     6   Native Hawaiian or Other Pacific Islander

    87   Other (specify): _____

    88   REFUSED

    99   D/K

c. **Plastic Surgeon**

     1   White

     2   Latino or Hispanic

     3   Black or African American

     4   Asian (specify): _____

     5   American Indian or Alaskan Native

     6   Native Hawaiian or Other Pacific Islander

    87   Other (specify): _____

    88   REFUSED

    99   D/K

P7(cont.)

    d. **Oncologist**

        1 White

        2 Latino or Hispanic

        3 Black or African American

        4 Asian (specify): _____

        5 American Indian or Alaskan Native

        6 Native Hawaiian or Other Pacific Islander

      87 Other (specify): _____

      88 REFUSED

      99 D/K

    e. **Radiation Oncologist**

        1 White

        2 Latino or Hispanic

        3 Black or African American

        4 Asian (specify): _____

        5 American Indian or Alaskan Native

        6 Native Hawaiian or Other Pacific Islander

      87 Other (specify): _____

      88 REFUSED

      99 D/K

    f. **Other MD (specify _____)**

        1 White

        2 Latino or Hispanic

        3 Black or African American

        4 Asian (specify): _____

        5 American Indian or Alaskan Native

        6 Native Hawaiian or Other Pacific Islander

      87 Other (specify): _____

      88 REFUSED

      99 D/K

P8. **If you could choose, would you prefer to be treated by doctors of your own racial/ethnic group, another racial/ethnic group, or do you NOT have a preference?**

(*Circle one*)

1. Your own racial/ethnic group → *Go to P9*
2. Another racial/ethnic group ⎫
3. No preference   ⎬ *Go to P10*
88. REFUSED   ⎪
99. D/K   ⎭

P9. **Why would you prefer to have a doctor who is of the <u>same</u> race/ethnicity as you? Is it because:**

(*Read each reason and circle 'Y' or 'N' for each*)

1	She or he would understand your disease better than others (that is, the type of cancer you have, your biology or physiology)	Y	N
2	She or he would be able to speak your language.	Y	N
3	She or he would understand your cultural beliefs.	Y	N
4	She or he would be able to relate to you better.	Y	N
5	You feel you would be more involved in making decisions about your care	Y	N
6	Other: please specify _____		
88	REFUSED		
99	D/K		

P10. **Now I would like you to think about all of your care that you had for your breast cancer.**

(Read each question and circle one response for each)

		Always	Usually	Sometimes	Never	Refused	D/K
a.	**How often did your doctors carefully listen to you?** READ *"Would you say Always, Usually, Sometimes, Never" after the first 2 questions and then as necessary.*	1	2	3	4	88	99
b.	**How often did your doctors encourage you to ask questions?**	1	2	3	4	88	99
c.	**How often were your nurses helpful to you?**	1	2	3	4	88	99
d.	**How often did you think that problems were handled quickly enough?**	1	2	3	4	88	99
e.	**How often did the doctors, nurses, and other medical staff seem to work well together as a team?**	1	2	3	4	88	99
f.	**How often did you know whom to ask when you had any questions?**	1	2	3	4	88	99

P11. **OVERALL, on a scale of 1 to 10 where 1 is the worst health care possible and 10 is the best health care possible, what number would you use to rate the breast cancer care you have received ?**

(Write down number)

_____

88 REFUSED
99 D/K

Section 6: MEDICAL DISCRIMINATION (M)

There have been many stories about people experiencing unfair treatment for many reasons by their health care team (including doctors, nurses, office staff and technicians).

M1.   **While getting medical care for breast cancer, did you feel you were treated unfairly by having <u>any</u> of the following things happen to you?**

(Read each question and circle one response for each)

HOW OFTEN...	Never	Rarely	Sometimes	Often	REFUSED	D/K
a. were you treated with less respect than other people **READ** *"Would you say Never, Rarely, Sometimes, or Often" after the first 2 questions and then as necessary.*	1	2	3	4	88	99
b. did you receive poorer service than others	1	2	3	4	88	99
c. did someone from your health care team act as if he or she thinks you are not smart	1	2	3	4	88	99
d. did someone from your health care team act as if he or she is better than you	1	2	3	4	88	99
e. did you feel like someone was not listening to what you were saying	1	2	3	4	88	99
f. did someone make inappropriate comments to you or about you	1	2	3	4	88	99
g. did you have to wait longer than other people to be seen by your health care team	1	2	3	4	88	99
h. did you feel that you were denied a test or treatment	1	2	3	4	88	99
i. did you feel that you had to insist on receiving a test or treatment	1	2	3	4	88	99

If **ANY** *"2," "3," or "4" Go to* **M2**

If **ALL** *"1," "88,"or "99" Go to* **M3**

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M2. **Please see Show Card #12. I will read through each option. Please tell me which of these may be the reasons why you were treated unfairly while getting medical care for breast cancer?**

(Read each reason and circle one response for each)

Was it because of...	Yes	No	Refused	D/K
a. Your health insurance (or lack of)	1	2	88	99
b. The way you speak English	1	2	88	99
c. Your birthplace	1	2	88	99
d. Your gender	1	2	88	99
e. Your race/ethnicity	1	2	88	99
f. Your age	1	2	88	99
g. Your religion	1	2	88	99
h. Your height or weight	1	2	88	99
i. Your skin color	1	2	88	99
j. Your sexual orientation	1	2	88	99
k. Your education	1	2	88	99
l. How much money you have	1	2	88	99
m. A physical disability	1	2	88	99
n. Your appearance on a given day	1	2	88	99
o. Other: please specify _____	1	2	88	99

Now, I would like you to think about medical care in general, not just care related to your breast cancer.

M3. **In general, how concerned are you that you may be treated unfairly *because* of your race/ethnicity <u>when seeking medical care</u>?**

(Read responses and circle one)

      1   Not at all concerned

      2   A little concerned

      3   Somewhat concerned

      4   Extremely concerned

    88   REFUSED

    99   D/K

M4. **In general, how concerned are you that people of your same race/ethnicity may be treated unfairly *because* of their race/ethnicity <u>when seeking medical care</u>? This could include a family member, friend, or someone you do not know personally.**

(Read responses and circle one)

      1   Not at all concerned

      2   A little concerned

      3   Somewhat concerned

      4   Extremely concerned

    88   REFUSED

    99   D/K

M5. **For this next set of questions, please indicate whether you think these statements are True or False.**

(*Read each statement and circle one response for each*)

		True	False	REF	D/K
a.	Patients have sometimes been deceived or misled at hospitals.	1	2	88	99
b.	Hospitals often want to know more about your personal affairs or business than they really need to know.	1	2	88	99
c.	Hospitals have sometimes done harmful experiments on patients without their knowledge.	1	2	88	99
d.	Hospitals give the best care to people with the most money.	1	2	88	99
e.	Hospitals will treat you differently depending on what insurance you have.	1	2	88	99

M6. **For the next items, please tell me how much you agree with each one.**

(*Read and circle one response for each item*)

		Strongly Agree	Agree	Disagree	Strongly Disagree	REF	D/K
a.	**In general, you find it difficult to trust doctors.** READ *"Would you say Strongly Agree, Agree, Disagree, or Strongly Disagree" after the first 2 questions and then as necessary.*	1	2	3	4	88	99
b.	**In general, you find it difficult to trust nurses.**	1	2	3	4	88	99
c.	**Your doctor has made references to your race/ethnicity or skin color when it did not seem important.**	1	2	3	4	88	99
d.	**You trust your doctor's advice because you were treated at a very prestigious/well-known medical facility.**	1	2	3	4	88	99
e.	*Check Reference sheet responses for items H3 and H4. If H3 = 1 OR if H4 = 3, 4, 6, or 7 (no other numbers circled), ask:* **Because of your insurance status, you are happy to receive any medical treatment you can get.**	1	2	3	4	88	99

M7. **How often have you felt that you were treated badly or unfairly because of your race or ethnicity <u>while getting breast cancer care</u>?**

(*Read responses and circle one*)

1. Never
2. Rarely
3. Sometimes
4. Often
88. REFUSED
99. D/K

Section 7: SOCIAL SUPPORT, STRESS, COPING (S)0

These next questions focus on your support networks within the **FIRST YEAR** of your breast cancer diagnosis.

S1.

(Read each reason and circle one response for each item)	None	1 or 2	3 to 5	6 to 9	10 or more	REF	D/K
a. How many close relatives did you have? (By close we mean people you felt at ease with, could talk to about private matters, and could call on for help)	0	1	2	3	4	88	99
b. How many close friends did you have (who were not relatives)?	0	1	2	3	4	88	99

If 1 – 4 circled for either question, Go to S2

If BOTH questions "0," "88," or "99" Go to S3

S2. **How many of these friends and/or family members did you see or talk to at least once a month?**

(Read responses and circle one)

- 0. None
- 1. 1 or 2
- 2. 3 to 5
- 3. 6 to 9
- 4. 10 or more
- 88. REFUSED
- 99. D/K

S3. **Did you belong to any of these kinds of groups:**

(Read each group and circle one response for each item)

	Yes	No	REF	D/K
a. A social or recreational group	1	2	88	99
b. A labor union, commercial group, or professional association	1	2	88	99
c. A church or temple group	1	2	88	99
d. A group concerned with children	1	2	88	99
e. A group concerned with community betterment, charity or service	1	2	88	99
f. Any other group: please specify _____	1	2	88	99

S4. **Still thinking about the first year within your diagnosis, did you have any close friends who were ever diagnosed with breast cancer?**

(Circle one)

1. Yes → *Go to S5*

2. No

88. REFUSED } *Go to S6*

99. D/K

S5. **Did you meet any of these people as a result of you both having breast cancer?**

(Circle one)

1. Yes

2. No

88. REFUSED

99. D/K

S6. **Within the first year of your diagnosis, did you know of any family members who were ever diagnosed with breast cancer?**

(*Circle one*)

1. Yes

2. No

88. REFUSED

99. D/K

S7. **Still thinking about the first year within your diagnosis, was it helpful to you to share your breast cancer experience with people in general?**

(*Circle one*)

1. Yes

2. No

88. REFUSED

99. D/K

S8. Did you ever attend any of the following support group meetings for cancer patients **within the first year of your diagnosis?**	Yes	No	REF	D/K	S9. In general, how helpful did you find this support group?	Very helpful	Somewhat helpful	Not at all helpful	REF	D/K
a. a support group at your church?	1	2	88	99	[If **YES**:] a. In general, how helpful did you find this support group?	1	2	3	88	99
b. a support group at your hospital or clinic?	1	2	88	99	[If **YES**:] b. In general, how helpful did you find this support group?	1	2	3	88	99

S8bx: [If **NO** to item **b**:]
What was the main reason why you did not attend?

(*Read and circle one*)

1. Too busy to attend
2. Other obligations (such as work or job, child or dependent care)
3. Didn't think it would be useful
4. Too difficult to travel to support group location
5. Could not find a support group
6. Didn't feel comfortable sharing your experience with people you don't know
87. Other, specify: _____
88 REFUSED
99 D/K

Are there any other types of cancer support groups I have not yet mentioned that you attended?	Yes	No	REF	D/K		Very helpful	Somewhat helpful	Not at all helpful	REF	D/K
c. Other support group (specify): _____	1	2	88	99	[If **YES**:] In general, how helpful did you find this support group?	1	2	3	88	99
d. Other support group (specify): _____	1	2	88	99	[If **YES**:] In general, how helpful did you find this support group?	1	2	3	88	99

S10. **These next questions focus on support you may have received within the <u>first</u> <u>year</u> of your breast cancer diagnosis.**

(Read each statement and circle one response for each)

How much of the time did you have...	All of the time	Most of the time	Some of the time	A little bit of the time	None of the time	REF	D/K
a. someone you could count on to listen to you when you needed to talk? READ *"Would you say All of the time, Most of the time, Some of the time, A little bit of the time, None of the time"* **after the first 2 questions and then as necessary**.	1	2	3	4	5	88	99
b. someone to give you information to help you understand a situation?	1	2	3	4	5	88	99
c. someone to share your most private worries and fears with?	1	2	3	4	5	88	99
d. someone to help you if you were confined to bed?	1	2	3	4	5	88	99
e. someone to take you to the doctor if you needed it?	1	2	3	4	5	88	99
f. someone to prepare your meals if you were unable to do it yourself?	1	2	3	4	5	88	99
g. someone to help with daily chores if you were sick?	1	2	3	4	5	88	99

S11. **The next questions ask about the overall stress you felt within the first year of your breast cancer diagnosis.**

(Read each statement and circle one response for each)

Within the first year of your breast cancer diagnosis, **how often...**		Never	Almost Never	Some-times	Fairly Often	Very Often	REF	D/K
a.	were you upset because of something that happened unexpectedly? READ "Would you say Never, Almost Never, Sometimes, Fairly Often, or Very Often" after the first 2 questions and then as necessary.	0	1	2	3	4	88	99
b.	did you feel that you were unable to control the important things in your life?	0	1	2	3	4	88	99
c.	did you feel "stressed"?	0	1	2	3	4	88	99
d.	did you feel confident about your ability to handle your personal problems?	0	1	2	3	4	88	99
e.	did you feel that things were going your way?	0	1	2	3	4	88	99
f.	did you feel that you could not cope with all the things that you had to do?	0	1	2	3	4	88	99
g.	were you able to control irritations in your life?	0	1	2	3	4	88	99
h.	did you feel that you were on top of things?	0	1	2	3	4	88	99
i.	were you angered because of things that were outside of your control?	0	1	2	3	4	88	99
j.	did you feel difficulties were piling up so high that you could not overcome them?	0	1	2	3	4	88	99

Section 8: QUALITY OF LIFE (Q)

Q1: **For the next section, please think about your general health <u>over the past 4 weeks</u>.**

(Read each statement and circle one response for each)

	Excellent	Very Good	Good	Fair	Poor	REF	D/K
a. In general, over the past 4 weeks, would you say your health was: READ "Excellent, Very Good, Good, Fair, or Poor" after the first 2 questions and then as necessary.	1	2	3	4	5	88	99
b. In general, over the past 4 weeks, would you say your quality of life was:	1	2	3	4	5	88	99
c. In general, over the past 4 weeks, how would you rate your physical health?	1	2	3	4	5	88	99
d. In general, [over the past 4 weeks], how would you rate your mental health, including your mood and your ability to think?	1	2	3	4	5	88	99
e. In general, [over the past 4 weeks], how would you rate your satisfaction with your social activities and relationships?	1	2	3	4	5	88	99
f. In general, [over the past 4 weeks], please rate how well you carried out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)	1	2	3	4	5	88	99

Q2. **Still thinking about the past 4 weeks, to what extent were you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?**

(Read responses and circle one)

1. Completely
2. Mostly
3. Moderately
4. A Little
5. Not at all
88. REFUSED
99. D/K

Q3. **<u>OVER THE PAST 4 WEEKS</u> how often were you bothered by emotional problems such as feeling anxious, depressed, or irritable?**

(Read responses and circle one)

1. Never
2. Rarely
3. Sometimes
4. Often
5. Always
88. REFUSED
99. D/K

Q4. **<u>OVER THE PAST 4 WEEKS</u> how would you rate your fatigue on average?**

(Read responses and circle one)

1. None
2. Mild
3. Moderate
4. Severe
5. Very Severe
88. REFUSED
99. D/K

Q5. **On a scale of 1 to 10, <u>OVER THE PAST 4 WEEKS,</u> how would you rate your pain on average? Zero is no pain and 10 is the worst pain imaginable.**

(Circle one)

0	1	2	3	4	5	6	7	8	9	10
No pain										Worst Pain Imaginable

Q6: **For each statement please tell me how true each one is for you.**

(Read each statement and circle one response for each)

OVER THE PAST 4 WEEKS...	Not at all	A little bit	Somewhat	Quite a bit	Very Much	REF	D/K
a. You were self-conscious about the way you dress *READ "Would you say Not at all, A little bit, Somewhat, Quite a bit, or Very Much" after the first 2 questions and then as necessary.*	1	2	3	4	5	88	99
b. One or both of your arms were swollen or tender	1	2	3	4	5	88	99
c. You felt sexually attractive	1	2	3	4	5	88	99
d. You were bothered by a change in weight	1	2	3	4	5	88	99
e. You were bothered by side effects from treatment (such as insomnia, hot flashes, joint pain, etc.).	1	2	3	4	5	88	99
f. You worried about the risk of cancer in other family members	1	2	3	4	5	88	99

Q7.   **Now I'd like you to think about the future. Next year, at this time, would you predict that your overall health will be better, about the same, or worse?**

(*Circle one*)

    1   Better

    2   About the same

    3   Worse

    88   REFUSED

    99   D/K

[Go to Next Page]

Thinking about how your breast cancer diagnosis has affected you, please rate how true these statements were for you <u>before your breast cancer diagnosis</u> and again now, <u>since your breast cancer diagnosis</u>.

Q8.   **You are comfortable with who you are:**

(Read and circle one response for each)

	Not at all	A little bit	Somewhat	Quite a bit	Very Much	Refused	D/K
a. **How true was this <u>before</u> your breast cancer diagnosis?** *READ "Would you say Not at all, A little bit, Somewhat, Quite a bit or Very Much" after the first 2 questions and then as necessary.*	1	2	3	4	5	88	99
b. **How true is this now <u>since</u> your breast cancer diagnosis?**	1	2	3	4	5	88	99

Q9.   **You realize who your real friends are:**

(Read and circle one response for each)

	Not at all	A little bit	Somewhat	Quite a bit	Very Much	Refused	D/K
a. **How true was this <u>before</u> your breast cancer diagnosis?**	1	2	3	4	5	88	99
b. **How true is this now <u>since</u> your breast cancer diagnosis?**	1	2	3	4	5	88	99

Q10.   **You can adjust to things you cannot change:**

(Read and circle one response for each)

	Not at all	A little bit	Somewhat	Quite a bit	Very Much	Refused	D/K
a. **How true was this <u>before</u> your breast cancer diagnosis?**	1	2	3	4	5	88	99
b. **How true is this now <u>since</u> your breast cancer diagnosis?**	1	2	3	4	5	88	99

Q11.   **Your life is meaningful:**

(Read and circle one response for each)

	Not at all	A little bit	Somewhat	Quite a bit	Very Much	Refused	D/K
a. **How true was this <u>before</u> your breast cancer diagnosis?**	1	2	3	4	5	88	99
b. **How true is this now <u>since</u> your breast cancer diagnosis?**	1	2	3	4	5	88	99

Q12. **Please see Show Card #13. The next series of questions are about other medical conditions you may have had besides breast cancer.**

Some of these medical terms may sound unfamiliar to you. Generally if people have not heard of these, this usually means that they do not have this medical condition.

(If R answers yes to any of the items below, then ask about treatment and limitation of activities.)

		Yes	No	N/A	D/K	In what year were you first diagnosed with this condition? Year	Are you under treatment for your condition?				Are any of your regular activities currently limited because of your condition?			
							Yes	No	N/A	D/K	Yes	No	N/A	D/K
a.	Have you ever had a heart attack?[1]	1	2	77	99		1	2	77	99	1	2	77	99
b.	Have you ever been treated for heart failure? (You may have been short of breath and the doctor may have told you that you had fluid in your lungs or that your heart was not pumping well.)[2]	1	2	77	99		1	2	77	99	1	2	77	99
c.	Have you had an operation to unclog or bypass the arteries in your legs?[3]	1	2	77	99		1	2	77	99	1	2	77	99
d.	Have you had a stroke, cerebrovascular accident, blood clot or bleeding in the brain, or transient ischemic attack (TIA)?	1	2	77	99		1	2	77	99	1	2	77	99
e.	Have you ever had angina, also called angina pectoris?	1	2	77	99		1	2	77	99	1	2	77	99
f.	Do you have coronary heart disease?	1	2	77	99		1	2	77	99	1	2	77	99

[1] Myocardial infarction
[2] Congestive heart failure
[3] Peripheral vascular disease

		Yes	No	N/A	D/K	In what year were you first diagnosed with this condition? Year	Are you under treatment for your condition?				Are any of your regular activities currently limited because of your condition?			
							Yes	No	N/A	D/K	Yes	No	N/A	D/K
g.	Do you have hypertension, also called high blood pressure?	1	2	77	99		1	2	77	99	1	2	77	99
h.	Do you have asthma?	1	2	77	99		1	2	77	99	1	2	77	99
i.	Do you have emphysema, chronic bronchitis, or chronic obstructive lung disease? [4]	1	2	77	99		1	2	77	99	1	2	77	99
j.	Do you have stomach ulcers, or peptic ulcer disease? [5]	1	2	77	99		1	2	77	99	1	2	77	99
	jx. [If yes] Has this condition been diagnosed by endoscopy?	1	2	77	99									
k.	Do you have diabetes (high blood sugar)?	1	2	77	99		1	2	77	99	1	2	77	99
l.	Have you ever had poor kidney function (blood tests show high creatinine)? [6]	1	2	77	99		1	2	77	99	1	2	77	99

[4] Chronic obstructive pulmonary disease (participant is considered to have pulmonary disease if she takes medications regularly (without flare-ups) or only for flare-ups)
[5] Ulcer disease
[6] Renal

	In what year were you first diagnosed with this condition?	Are you under treatment for your condition?				Are any of your regular activities currently limited because of your condition?			
	Yes	No	N/A	D/K	Year	Yes	No	N/A	D/K	Yes	No	N/A	D/K
m. Do you have rheumatoid arthritis?[7]	1	2	77	99		1	2	77	99	1	2	77	99
n. Do you have hepatitis, cirrhosis, or serious liver damage?	1	2	77	99		1	2	77	99	1	2	77	99
o. Have you been diagnosed with another cancer? If yes, please specify: _____; *If Yes, go to a. below.; If No, go to p*	1	2	77	99		1	2	77	99	1	2	77	99
a. Has the cancer spread, or metastasized to other parts of your body?	1	2	77	99									
p. Have you been diagnosed with any other health problem? [If yes]Specify:_____	1	2	77	99		1	2	77	99	1	2	77	99

[7] Connective tissue disease

Section 9: DISCRIMINATION (D)

These next questions are not directly about your breast cancer experiences, but about other experiences you may have had in general. These are also important for understanding why women may have different breast cancer experiences.

D1. **First, I would like you to think about situations where you have been treated unfairly over your entire lifetime.**

(Read and circle one response for each)

Over your entire lifetime, how often....	Never	Rarely	Sometimes	Often	REF	D/K
a. **have you been treated unfairly at school?** *READ "Would you say Never, Rarely, Sometimes or Often" after the first 2 questions and then as necessary.*	1	2	3	4	88	99
b. **have you been treated unfairly when getting hired or getting a job?**	1	2	3	4	88	99
c. **have you been treated unfairly at work?**	1	2	3	4	88	99
d. **have you been treated unfairly when getting housing?**	1	2	3	4	88	99
e. **have you been treated unfairly when getting medical care?**	1	2	3	4	88	99
f. **have you been treated unfairly when getting credit, bank loans, or a mortgage?**	1	2	3	4	88	99
g. **have you been treated unfairly when seeking legal services related to immigration?**	1	2	3	4	88	99
h. **have you been treated unfairly from the police or in the courts?**	1	2	3	4	88	99

*If **ANY** "2," "3," or "4" Go to **D2***

*If **ALL** "1," "88," or "99" Go to **D4***

D2. **Please see Show Card #12. I will read through each option. Please tell me which of these may be the reasons why you were treated unfairly over your lifetime?**

(Read and circle one response for each)

	Was it because of...	Yes	No	REF	D/K
a.	Your health insurance (or lack of)	1	2	88	99
b.	The way you speak English	1	2	88	99
c.	Your birthplace	1	2	88	99
d.	Your gender	1	2	88	99
e.	Your race/ethnicity	1	2	88	99
f.	Your age	1	2	88	99
g.	Your religion	1	2	88	99
h.	Your height or weight	1	2	88	99
i.	Your skin color	1	2	88	99
j.	Your sexual orientation	1	2	88	99
k.	Your education	1	2	88	99
l.	How much money you have	1	2	88	99
m.	A physical disability	1	2	88	99
n.	Your appearance on a given day	1	2	88	99
o.	Other: please specify _____	1	2	88	99

D3.   **How stressful has this/have these experience(s) of unfair treatment usually been for you?**

(*Read responses and circle one*)

1.   Not at all stressful

2.   A little stressful

3.   Somewhat stressful

4.   Extremely stressful

88.   REFUSED

99.   D/K

[Go to next page]

Now I am going to ask you about unfair treatment in your everyday life.

D4. <u>Over the past 12 months</u>, how often have any of the following things happened to you in your day-to-day life?

(Read and circle one response for each)

Over the past 12 months, how often….	Never	Rarely	Sometimes	Often	REF	D/K
a. **have you been treated with less respect than other people?** READ *"Would you say Never, Rarely, Sometimes or Often"* after the first 2 questions and then as necessary.	1	2	3	4	88	99
b. **have you received poorer service than other people at restaurants or stores?**	1	2	3	4	88	99
c. **have people acted as if they think you are not smart?**	1	2	3	4	88	99
d. **have people acted as if they are afraid of you?**	1	2	3	4	88	99
e. **have people acted as if they think you are dishonest?**	1	2	3	4	88	99
f. **have people acted as if they're better than you?**	1	2	3	4	88	99
g. **have you been called names or were insulted?**	1	2	3	4	88	99
h. **have you been threatened or harassed?**	1	2	3	4	88	99
i. **have you been followed around in stores?**	1	2	3	4	88	99

Box A
If **2 or more** *"2"*
check box **A**

Box B
If **ANY** *"3," or "4,"*
check box **B**

Box C
If **ALL** *"88," or "99"*
check box **C**

*Check Boxes **A, B,** and **C**, page 54.*
*If Box **A OR** Box **B** checked, Go to **D5**.*

*If Box **C** checked, determine why **Refused** or **D/K for all,** then Go to **D8**, page 57.*

*If **No Boxes** checked, Go to **D8**, page 57.*

D5.   **Please see Show Card #12. I will read through each option. Please tell me which of these may be the reasons why you were treated unfairly <u>over the past 12 months</u>?**

(*Read and circle one response for each*)

Was it because of...	Yes	No	Refused	D/K
a. Your health insurance (or lack of)	1	2	88	99
b. The way you speak English	1	2	88	99
c. Your birthplace	1	2	88	99
d. Your gender	1	2	88	99
e. Your race/ethnicity	1	2	88	99
f. Your age	1	2	88	99
g. Your religion	1	2	88	99
h. Your height or weight	1	2	88	99
i. Your skin color	1	2	88	99
j. Your sexual orientation	1	2	88	99
k. Your education	1	2	88	99
l. How much money you have	1	2	88	99
m. A physical disability	1	2	88	99
n. Your appearance on a given day	1	2	88	99
o. Other: please specify _____	1	2	88	99

D6. **How stressful has this/have these experience(s) of unfair treatment usually been for you?**

(Read responses and circle one)

    1. Not at all stressful

    2. A little stressful

    3. Somewhat stressful

    4. Extremely stressful

    88. REFUSED

    99. D/K

D7. **How did you respond to this/these experience(s)? Did you:**

(Read and circle one response for each)

		Yes	No	N/A	REF	D/K
a.	try to do something about it	1	2	77	88	99
b.	accept it as a fact of life	1	2	77	88	99
c.	work harder to prove them wrong	1	2	77	88	99
d.	believe that you brought it on yourself	1	2	77	88	99
e.	talk to someone about how you were feeling	1	2	77	88	99
f.	express anger or get mad	1	2	77	88	99
g.	pray about the situation	1	2	77	88	99

D8. **Over the past 12 months how often have you felt that you were treated badly or unfairly because of your race or ethnicity?**

(Read responses and circle one)

    1. Never

    2. Rarely

    3. Sometimes

    4. Often

    88. REFUSED

    99. D/K

[Go to next page]

D9. **I will now ask you some questions about how you see yourself. Please tell me how much you agree with each statement.**

(Read and circle one response for each)	Strongly Agree	Agree	Disagree	Strongly Disagree	REF	D/K
a. You've always felt that you could make of your life pretty much what you wanted to make of it. READ "Would you say Strongly Agree, Agree, Disagree, or Strongly Disagree" after the first 2 questions and then as necessary.	1	2	3	4	88	99
b. Once you make up your mind to do something, you stay with it until the job is completely done.	1	2	3	4	88	99
c. You like doing things that other people thought could not be done.	1	2	3	4	88	99
d. When things don't go the way you want them to, that just makes you work even harder.	1	2	3	4	88	99
e. Sometimes, you feel that if anything is going to be done right, you have to do it yourself.	1	2	3	4	88	99
f. It's not always easy, but you manage to find a way to do the things you really need to get done.	1	2	3	4	88	99
g. Very seldom have you been disappointed by the results of your hard work.	1	2	3	4	88	99
h. You feel you are the kind of individual who stands up for what she believes in, regardless of the consequences.	1	2	3	4	88	99
i. In the past, even when things got really tough, you never lost sight of your goals.	1	2	3	4	88	99
j. It's important for you to be able to do things the way you want to do them rather than the way other people want you to do them.	1	2	3	4	88	99
k. You don't let your personal feelings get in the way of doing a job.	1	2	3	4	88	99
l. Hard work has really helped you to get ahead in life.	1	2	3	4	88	99

Section 10: NEIGHBORHOOD (N)

We would like to know about the area you live in. The following questions are about your current neighborhood.

N1. In what year did you first move to your current address? _____

                                              year

N2. The next questions are about your neighbors:

(Read and circle one response for each)

		Often	Sometimes	Rarely	Never	REF	D/K
a.	How often do you see neighbors talking outside in the yard, on the street, at the corner park, etc?	1	2	3	4	88	99
b.	How often do neighbors watch out for each other, such as calling if they see a problem?	1	2	3	4	88	99

		A lot	Some	A Few	None	REF	D/K
c.	How many neighbors do you know by name?	1	2	3	4	88	99
d.	How many neighbors do you have a friendly talk with at least once a week?	1	2	3	4	88	99
e.	How many neighbors could you call on for assistance in doing something around your home or yard or to "borrow a cup of sugar" or some other small favor?	1	2	3	4	88	99

Section 11: EDUCATION, OCCUPATION, AND INCOME (E)

The next section will focus on your education and occupation.

E1. Please look at Show Card #14. What is the <u>HIGHEST</u> level of school you have completed or the highest degree you have received?

(Circle one)

1. Never attended/kindergarten only
2. 1st grade
3. 2nd grade
4. 3rd grade
5. 4th grade
6. 5th grade
7. 6th grade
8. 7th grade
9. 8th grade
10. 9th grade
11. 10th grade
12. 11th grade
13. 12th grade, High School Graduate
14. 12th grade, did not graduate
15. GED or took a test to graduate
16. Some college, no degree
17. Associate degree (such as AA, AS, ABA)
18. Bachelor's degree (such as BA, BS, BBA)
19. Master's degree (such as MA, MS, MBA)
20. Professional degree (such as MD, DDS, JD)
21. Doctoral degree (such as PhD, EdD)
88. REFUSED
99. D/K

E2. Please look at Show Card #15. Which of the following best describes what you currently do?

(*Circle One*)

1. Currently working full-time
2. Currently working part-time
3. Unemployed or looking for work
4. Retired
5. On disability permanently
6. On disability for a period of time (on sick leave or maternity leave or disability leave for other reasons)
7. Keeping house/homemaker
8. Student
9. Volunteer/work without pay
87. Other, specify: _____
88. REFUSED
99. D/K

E3. We would like to know about your usual occupation. This would be the longest held job that best describes the kind of work you do (did):

(*Read below questions and enter responses*)

a. **In what kind of business or industry do (did) you work?**

_____

(**For example:** health care, banking, education, manufacturing, retail)

b. **What kind of work do (did) you do or what was your job title?**

_____

(**For example:** registered nurse, personnel manager, supervisor of order department, machine operator.)

E4. How many people are currently living in your household, including yourself?

(Write in number and follow skip pattern instructions)

    1.   Number of people _____ *If "1" Go to **E5**, otherwise go to **2-4** below*

    2.   Of these people, how many are children? _____

    3.   Of these people, how many are adults? _____

    4.   Of the adults, how many bring income into the household? _____

    88. REFUSED ⎫ *GO TO **E5***

    99. D/K   ⎬

E5. Which of the following best describes the home where you live. Is it...?

(Read responses and circle one)

    1.   Owned or being bought by you (or someone in the household)?

    2.   Rented for money?

    3.   Occupied without payment of money or rent?

    4.   Other (specify)_____

    88.   REFUSED

    99.   D/K

E6. **Please look at Show Card #16. Which of these categories best describes your total combined family income for the past 12 months? This should include income (before taxes) from all sources, wages, rent from properties, social security, disability and/or veteran's benefits, unemployment benefits, workman's compensation, help from relatives (including child payments and alimony), and so on.**
(*Circle one*)

1. $24,000 or less
2. $25,000 through $35,000
3. $36,000 through $45,000
4. $46,000 through $55,000
5. $56,000 through $65,000
6. $66,000 through $75,000
7. $76,000 through $99,000
8. $100,000 through $149,000
9. $150,000 through $199,000
10. $200,000 or more
88. REFUSED
99. D/K

SECTION12: IMMIGRATION (I)

The following questions are about your family's background/ancestry.

I1.   **In what state or country was:**

	STATE	COUNTRY
a. **Your biological father born?**	_____	_____
b. **Your father's mother (your grandmother) born?**	_____	_____
c. **Your father's father (your grandfather) born?**	_____	_____
d. **Your biological mother born?**	_____	_____
e. **Your mother's mother (your grandmother) born?**	_____	_____
f. **Your mother's father (your grandfather) born?**	_____	_____

*Check Reference Sheet, page1, item **G14.***

*If **not** checked, Go to I4, page 66.*

If checked, continue below.

Now we would like to know about <u>your</u> background.

I2.   **How old were you when you first came to this country to live?**

___ ___ years old

88   REFUSED
99   D/K

I3. **The following are a list of reasons that people give for coming to the United States. Please tell us how important each one of these reasons was for you and/or your family to come to the US.**

(Read responses and circle one response for each item)	Not important	Somewhat important	Very important	N/A	REF	D/K
a. **To find employment or a job** *READ "How important was this? Not Important, Somewhat Important, or Very Important" after the first 2 questions and then as necessary.*	1	2	3	77	88	99
b. **To improve your life or that of your family and look for better opportunities**	1	2	3	77	88	99
c. **To join other family members already living in the US**	1	2	3	77	88	99
d. **Because of the political situation in your country of origin**	1	2	3	77	88	99
e. **Because you (or your family) were mistreated for political reasons**	1	2	3	77	88	99
f. **For medical care**	1	2	3	77	88	99
g. **To get a better education**	1	2	3	77	88	99
h. **Because of marital or family problems**	1	2	3	77	88	99

I4.   **We would like to know about which languages you speak and prefer.**

      What languages do you speak at home?

_____   → | If **non**-English language only, check box here and also on Reference Sheet, page 5, item **I4**. | ☐

I5.   **What languages did you speak while growing up?**

_____   →*If more than one language Go to **a.** below:*

      a.   **Which language did you speak the most?**

      _____

*Check responses to items **I4** and **I5** above:*

    →   *If **only** "ENGLISH" → Check Reference sheet, page 1, item **G14**.*

                                       ↓
                               *If **not** checked, Go to **End of survey** page 71.*
                               *If checked, Go to **I10**, page 69.*

    →   *Else (if other language[s] listed) → Go to **I6**, page 67.*

I6. **The next few questions are about speaking English.**

(Read responses and circle one response for each item)

	Not at all well	Poorly	OK	Well	Very well	REF	D/K
a. **How well do you speak English?** *READ "Not at all well, Poorly, OK, Well, Very well" after the first 2 questions and then as necessary.*	1	2	3	4	5	88	99
b. **How well do you understand spoken English?**	1	2	3	4	5	88	99
c. **How well do you read English?**	1	2	3	4	5	88	99
d. **How well do you write English?**	1	2	3	4	5	88	99

I7. **Please tell me how often you experience difficulties in the following areas BECAUSE of your ability to speak and understand English?**

(Read responses and circle one response for each item)

How often do you experience difficulties when….	Never	Sometimes	Often	Very often	N/A	REF	D/K
a. **you are at work?** *READ "Never, Sometimes, Often, Very Often" after the first 2 questions and then as necessary.*	1	2	3	4	77	88	99
b. **you try to understand official documents, such as tax forms?**	1	2	3	4	77	88	99
c. **you go shopping and have to talk to a sales clerk?**	1	2	3	4	77	88	99

Check Reference sheet, page 5, item **I4**:

> *If checked* → *Go to* **I8**, *page 68.*

> *If **not** checked* → *Check Reference sheet, page 1, item* **G14**.

>> *If checked, Go to* **I10**, *page 69.*

>> *If **not** checked, Go to* **End of Survey**, *page 71.*

I8.   **Does anyone in your household <u>speak</u> English?**

(*Circle one*)

       1. Yes

       2. No

     88. REFUSED

     99. D/K

I9.   **Does anyone in your household <u>read</u> English?**

(*Circle one*)

       1. Yes

       2. No

     88. REFUSED

     99. D/K

*Check Reference sheet item, page 1, item **G14**.*

↓

*If checked, Go to **I10**, page 69.*

*If **not** checked, Go to **End of Survey**, page 71.*

I10. **Next, I would like to ask about your current level of stress [or stress you feel] about living in the US. Please remember that any information you provide will be kept confidential.**

(Read responses and circle one response for each item)

You feel that living in the US is stressful:	Never	Sometimes	Often	Very often	N/A	REF	D/K
a. because you lack the opportunity to visit your country of origin. READ *"Would you say Never, Sometimes, Often, or Very Often" after the first 2 questions and then as necessary*.	1	2	3	4	77	88	99
b. because you are living away from your family, relatives, and friends.	1	2	3	4	77	88	99
c. because you are unable to do the things you used to enjoy when you were in your country of origin.	1	2	3	4	77	88	99
d. because you are mistreated by others of your ethnic group.	1	2	3	4	77	88	99
e. because you have or had a job that is below your experience and qualifications.	1	2	3	4	77	88	99
f. because you are treated as an outsider by other Americans.	1	2	3	4	77	88	99
g. because you have few, if any, opportunities to participate in American politics.	1	2	3	4	77	88	99
h. because you are constantly reminded of your minority status.	1	2	3	4	77	88	99
i. because you are disappointed that your standard of living is not what you had hoped for when you first came to the US.	1	2	3	4	77	88	99

I10 Continued:

You feel that living in the US is stressful:	Never	Sometimes	Often	Very often	N/A	REF	D/K
o. because you have to depend on others for understanding how to access support services that you need.	1	2	3	4	77	88	99
p. because you don't understand the healthcare system here in the U.S.	1	2	3	4	77	88	99
q. because you feel you have heavy responsibilities for BOTH your family here in the U.S. as well as family in your country of origin.	1	2	3	4	77	88	99
r. because you worry about losing ties to your parents' culture.	1	2	3	4	77	88	99
s. because you feel you are obligated to take care of your parents in their old age.	1	2	3	4	77	88	99

I11. **Finally, my last few questions are about some immigration experiences you may have had.**

(Read questions and circle one response for each item)

	Yes	No	N/A	REF	D/K
a. Do you feel guilty for leaving family or friends in your country of origin?	1	0	77	88	99
b. Have you been questioned about your legal status?	1	0	77	88	99
c. Do you think you will be deported if you go to a social or government agency, regardless of your legal status?	1	0	77	88	99
d. Do you avoid seeking health services due to fear of immigration officials, regardless of your legal status?	1	0	77	88	99

END OF SURVEY

That concludes the interview. Thank you so much for taking the time to answer our questions.

C1.   **[If participant has been identified as a 10% retest participant]: In order to make sure we are getting the most accurate data, we will be re-contacting participants in about two weeks to ask just a few of the same questions I have just asked you. May I call you in about two weeks to conduct a very short interview – about 15 minutes – asking a few of the same questions we went over today?**

        1   Yes   → Proceed to schedule convenient time for re-test below.
        2   No   → Comments regarding refusal: _____ → Go to **C2**

        RETEST DATE: _____

        TIME: _____   → Go to **C2**

        PHONE NUMBER: _____

C2.   **Our study team may be involved with future studies that aim to better understand women's breast cancer experiences. Would you be interested in being contacted by us again to learn about potential opportunities to participate in future studies? If you say "yes," this does not mean you are consenting to participate in future studies, just that you are allowing us to inform you about them.**

        1   Yes →   Go to **C3**, next page
        2   No →   Comments regarding refusal: _____ → Go to **Thank you**, next page.

C3.   **I would like to confirm your best contact information.** *(Confirm address and telephone information. If any new information, or additional phone numbers, indicate below).*

PARTICIPANT'S Current Contact Information (if different from Assignment Sheet):

Name	Phone Number(s) ( ) - ( ) -
Street Address	City, State, Zip
Email address	

↓

Would you also be able to provide the contact information of one or two people who might help us locate you in case you move?

Contact information for people who might help us locate participant:

Name #1	Phone Number(s) ( ) - ( ) -
Street Address	City, State, Zip

Name #2	Phone Number(s) ( ) - ( ) -
Street Address	City, State, Zip

→ THANK YOU: **We are very grateful for your input and participation in this research.**
   Thank you so much for taking the time to speak with me.

Appendix B

Manuscript

Quach T, Nuru-Jeter A, Morris P, Allen L, Shema SJ, Winters JK, Le GM, Gomez SL. Experiences and perceptions of medical discrimination among a multi-ethnic sample of breast cancer patients in the San Francisco Bay Area. American Journal of Public Health 2012;102(5):1027-34.

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

Thu Quach, PhD, MPH, Amani Nuru-Jeter, PhD, MPH, Pagan Morris, MPH, Laura Allen, BA, Sarah J. Shema, MS, June K. Winters, BA, Gem M. Le, PhD, MHS, and Scarlett Lin Gomez, PhD

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 framework [11]) 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., 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, Latinos, and Asians have been found to report more medical mistrust[27] and provider discrimination, which is associated with lower satisfaction with

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)

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 Jones'[44] 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 noncompliance. 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)

[a]Data were merged in accordance with cancer registry guidelines requiring that all cells have at least 5 counts.

discrepancy[48] 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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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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Appendix C

Poster presented at the NIH Science of Discrimination Meeting (February 2011) and DOD BCRP Era of Hope Meeting (August 2011)

Gomez SL, Le GM, Quach T, Allen L, Morris P, Shema SJ, Winters JK, Nuru-Jeter A. Using a mixed-methods approach to develop self-reported measures of health care discrimination in a multiethnic sample of breast cancer patients in the San Francisco Bay Area.

Using a mixed-methods approach to develop self-reported measures of health care discrimination in a multiethnic sample of breast cancer patients in the San Francisco Bay Area

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BACKGROUND

Few measures have been developed to:
- assess discrimination in a health care setting
- study discrimination in a breast cancer context
- study the impact of discrimination on health care & other outcomes in multiethnic populations
- assess multiple dimensions of discrimination (Jones CP*)
  - institutionalized: structural and differential access to goods, services, and opportunities within society, manifesting as material conditions and access to power
  - personally-mediated: differential assumptions about and actions toward others on the basis of race or other factors
  - internalized: acceptance of members of the stigmatized group of negative assumptions about their own abilities and worth and embracing attributes of the dominant group

* Jones CP. Levels of racism: a theoretic framework and a gardener's tale. Am J Public Health. 2000 Aug;90(8):1212-5.

STUDY OBJECTIVES

Apply mixed-methods to select, develop, and test survey items for assessing health care discrimination in breast cancer survivors
- selected existing or developed de-novo survey items based on:
  - emergent discrimination themes from qualitative interviews
  - comprehensive literature review of existing survey items
- conducted cognitive testing of survey items
- will conduct epidemiologic telephone interviews with finalized survey

METHODS

Context of larger project – "Equality in Breast Cancer Care" (EBCC)
Health care discrimination measures were developed as part of a 2-phase study to determine whether differential exposure to discrimination explains racial/ethnic disparities in breast cancer care and outcomes, including treatment and quality of life.
Phase 1: Developmental phase - develop survey items
Phase 2: Application phase - apply survey to ~1100 patients

Focus groups → Develop tailored questionnaire → Cognitive interviews → Refine questionnaire → Epidemiologic interviews
Qualitative interviews ↗
Developmental phase | Application phase

Study population
- female patients diagnosed with first primary, invasive breast cancer
- ages 20+ at diagnosis
- diagnosis years: 2006-2009
- residing in 5-county San Francisco Bay Area
- reported to the SEER Greater Bay Area Cancer Registry
- over-sampled minority race/ethnic groups
- interviews conducted by bilingual, bi-cultural interviewers

Table 1. Participant sample sizes by race/ethnicity and type of interview

Race/ethnicity	Type of interview			
	Focus group	Qual 1-on-1	Cognitive*	Epidemiologic*
Non-Hispanic White	6	3	6	306
Hispanic	5	3	2	246
African American	6	3	5	214
Chinese	12**	6**	6**	144
Filipina	3	3		23
Japanese	5	3		95
Other***	--	3		112

* Cognitive and Epi Phases are in progress. Cognitive numbers represent completed interviews to date; Epi numbers represent anticipated numbers.
** FG: 6 Mandarin, 5 Cantonese; Qual: 3 Mandarin, 3 Cantonese; Cog: 3 Mandarin, 3 Cantonese
*** "Other" represents all other race categories, except those identified as a separate group above.

Qualitative Interview Phase
- conducted focus group and one-on-one interviews with 6 race/ethnic groups
- transcripts analyzed by a multi-cultural team of 6 coders; developed codebook to identify themes
- thematic analysis conducted using a tabulated matrix of ideas identified through the coding process

Cognitive Testing Phase
- survey items systematically assessed for potential problem areas
- responses to probed questions and overall respondent feedback coded to highlight specific item problems, including translation issues
- analyze interviewer Rating System data - quantify interviewer impressions of problematic q's
- survey items revised based on cognitive testing results

RESULTS

Table 2. Examples of emergent qualitative themes, preliminary cognitive testing results, potential survey item revisions, and summary of major issues

Discrimination dimension	Emergent Theme from Interviews and Focus Groups with Breast Cancer Survivors	Example of Survey Item	Cognitive Testing Results	Problems, Potential Revisions and Successes
Institutionalized discrimination	Economic inequities • Income is positively associated with quality of care. • Income is positively associated with quality of insurance.	"Hospitals will treat you differently depending on what insurance you have." Strongly disagree Disagree Agree Strongly agree	Participants had difficulty with response options: • remembering response options • distinguishing between "strongly agree" and "agree" • preferred a "somewhat" or "sometimes" option	Inadequate response options: No neutral or intermittent response option and ambiguous scale interpretation. Consider changing the response options to "Always, Sometimes, Never" if the problem persists.
Personally-mediated discrimination	Provider prejudice: Assumptions about patient based on race/ethnicity, education and immigrant status. • Providers may withhold information based on assumptions regarding patient's limited ability to comprehend information. • Providers may respond to patient's questions with some degree of disrespect.	"At any time during your breast cancer medical experience, did you ever feel that were denied a test or treatment?" Yes No Don't know	No problems were reported by participants. Only one participant responded "Yes" to this question and felt that it was clear. She had been denied a test that she requested to determine the level of 'nutrients' in her blood since she was taking holistic remedies and supplements.	Not capturing intent of question: The intent of this question was to capture subtle, or less overt, experiences of discrimination. For the one participant who responded "Yes," it did not appear to capture the intent of the question. More cognitive interviewing data is needed for women who respond "Yes" to assess whether the intent of the question is captured.
		"At any time during your breast cancer medical experience, did you find that you had to insist on receiving a test or treatment?" Yes No Don't know	No problems were reported for this question. Two participants responded "Yes"; one felt the question was clear, the other felt the word "insist" was ambiguous and explained that she had to be very "proactive" with her care.	Ambiguous wording: Consider changing "insist" to "be proactive" or a more specific term if the problem persists.
Internalized discrimination	Personal/ group discrimination discrepancy: • Limited individual reports of discrimination versus frequent reports of discrimination directed towards patient's own racial/ethnic group. John Henryism – active coping: • Minority patients must work harder to receive optimal health care. Seen in African American and Asian groups.	"Racial/ethnic minorities have to work harder than others to be successful." Strongly disagree Disagree Agree Strongly agree	When asked what this question meant in their own words, one Non-Hispanic White participant responded: "Some are not as gifted as others, but you have to dig your heels in and just do the same as white people do, so it doesn't make any difference really." and one African American participant: "It means the country we live in is set-up that way. If you are a minority you have to work harder."	Supporting data that question is working as intended: Using the method of requesting participant to "tell us in your own words" what the question meant to them, the results thus far indicate that this question is working to capture the perception that people of different races/ethnicities have different perceptions regarding the existence of discrimination and its implications.

Summary of broader issues with survey items:

- Non-Hispanic White participants often did not understand the relevance of race-related discrimination questions and felt questions were often "loaded," "vague," about "stereotypes," and "should not be asked". However, African American participants felt the same questions were "necessary," "well-worded," and "important".
- Survey items based on others' experience are testing as having inherent knowledge issues. For example, several participants responded "I don't know how other doctors treat people" to survey items.
- Both groups described awareness of discrimination practices, however, Non-Hispanic Whites' knowledge tended to be more theoretical ("people say they get treated differently because they are a different race, but as far as I know, I don't know that"), whereas African American participants' perceptions were more literal ("It is not my own experience, ...but because racism exists, blacks have to do more to be accepted into society").
- Vastly different reactions to sensitive survey items may implicate quality of data vis-à-vis item intent.

CONCLUSIONS

- Experiences of discrimination in the health care setting may be differentially expressed across different racial/ethnic groups.
- Qualitative analysis revealed several themes at each dimension (institutional, personally-mediated, internalized), in the health care setting.
- Findings from our developmental work in this study will have implications for measurement issues in multiethnic populations, including knowing when measures are culturally appropriate, choosing measures for multiethnic populations, conceptual and psychometric issues, and potential bias in measures across multiethnic populations.
- Using a mixed-methods approach is valuable for understanding the complexity of measuring self-reported heath care discrimination in a multiethnic population.
- The depth, range, and complexity of health care discrimination may be difficult to capture using quantitative methods.

Appendix D

Tables

Table 1. Study final interview outcomes and response rates by ethnic group and interview type

Interview type / Outcome	Numbers of subjects by race/ethnicity							TOTAL
	White	Chinese	African American	Hispanic	Filipina	Japanese	Other	
Focus group								
Invitation letter sent	50	87	46	52	61	33	n/a	329
Ineligible	7	2	1	14	16	7	n/a	47
Refused	15	29	3	14	31	11	n/a	103
Participated	6	11*	6	5	3	6	n/a	37
Lost to follow up	5	-	-	10	9	1	n/a	25
Not needed**	12	23	7	7	-	8	n/a	57
Not reached***	5	22	29	2	2	1	n/a	61
Response rate, % (of contacted and eligible)	28.6%	27.5%	66.7%	26.3%	8.8%	31.3%	n/a	25.9%

* 2 focus groups; 6 participants in Mandarin focus group and 5 participants in Cantonese focus group.

** Hold/Not needed = participants who were contacted but not needed because the goal for number of participants was reached, or participants who could not participate in this phase but agreed to be contacted for later phases of the study.

*** Not reached = participants who had not been reached by the time we reached our goal numbers or ended recruitment, but who are not necessarily lost to follow up or whose addresses still need to be traced.

Interview type / Outcome	White	Chinese	African American	Hispanic	Filipina	Japanese	Other	TOTAL
Qualitative (one-on-one) interview								
Invitation letter sent	20	45	18	18	20	19	21	161
Ineligible	2	4	-	5	1	1	7	20
Refused	4	19	1	6	5	11	4	50
Participated	3	6+	3	3	3	3	5++	26
Lost to follow up	1	3	-	1	-	1	1	7
Not needed**	10	6	6	3	2	2	-	29
Not reached***	-	7	8	-	9	1	4	29
Response rate, % (of contacted and eligible)	42.9%	24.0%	75.0%	33.3%	37.5%	21.4%	55.6%	34.2%

+ 3 Mandarin; 3 Cantonese

++ 2 Vietnamese, 1 Asian Indian. 2 Discovered ineligible after interviewing.

** Hold/Not needed = participants who were contacted but not needed because the goal for number of participants was reached, or participants who could not participate in this phase but agreed to be contacted for later phases of the study.

*** Not reached = participants who had not been reached by the time we reached our goal numbers or ended recruitment, but who are not necessarily lost to follow up or whose addresses still need to be traced.

Interview type / Outcome	White	Chinese	African American	Hispanic	Filipina	Japanese	Other	TOTAL
Cognitive interview								
Invitation letter sent	39	21	16	20	32	25	48	200
Ineligible	8	-	3	2	1	-	6	20
Refused^	8	2	5	5	5	12	17	54
Participated	6	6	6	6	2	6	4^^	36
Lost to follow up	4	1	2	1	-	4	13	25
Not needed**	1	2	-	3	2	1	2	11
Not reached***	12	10	-	3	22	3	4	54
Response rate, % (of contacted and eligible)	42.9%	75.0%	54.5%	54.5%	28.6%	33.3%	19.0%	40.0%

^ Includes MD Refusals

^^ 1 American Indian, 1 Asian Indian, 1 Fiji Islander, 1 Tongan

** Hold/Not needed = participants who were contacted but not needed because the goal for number of participants was reached, or participants who could not participate in this phase but agreed to be contacted for later phases of the study.

*** Not reached = participants who had not been reached by the time we reached our goal numbers or ended recruitment, but who are not necessarily lost to follow up or whose addresses still need to be traced.

	Epidemiologic Telephone Survey							
	White	**Chinese**	**African American**	**Hispanic**	**Filipina**	**Japanese**	**Other**	**TOTAL**
Invitation letter sent	526	439	422	347	315	74	396[a]	2519
Ineligible	58	32	41	33	34	7	80[b]	283
Refused	224	230	128	140	95	41	173[c]	1018
Participated	197	107	67	45	46	18	43[d]	523
Lost to follow up	40	64	77	60	55	8	75[e]	375
Not reached***	7	6	109	69	85	-	25[f]	320
Response rate, % (of contacted and eligible)	46.8%	31.8	37.6	24.3	34.8	30.5	19.9%	33.9%

[a] 5 American Indian, 1 Burmese, 1 Indonesian, 4 Hawaiian, 45 Korean, 101 Asian Indian, 91 Vietnamese, 3 Laotian, 1 Cambodian, 5 Thai, 1 Pakistani, 3 Samoan, 7 Tongan, 8 Fiji Islander, 62 Other Asian NOS, 9 Pacific Islander NOS, 22 Other NOS, 27 Unknown.

[b] 1 Hawaiian, 14 Korean, 15 Asian Indian, 24 Vietnamese, 1 Laotian, 1 Samoan, 3 Tongan, 1 Fiji Islander, 6 Other Asian NOS, 2 Other Pacific Islander NOS, 5 Other NOS, 7 Unknown.

[c] 3 American Indian, 2 Hawaiian, 12, Korean, 40 Asian Indian, 33 Vietnamese, 2 Laotian, 1 Cambodian, 2 Thai, 1 Pakistani, 2 Samoan, 1 Fiji Islander, 1 Tongan, 40 Other Asian NOS, 5 Other Pacific Islander NOS, 17 Other NOS, 11 Unknown.

[d] 1 American Indian, 1 Burmese, 1 Indonesian, 1 Hawaiian, 5 Korean, 24 Asian Indian, 7 Vietnamese, 1 Thai, 1 Tongan, 1 Fiji Islander

[e] 1 American Indian, 12 Korean, 11 Asian Indian, 20 Vietnamese, 1 Laotian, 2 Tongan, 4 Fiji Islander, 15 Other Asian NOS, 2 Other Pacific Islander NOS, 7 Unknown.

[f] 2 Korean, 11 Asian Indian, 7 Vietnamese, 1 Thai, 1 Fiji Islander, 1 Other Asian NOS, 2 Unknown

*** Not reached = participants who had not been reached by the time we ended recruitment, but who are not necessarily lost to follow up or whose addresses still need to be traced.

Table 2. Representativeness of Equality in Breast Cancer (EBCC) study responders by race/ethnicity (responders vs. registry-eligible cases), Greater San Francisco Bay Area, 2006-2009

Sociodemographic or clinical characteristic	Non-Hispanic White		African American		Hispanic		Chinese		Filipino		Other		Total	
	Responders	Registry-eligible cases[2]	Responders	Registry-eligible cases[2]	Responders	Registry-eligible cases[2]	Responders	Registry-eligible cases[2]	Responders	Registry-eligible cases[2]	Responders	Registry-eligible cases[2]	Responders	Registry-eligible cases[2]
	n=180	n=6,902	n=66	n=773	n=57	n=1,361	n=91	n=1,022	n=35	n=765	n=94	n=1,102	n=523	n=11,925
Age at diagnosis, Mean (SD)	58.8 (9.4)	60.3 (13.1)	60.4 (10.0)	57.5 (13.0)	54.2 (12.1)	55.6 (13.4)	53.4 (10.9)	55.7 (13.1)	53.7 (10.8)	57.4 (12.3)	50.4 (9.9)	54.9 (13.7)	55.7 (10.8)	58.5 (13.3)
Age at diagnosis, T test	p=0.04		p=0.03		p=0.46		p=0.06		p=0.08		p<0.01		p<0.01	
Foreign born, N(%)	<5 (2.2%)	382 (5.5%)	<5 (1.5%)	29 (3.8%)	23 (40.4%)	657 (48.3%)	61 (67.0%)	692 (67.7%)	30 (85.7%)	611 (79.9%)	37 (39.4%)	597 (54.2%)	156 (29.8%)	2,968 (24.9%)
Foreign born, Chi-square test	p=0.12		p=0.09		p=0.24		p=0.89		p=0.40		p=0.02		p<0.01	
County of residence, N(%)														
Alameda	49 (27.2%)	1,536 (22.3%)	26 (39.4%)	372 (48.1%)	16 (28.1%)	317 (23.3%)	15 (16.5%)	243 (23.8%)	5 (14.3%)	168 (22.0%)	28 (29.8%)	278 (25.2%)	139 (26.6%)	2,914 (24.4%)
Contra Costa	57 (31.7%)	1,530 (22.2%)	20 (30.3%)	178 (23.0%)	10 (17.5%)	250 (18.4%)	5 (5.5%)	75 (7.3%)	5 (14.3%)	121 (15.8%)	12 (12.8%)	129 (11.7%)	109 (20.8%)	2,283 (19.1%)
San Francisco	6 (3.3%)	715 (10.4%)	11 (16.7%)	106 (13.7%)	<5 (7.0%)	131 (9.6%)	34 (37.4%)	321 (31.4%)	5 (14.3%)	122 (15.9%)	8 (8.5%)	121 (11.0%)	68 (13.0%)	1,516 (12.7%)
San Mateo	18 (10.0%)	1,038 (15.0%)	<5 (6.1%)	52 (6.7%)	14 (24.6%)	196 (14.4%)	7 (7.7%)	123 (12.0%)	<5 (11.4%)	187 (24.4%)	12 (12.8%)	114 (10.3%)	59 (11.3%)	1,710 (14.3%)
Santa Clara	50 (27.8%)	2,083 (30.2%)	5 (7.6%)	65 (8.4%)	13 (22.8%)	467 (34.3%)	30 (33.0%)	260 (25.4%)	16 (45.7%)	167 (21.8%)	34 (36.2%)	460 (41.7%)	148 (28.3%)	3,502 (29.4%)
Chi-square test	p<0.01		p=0.59		p=0.14		p=0.17		p=0.02		p=0.66		p=0.27	
Year of diagnosis, N(%)														
2006	102 (56.7%)	1,718 (24.9%)	7 (10.6%)	173 (22.4%)	19 (33.3%)	340 (25.0%)	24 (26.4%)	183 (17.9%)	12 (34.3%)	175 (22.9%)	31 (33.0%)	265 (24.0%)	195 (37.3%)	2,854 (23.9%)
2007	14 (7.8%)	1,638 (23.7%)	13 (19.7%)	180 (23.3%)	11 (19.3%)	341 (25.1%)	29 (31.9%)	273 (26.7%)	7 (20.0%)	168 (22.0%)	29 (30.9%)	271 (24.6%)	103 (19.7%)	2,871 (24.1%)
2008	64 (35.6%)	1,797 (26.0%)	25 (37.9%)	203 (26.3%)	27 (47.4%)	332 (24.4%)	38 (41.8%)	291 (28.5%)	16 (45.7%)	205 (26.8%)	33 (35.1%)	271 (24.6%)	203 (38.8%)	3,099 (26.0%)
2009	0 (0.0%)	1,749 (25.3%)	21 (31.8%)	217 (28.1%)	<5 (0.0%)	348 (25.6%)	<5 (0.0%)	275 (26.9%)	<5 (0.0%)	217 (28.4%)	<5 (1.1%)	295 (26.8%)	22 (4.2%)	3,101 (26.0%)
Chi-square test	p<0.01		p=0.06		p<0.01		p<0.01		p<0.01		p<0.01		p<0.01	
Marital status at diagnosis, N(%)														
Single	24 (13.3%)	1,161 (16.8%)	26 (39.4%)	259 (33.5%)	7 (12.3%)	261 (19.2%)	12 (13.2%)	124 (12.1%)	5 (14.3%)	125 (16.3%)	12 (12.8%)	158 (14.3%)	86 (16.4%)	2,088 (17.5%)
Married	124 (68.9%)	3,977 (57.6%)	23 (34.8%)	263 (34.0%)	40 (70.2%)	788 (57.9%)	73 (80.2%)	730 (71.4%)	24 (68.6%)	485 (63.4%)	65 (69.1%)	723 (65.6%)	349 (66.7%)	6,966 (58.4%)
Separated/widowed	29 (16.1%)	1,676 (24.3%)	17 (25.8%)	239 (30.9%)	9 (15.8%)	295 (21.7%)	6 (6.6%)	151 (14.8%)	6 (17.1%)	150 (19.6%)	13 (13.8%)	199 (18.1%)	80 (15.3%)	2,710 (22.7%)
Unknown	<5 (1.7%)	88 (1.3%)	<5 (0.0%)	12 (1.6%)	<5 (1.8%)	17 (1.2%)	<5 (0.0%)	17 (1.7%)	<5 (0.0%)	5 (0.7%)	<5 (4.3%)	22 (2.0%)	8 (1.5%)	161 (1.4%)
Chi-square test	p=0.02		p=0.53		p=0.29		p=0.09		p=0.91		p=0.36		p<0.01	
SEER summary stage at diagnosis, N(%)														
Localized	135 (75.0%)	4,807 (69.6%)	47 (71.2%)	488 (63.1%)	39 (68.4%)	855 (62.8%)	68 (74.7%)	701 (68.6%)	20 (57.1%)	508 (66.4%)	63 (67.0%)	714 (64.8%)	372 (71.1%)	8,073 (67.7%)
Regional	43 (23.9%)	1,943 (28.2%)	17 (25.8%)	262 (33.9%)	18 (31.6%)	466 (34.2%)	23 (25.3%)	296 (29.0%)	14 (40.0%)	235 (30.7%)	30 (31.9%)	350 (31.8%)	145 (27.7%)	3,552 (29.8%)
Distant	<5 (1.1%)	136 (2.0%)	<5 (1.5%)	18 (2.3%)	<5 (0.0%)	30 (2.2%)	<5 (0.0%)	19 (1.9%)	<5 (2.9%)	19 (2.5%)	<5 (1.1%)	25 (2.3%)	5 (1.0%)	247 (2.1%)
Unknown	<5 (0.0%)	16 (0.2%)	<5 (1.5%)	5 (0.6%)	<5 (0.0%)	10 (0.7%)	<5 (0.0%)	6 (0.6%)	<5 (0.0%)	<5 (0.4%)	<5 (0.0%)	13 (1.2%)	<5 (0.2%)	53 (0.4%)
Chi-square test	p=0.40		p=0.45		p=0.56		p=0.38		p=0.68		p=0.62		p=0.14	
AJCC stage at diagnosis, N(%)														
Stage I	102 (56.7%)	3,694 (53.5%)	36 (54.5%)	339 (43.9%)	28 (49.1%)	611 (44.9%)	58 (63.7%)	525 (51.4%)	14 (40.0%)	360 (47.1%)	45 (47.9%)	507 (46.0%)	283 (54.1%)	6,036 (50.6%)
Stage II	57 (31.7%)	2,238 (32.4%)	23 (34.8%)	303 (39.2%)	21 (36.8%)	479 (35.2%)	29 (31.9%)	365 (35.7%)	12 (34.3%)	287 (37.5%)	40 (42.6%)	432 (39.2%)	182 (34.8%)	4,104 (34.4%)
Stage III	16 (8.9%)	681 (9.9%)	5 (7.6%)	86 (11.1%)	5 (8.8%)	199 (14.6%)	4 (4.4%)	91 (8.9%)	6 (17.1%)	76 (9.9%)	<5 (3.2%)	101 (9.2%)	39 (7.5%)	1,234 (10.3%)
Stage IV	<5 (1.1%)	130 (1.9%)	<5 (1.5%)	18 (2.3%)	<5 (0.0%)	26 (1.9%)	<5 (0.0%)	15 (1.5%)	<5 (2.9%)	19 (2.5%)	<5 (1.1%)	22 (2.0%)	5 (1.0%)	230 (1.9%)
Unknown	<5 (1.7%)	159 (2.3%)	<5 (1.5%)	27 (3.5%)	<5 (5.3%)	46 (3.4%)	<5 (0.0%)	26 (2.5%)	<5 (5.7%)	23 (3.0%)	5 (5.3%)	40 (3.6%)	14 (2.7%)	321 (2.7%)
Chi-square test	p=0.84		p=0.49		p=0.52		p=0.08		p=0.57		p=0.30		p=0.10	
Histologic subtype, N(%)														
Ductal	114 (63.3%)	5,067 (73.4%)	47 (71.2%)	586 (75.8%)	40 (70.2%)	1,047 (76.9%)	70 (76.9%)	809 (79.2%)	25 (71.4%)	608 (79.5%)	80 (85.1%)	890 (80.8%)	376 (71.9%)	9,007 (75.5%)
Lobular	54 (30.0%)	1,426 (20.7%)	12 (18.2%)	110 (14.2%)	14 (24.6%)	209 (15.4%)	13 (14.3%)	124 (12.1%)	<5 (11.4%)	105 (13.7%)	11 (11.7%)	140 (12.7%)	108 (20.7%)	2,114 (17.7%)
Other	12 (6.7%)	409 (5.9%)	7 (10.6%)	77 (10.0%)	<5 (5.3%)	105 (7.7%)	8 (8.8%)	89 (8.7%)	6 (17.1%)	52 (6.8%)	<5 (3.2%)	72 (6.5%)	39 (7.5%)	804 (6.7%)
Chi-square test	p<0.01		p=0.65		p=0.16		p=0.83		p=0.07		p=0.40		p=0.16	
Grade, N(%)														
Grade I	48 (26.7%)	1,923 (27.9%)	14 (21.2%)	150 (19.4%)	11 (19.3%)	282 (20.7%)	26 (28.6%)	238 (23.3%)	7 (20.0%)	147 (19.2%)	17 (18.1%)	229 (20.8%)	123 (23.5%)	2,969 (24.9%)
Grade II	91 (50.6%)	2,971 (43.0%)	33 (50.0%)	275 (35.6%)	28 (49.1%)	535 (39.3%)	36 (39.6%)	404 (39.5%)	12 (34.3%)	326 (42.6%)	48 (51.1%)	453 (41.1%)	248 (47.4%)	4,964 (41.6%)
Grade III/IV	35 (19.4%)	1,635 (23.7%)	17 (25.8%)	292 (37.8%)	13 (22.8%)	441 (32.4%)	23 (25.3%)	319 (31.2%)	11 (31.4%)	238 (31.1%)	26 (27.7%)	353 (32.0%)	125 (23.9%)	3,278 (27.5%)
Unknown	6 (3.3%)	373 (5.4%)	<5 (3.0%)	56 (7.2%)	5 (8.8%)	103 (7.6%)	6 (6.6%)	61 (6.0%)	5 (14.3%)	54 (7.1%)	<5 (3.2%)	67 (6.1%)	27 (5.2%)	714 (6.0%)
Chi-square test	p=0.16		p=0.06		p=0.38		p=0.57		p=0.40		p=0.25		p=0.06	
YOST SES Quintile, N(%)														
Q1-low SES	<5 (1.1%)	53 (0.8%)	5 (7.6%)	90 (11.6%)	<5 (5.3%)	52 (3.8%)	<5 (1.1%)	33 (3.2%)	<5 (2.9%)	20 (2.6%)	<5 (1.1%)	20 (1.8%)	13 (2.5%)	268 (2.2%)
Q2	5 (2.8%)	272 (3.9%)	10 (15.2%)	172 (22.3%)	6 (10.5%)	184 (13.5%)	<5 (4.4%)	53 (5.2%)	<5 (2.9%)	60 (7.8%)	<5 (4.3%)	87 (7.9%)	30 (5.7%)	828 (6.9%)
Q3	13 (7.2%)	630 (9.1%)	17 (25.8%)	170 (22.0%)	14 (24.6%)	293 (21.5%)	13 (14.3%)	112 (11.0%)	5 (14.3%)	133 (17.4%)	7 (7.4%)	133 (12.1%)	69 (13.2%)	1,471 (12.3%)
Q4	35 (19.4%)	1,658 (24.0%)	20 (30.3%)	200 (25.9%)	13 (22.8%)	386 (28.4%)	28 (30.8%)	258 (25.2%)	8 (22.9%)	267 (34.9%)	27 (28.7%)	303 (27.5%)	131 (25.0%)	3,072 (25.8%)
Q5-high SES	125 (69.4%)	4,289 (62.1%)	14 (21.2%)	141 (18.2%)	21 (36.8%)	446 (32.8%)	45 (49.5%)	566 (55.4%)	20 (57.1%)	285 (37.3%)	55 (58.5%)	559 (50.7%)	280 (53.5%)	6,286 (52.7%)
Chi-square test	p=0.33		p=0.49		p=0.78		p=0.45		p=0.19		p=0.35		p=0.80	

[1] All data, including race/ethnicity, from CCR data

[2] Registry eligible case inclusion criteria: diagnosis with first primary malignant breast cancer in the years 2006-2009, alive at contact (September, 20th, 2011), age > 20 at diagnosis, and residence in one of five selected Bay Area counties (Alameda, Contra Costa, San Francisco, San Mateo and Santa Clara).

Table 3. Sociodemographic and clinical characteristics of breast cancer cases by race/ethnicity and respondent status, Equality in Breast Cancer Care (EBCC) Study, Greater San Francisco Bay Area, 2006-2009

Sociodemographic or clinical characteristic	Race/Ethnicitiy[1]													
	Non-Hispanic White		African American		Hispanic		Chinese		Filipino		Other		Total	
	Responders	Non-responders	Responders	Non-responders	Responders	Non-responders	Responders	Non-responders	Responders	Non-responders	Responders	Non-responders	Responders	Non-responders
	n=180	n=304	n=66	n=339	n=57	n=310	n=91	n=325	n=35	n=255	n=94	n=367	n=523	n=1900[2]
Age at diagnosis, Mean (SD)	58.8 (9.4)	60.4 (11.3)	60.4 (10.0)	57.3 (12.4)	54.2 (12.1)	59.5 (13.1)	53.4 (10.9)	55.8 (13.3)	53.7 (10.8)	59.1 (12.1)	50.4 (9.9)	58.1 (14.7)	55.7 (10.8)	58.3 (13.0)
Age at diagnosis, T test	p=0.09		p=0.03		p<0.01		p=0.09		p=0.01		p<0.01		p<0.01	
Foreign born, N(%)	<5 (2.2%)	22 (7.2%)	<5 (1.5%)	10 (2.9%)	23 (40.4%)	149 (48.1%)	61 (67.0%)	225 (69.2%)	30 (85.7%)	218 (85.5%)	37 (39.4%)	213 (58.0%)	156 (29.8%)	837 (44.1%)
Foreign born, Chi-square test	p=0.06		p=0.34		p=0.28		p=0.69		p=0.97		p<0.01		p<0.01	
County of residence, N(%)														
Alameda	49 (27.2%)	89 (29.3%)	26 (39.4%)	174 (51.3%)	16 (28.1%)	65 (21.0%)	15 (16.5%)	69 (21.2%)	5 (14.3%)	53 (20.8%)	28 (29.8%)	94 (25.6%)	139 (26.6%)	544 (28.6%)
Contra Costa	57 (31.7%)	59 (19.4%)	20 (30.3%)	71 (20.9%)	10 (17.5%)	55 (17.7%)	5 (5.5%)	30 (9.2%)	5 (14.3%)	36 (14.1%)	12 (12.8%)	36 (9.8%)	109 (20.8%)	287 (15.1%)
San Francisco	6 (3.3%)	24 (7.9%)	11 (16.7%)	37 (10.9%)	<5 (7.0%)	36 (11.6%)	34 (37.4%)	97 (29.8%)	5 (14.3%)	41 (16.1%)	8 (8.5%)	37 (10.1%)	68 (13.0%)	272 (14.3%)
San Mateo	18 (10.0%)	40 (13.2%)	<5 (6.1%)	27 (8.0%)	14 (24.6%)	54 (17.4%)	7 (7.7%)	38 (11.7%)	<5 (11.4%)	78 (30.6%)	12 (12.8%)	39 (10.6%)	59 (11.3%)	276 (14.5%)
Santa Clara	50 (27.8%)	92 (30.3%)	5 (7.6%)	30 (8.8%)	13 (22.8%)	100 (32.3%)	30 (33.0%)	91 (28.0%)	16 (45.7%)	47 (18.4%)	34 (36.2%)	161 (43.9%)	148 (28.3%)	521 (27.4%)
Chi-square test	p=0.02		p=0.23		p=0.31		p=0.30		p<0.01		p=0.61		p=0.01	
Year of diagnosis, N(%)														
2006	102 (56.7%)	152 (50.0%)	7 (10.6%)	91 (26.8%)	19 (33.3%)	63 (20.3%)	24 (26.4%)	72 (22.2%)	12 (34.3%)	85 (33.3%)	31 (33.0%)	130 (35.4%)	195 (37.3%)	593 (31.2%)
2007	14 (7.8%)	31 (10.2%)	13 (19.7%)	72 (21.2%)	11 (19.3%)	84 (27.1%)	29 (31.9%)	121 (37.2%)	7 (20.0%)	77 (30.2%)	29 (30.9%)	106 (28.9%)	103 (19.7%)	491 (25.8%)
2008	64 (35.6%)	121 (39.8%)	25 (37.9%)	102 (30.1%)	27 (47.4%)	157 (50.6%)	38 (41.8%)	130 (40.0%)	16 (45.7%)	93 (36.5%)	33 (35.1%)	126 (34.3%)	203 (38.8%)	729 (38.4%)
2009	<5 (0.0%)	<5 (0.0%)	21 (31.8%)	74 (21.8%)	<5 (0.0%)	6 (1.9%)	<5 (0.0%)	<5 (0.6%)	<5 (0.0%)	<5 (0.0%)	<5 (1.1%)	5 (1.4%)	22 (4.2%)	87 (4.6%)
Chi-square test	p=0.33		p=0.02		p=0.11		p=0.63		p=0.40		p=0.96		p=0.01	
Marital status at diagnosis, N(%)														
Single	24 (13.3%)	46 (15.1%)	26 (39.4%)	113 (33.3%)	7 (12.3%)	58 (18.7%)	12 (13.2%)	37 (11.4%)	5 (14.3%)	35 (13.7%)	12 (12.8%)	51 (13.9%)	86 (16.4%)	340 (17.9%)
Married	124 (68.9%)	165 (54.3%)	23 (34.8%)	120 (35.4%)	40 (70.2%)	180 (58.1%)	73 (80.2%)	226 (69.5%)	24 (68.6%)	161 (63.1%)	65 (69.1%)	218 (59.4%)	349 (66.7%)	1,070 (56.3%)
Separated/widowed	29 (16.1%)	86 (28.3%)	17 (25.8%)	100 (29.5%)	9 (15.8%)	69 (22.3%)	6 (6.6%)	52 (16.0%)	6 (17.1%)	58 (22.7%)	13 (13.8%)	91 (24.8%)	80 (15.3%)	456 (24.0%)
Unknown	<5 (1.7%)	7 (2.3%)	<5 (0.0%)	6 (1.8%)	<5 (1.8%)	<5 (1.0%)	<5 (0.0%)	10 (3.1%)	<5 (0.0%)	<5 (0.4%)	<5 (4.3%)	7 (1.9%)	8 (1.5%)	34 (1.8%)
Chi-square test	p<0.01		p=0.57		p=0.32		p=0.03		p=0.87		p=0.07		p<0.01	
SEER summary stage at diagnosis, N(%)														
Localized	135 (75.0%)	207 (68.1%)	47 (71.2%)	212 (62.5%)	39 (68.4%)	203 (65.5%)	68 (74.7%)	225 (69.2%)	20 (57.1%)	183 (71.8%)	63 (67.0%)	244 (66.5%)	372 (71.1%)	1,274 (67.1%)
Regional	43 (23.9%)	87 (28.6%)	17 (25.8%)	118 (34.8%)	18 (31.6%)	96 (31.0%)	23 (25.3%)	91 (28.0%)	14 (40.0%)	69 (27.1%)	30 (31.9%)	109 (29.7%)	145 (27.7%)	570 (30.0%)
Distant	<5 (1.1%)	10 (3.3%)	<5 (1.5%)	8 (2.4%)	<5 (0.0%)	6 (1.9%)	<5 (0.0%)	7 (2.2%)	<5 (2.9%)	<5 (1.2%)	<5 (1.1%)	9 (2.5%)	5 (1.0%)	43 (2.3%)
Unknown	<5 (0.0%)	<5 (0.0%)	<5 (1.5%)	<5 (0.3%)	<5 (0.0%)	5 (1.6%)	<5 (0.0%)	<5 (0.6%)	<5 (0.0%)	<5 (0.0%)	<5 (0.0%)	5 (1.4%)	<5 (0.2%)	13 (0.7%)
Chi-square test	p=0.14		p=0.33		p=0.56		p=0.29		p=0.19		p=0.68		p=0.07	
AJCC stage at diagnosis, N(%)														
Stage I	102 (56.7%)	165 (54.3%)	36 (54.5%)	153 (45.1%)	28 (49.1%)	147 (47.4%)	58 (63.7%)	161 (49.5%)	14 (40.0%)	136 (53.3%)	45 (47.9%)	175 (47.7%)	283 (54.1%)	937 (49.3%)
Stage II	57 (31.7%)	93 (30.6%)	23 (34.8%)	127 (37.5%)	21 (36.8%)	106 (34.2%)	29 (31.9%)	126 (38.8%)	12 (34.3%)	80 (31.4%)	40 (42.6%)	137 (37.3%)	182 (34.8%)	669 (35.2%)
Stage III	16 (8.9%)	31 (10.2%)	5 (7.6%)	42 (12.4%)	5 (8.8%)	40 (12.9%)	<5 (4.4%)	26 (8.0%)	6 (17.1%)	28 (11.0%)	<5 (3.2%)	33 (9.0%)	39 (7.5%)	200 (10.5%)
Stage IV	<5 (1.1%)	10 (3.3%)	<5 (1.5%)	8 (2.4%)	<5 (0.0%)	5 (1.6%)	<5 (0.0%)	6 (1.8%)	<5 (2.9%)	<5 (1.2%)	<5 (1.1%)	9 (2.5%)	5 (1.0%)	41 (2.2%)
Unknown	<5 (1.7%)	5 (1.6%)	<5 (1.5%)	9 (2.7%)	<5 (5.3%)	12 (3.9%)	<5 (0.0%)	6 (1.8%)	<5 (5.7%)	8 (3.1%)	5 (5.3%)	13 (3.5%)	14 (2.7%)	53 (2.8%)
Chi-square test	p=0.47		p=0.49		p=0.63		p=0.09		p=0.42		p=0.22		p=0.03	
Histologic subtype, N(%)														
Ductal	114 (63.3%)	224 (73.7%)	47 (71.2%)	258 (76.1%)	40 (70.2%)	241 (77.7%)	70 (76.9%)	265 (81.5%)	25 (71.4%)	195 (76.5%)	80 (85.1%)	292 (79.6%)	376 (71.9%)	1,475 (77.6%)
Lobular	54 (30.0%)	61 (20.1%)	12 (18.2%)	48 (14.2%)	14 (24.6%)	44 (14.2%)	13 (14.3%)	38 (11.7%)	<5 (11.4%)	43 (16.9%)	11 (11.7%)	50 (13.6%)	108 (20.7%)	284 (14.9%)
Other	12 (6.7%)	19 (6.3%)	7 (10.6%)	33 (9.7%)	<5 (5.3%)	25 (8.1%)	8 (8.8%)	22 (6.8%)	6 (17.1%)	17 (6.7%)	<5 (3.2%)	25 (6.8%)	39 (7.5%)	141 (7.4%)
Chi-square test	p=0.04		p=0.66		p=0.13		p=0.61		p=0.09		p=0.35		p<0.01	
Grade, N(%)														
Grade I	48 (26.7%)	79 (26.0%)	14 (21.2%)	76 (22.4%)	11 (19.3%)	83 (26.8%)	26 (28.6%)	76 (23.4%)	7 (20.0%)	51 (20.0%)	17 (18.1%)	78 (21.3%)	123 (23.5%)	443 (23.3%)
Grade II	91 (50.6%)	149 (49.0%)	33 (50.0%)	110 (32.4%)	28 (49.1%)	126 (40.6%)	36 (39.6%)	139 (42.8%)	12 (34.3%)	116 (45.5%)	48 (51.1%)	152 (41.4%)	248 (47.4%)	792 (41.7%)
Grade III/IV	35 (19.4%)	57 (18.8%)	17 (25.8%)	129 (38.1%)	13 (22.8%)	80 (25.8%)	23 (25.3%)	90 (27.7%)	11 (31.4%)	67 (26.3%)	26 (27.7%)	107 (29.2%)	125 (23.9%)	530 (27.9%)
Unknown	6 (3.3%)	19 (6.3%)	<5 (3.0%)	24 (7.1%)	5 (8.8%)	21 (6.8%)	6 (6.6%)	20 (6.2%)	5 (14.3%)	21 (8.2%)	<5 (3.2%)	30 (8.2%)	27 (5.2%)	135 (7.1%)
Chi-square test	p=1.00		p=0.03		p=0.36		p=0.57		p=0.57		p=0.41		p=0.07	
YOST SES Quintile, N(%)														
Q1-low SES	<5 (1.1%)	<5 (0.7%)	5 (7.6%)	41 (12.1%)	<5 (5.3%)	7 (2.3%)	<5 (1.1%)	10 (3.1%)	<5 (2.9%)	6 (2.4%)	<5 (1.1%)	6 (1.6%)	13 (2.5%)	72 (3.8%)
Q2	5 (2.8%)	15 (4.9%)	10 (15.2%)	75 (22.1%)	6 (10.5%)	35 (11.3%)	<5 (4.4%)	15 (4.6%)	<5 (2.9%)	20 (7.8%)	<5 (4.3%)	19 (5.2%)	30 (5.7%)	179 (9.4%)
Q3	13 (7.2%)	28 (9.2%)	17 (25.8%)	68 (20.1%)	14 (24.6%)	69 (22.3%)	13 (14.3%)	37 (11.4%)	5 (14.3%)	41 (16.1%)	7 (7.4%)	42 (11.4%)	69 (13.2%)	285 (15.0%)
Q4	35 (19.4%)	74 (24.3%)	20 (30.3%)	88 (26.0%)	13 (22.8%)	91 (29.4%)	28 (30.8%)	85 (26.2%)	8 (22.9%)	91 (35.7%)	27 (28.7%)	109 (29.7%)	131 (25.0%)	538 (28.3%)
Q5-high SES	125 (69.4%)	185 (60.9%)	14 (21.2%)	67 (19.8%)	21 (36.8%)	108 (34.8%)	45 (49.5%)	178 (54.8%)	20 (57.1%)	97 (38.0%)	55 (58.5%)	191 (52.0%)	280 (53.5%)	826 (43.5%)
Chi-square test	p=0.33		p=0.47		p=0.64		p=0.65		p=0.25		p=0.73		p<0.01	

[1] All data, including race/ethnicity, from CCR data

[2] Number of CCR cases contacted and eligible based on inclusion criteria at time of contact

Table 4. Sociodemographic and clinical characteristics of respondents by race/ethnicity, Equality in Breast Cancer Care (EBCC) Study, Greater San Francisco Bay Area, 2006-2009

Sociodemographic or clinical characteristic	Race/Ethnicity[1]							P-value
	Non-Hispanic White	African American	Hispanic	Chinese	Filipino	Other	Total	
	n=200	n=62	n=40	n=102	n=46	n=63	n=513	
Age at diagnosis (years), Mean (SD)[1]	58.1 (9.8)	60.8 (10.2)	56.9 (11.8)	52.7 (10.8)	51.7 (10.9)	51.3 (10.8)	55.8 (10.9)	
Age at interview (years), Mean (SD)[1]	63.0 (9.6)	64.6 (10.3)	61.5 (12.3)	57.5 (10.8)	56.5 (11.2)	55.6 (10.8)	60.5 (10.9)	p<0.01
Years since diagnosis, Mean (SD)[1]	4.5 (1.0)	3.2 (1.0)	4.2 (1.1)	4.1 (1.0)	4.1 (1.0)	3.8 (0.8)	4.1 (1.0)	
Foreign born, N(%)[1]	17 (8.5%)	3 (4.8%)	23 (57.5%)	83 (81.4%)	44 (95.7%)	42 (66.7%)	212 (41.3%)	
Language of interview, N(%)[1]								
English	200 (100.0%)	62 (100.0%)	20 (50.0%)	35 (34.3%)	23 (50.0%)	63 (100.0%)	425 (82.8%)	
Spanish	0 (0.0%)	0 (0.0%)	20 (50.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	20 (3.9%)	p<0.01
Tagalog	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	23 (50.0%)	0 (0.0%)	1 (0.2%)	
Chinese	0 (0.0%)	0 (0.0%)	0 (0.0%)	67 (65.7%)	0 (0.0%)	0 (0.0%)	67 (13.1%)	
County of residence, N(%)								
Alameda	54 (27.0%)	27 (43.5%)	11 (27.5%)	19 (18.6%)	11 (23.9%)	16 (25.4%)	138 (26.9%)	
Contra Costa	58 (29.0%)	18 (29.0%)	9 (22.5%)	7 (6.9%)	5 (10.9%)	10 (15.9%)	107 (20.9%)	
San Francisco	8 (4.0%)	9 (14.5%)	<5 (7.5%)	36 (35.3%)	7 (15.2%)	5 (7.9%)	68 (13.3%)	p<0.01
San Mateo	23 (11.5%)	<5 (6.5%)	8 (20.0%)	8 (7.8%)	6 (13.0%)	9 (14.3%)	58 (11.3%)	
Santa Clara	57 (28.5%)	<5 (6.5%)	9 (22.5%)	32 (31.4%)	17 (37.0%)	23 (36.5%)	142 (27.7%)	
Year of diagnosis, N(%)								
2006	112 (56.0%)	7 (11.3%)	13 (32.5%)	32 (31.4%)	15 (32.6%)	14 (22.2%)	193 (37.6%)	
2007	24 (12.0%)	13 (21.0%)	<5 (10.0%)	29 (28.4%)	9 (19.6%)	21 (33.3%)	100 (19.5%)	p<0.01
2008	64 (32.0%)	22 (35.5%)	23 (57.5%)	40 (39.2%)	22 (47.8%)	27 (42.9%)	198 (38.6%)	
2009	<5 (0.0%)	20 (32.3%)	<5 (0.0%)	<5 (1.0%)	<5 (0.0%)	<5 (1.6%)	22 (4.3%)	
Marital status at diagnosis, N(%)[1]								
Single	20 (10.0%)	19 (30.6%)	6 (15.0%)	15 (14.7%)	7 (15.2%)	14 (22.2%)	81 (15.8%)	
Married	146 (73.0%)	22 (35.5%)	23 (57.5%)	75 (73.5%)	30 (65.2%)	36 (57.1%)	332 (64.7%)	p<0.01
Separated/widowed	34 (17.0%)	21 (33.9%)	11 (27.5%)	12 (11.8%)	9 (19.6%)	13 (20.6%)	100 (19.5%)	
Highest level of education, N(%)[1]								
<= High school graduate	17 (8.5%)	12 (19.4%)	19 (47.5%)	27 (26.5%)	9 (19.6%)	8 (12.7%)	92 (17.9%)	
Some College	55 (27.5%)	29 (46.8%)	11 (27.5%)	15 (14.7%)	9 (19.6%)	16 (25.4%)	135 (26.3%)	
College graduate	79 (39.5%)	14 (22.6%)	4 (10.0%)	41 (40.2%)	23 (50.0%)	21 (33.3%)	182 (35.5%)	p<0.01
Graduate School	47 (23.5%)	6 (9.7%)	6 (15.0%)	19 (18.6%)	5 (10.9%)	16 (25.4%)	99 (19.3%)	
Unknown	2 (1.0%)	1 (1.6%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (3.2%)	5 (1.0%)	
Annual household income, N(%)[1]								
<=$55,000	42 (21.0%)	30 (48.4%)	14 (35.0%)	39 (38.2%)	10 (21.7%)	15 (23.8%)	150 (29.2%)	
$56,000-$99,000	55 (27.5%)	16 (25.8%)	5 (12.5%)	16 (15.7%)	12 (26.1%)	13 (20.6%)	117 (22.8%)	p<0.01
>=$100,000	84 (42.0%)	11 (17.7%)	8 (20.0%)	29 (28.4%)	15 (32.6%)	21 (33.3%)	168 (32.7%)	
Unknown	19 (9.5%)	5 (8.1%)	13 (32.5%)	18 (17.6%)	9 (19.6%)	14 (22.2%)	78 (15.2%)	
Insurance coverage/type, N(%)[1,2]								
Had health insurance through my job or my husband's/partner's job, N(%)	145 (72.5%)	44 (71.0%)	21 (52.5%)	62 (60.8%)	37 (80.4%)	50 (79.4%)	359 (70.0%)	p<0.01
Had individual health insurance not provided by my job or my husband's/ partner's job, N(%)	37 (18.5%)	4 (6.5%)	5 (12.5%)	12 (11.8%)	1 (2.2%)	3 (4.8%)	62 (12.1%)	p<0.01
Had MediCare Part A and/or B, N(%)	42 (21.0%)	8 (12.9%)	10 (25.0%)	15 (14.7%)	7 (15.2%)	9 (14.3%)	91 (17.7%)	p=0.39
Had MediCare Part D prescription drug coverage, N(%)	20 (10.0%)	2 (3.2%)	3 (7.5%)	9 (8.8%)	4 (8.7%)	5 (7.9%)	43 (8.4%)	p=0.71
Had extra insurance for MediCare, N(%)	6 (3.0%)	0 (0.0%)	0 (0.0%)	1 (1.0%)	0 (0.0%)	0 (0.0%)	7 (1.4%)	p=0.22
Had Medi-Cal, N(%)	3 (1.5%)	6 (9.7%)	9 (22.5%)	20 (19.6%)	6 (13.0%)	7 (11.1%)	51 (9.9%)	p<0.01
Had other government health program, N(%)	1 (0.5%)	3 (4.8%)	2 (5.0%)	0 (0.0%)	2 (4.3%)	1 (1.6%)	9 (1.8%)	p=0.05
Had Military Health care, N(%)	3 (1.5%)	0 (0.0%)	0 (0.0%)	1 (1.0%)	0 (0.0%)	1 (1.6%)	5 (1.0%)	p=0.81
Had Indian Health Service, N(%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	--
Had single-service plan, N(%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	--
Had other types of insurance, N(%)	5 (2.5%)	2 (3.2%)	1 (2.5%)	2 (2.0%)	0 (0.0%)	4 (6.3%)	14 (2.7%)	p=0.45
SEER summary stage at diagnosis, N(%)								
Localized	147 (73.5%)	45 (72.6%)	31 (77.5%)	75 (73.5%)	26 (56.5%)	40 (63.5%)	364 (71.0%)	
Regional	51 (25.5%)	15 (24.2%)	9 (22.5%)	27 (26.5%)	19 (41.3%)	22 (34.9%)	143 (27.9%)	p=0.29
Distant	<5 (1.0%)	<5 (1.6%)	<5 (0.0%)	<5 (0.0%)	<5 (2.2%)	<5 (1.6%)	5 (1.0%)	
Unknown	<5 (0.0%)	<5 (1.6%)	<5 (0.0%)	<5 (0.0%)	<5 (0.0%)	<5 (0.0%)	<5 (0.2%)	
AJCC stage at diagnosis, N(%)								
Stage I	110 (55.0%)	35 (56.5%)	21 (52.5%)	63 (61.8%)	17 (37.0%)	30 (47.6%)	276 (53.8%)	
Stage II	66 (33.0%)	20 (32.3%)	15 (37.5%)	33 (32.4%)	17 (37.0%)	28 (44.4%)	179 (34.9%)	
Stage III	18 (9.0%)	5 (8.1%)	<5 (5.0%)	<5 (3.9%)	8 (17.4%)	<5 (3.2%)	39 (7.6%)	p=0.27
Stage IV	<5 (1.0%)	<5 (1.6%)	<5 (0.0%)	<5 (0.0%)	<5 (2.2%)	<5 (1.6%)	5 (1.0%)	
Unknown	<5 (2.0%)	<5 (1.6%)	<5 (5.0%)	<5 (2.0%)	<5 (6.5%)	<5 (3.2%)	14 (2.7%)	
Histologic subtype, N(%)								
Ductal	129 (64.5%)	43 (69.4%)	28 (70.0%)	80 (78.4%)	36 (78.3%)	51 (81.0%)	367 (71.5%)	
Lobular	60 (30.0%)	12 (19.4%)	9 (22.5%)	13 (12.7%)	<5 (8.7%)	9 (14.3%)	107 (20.9%)	p<0.01
Other	11 (5.5%)	7 (11.3%)	<5 (7.5%)	9 (8.8%)	6 (13.0%)	<5 (4.8%)	39 (7.6%)	
Grade, N(%)								
Grade I	53 (26.5%)	13 (21.0%)	7 (17.5%)	27 (26.5%)	9 (19.6%)	13 (20.6%)	122 (23.8%)	
Grade II	105 (52.5%)	32 (51.6%)	14 (35.0%)	43 (42.2%)	17 (37.0%)	34 (54.0%)	245 (47.8%)	
Grade III/IV	35 (17.5%)	15 (24.2%)	15 (37.5%)	26 (25.5%)	16 (34.8%)	14 (22.2%)	121 (23.6%)	p=0.12
Unknown	7 (3.5%)	<5 (3.2%)	<5 (10.0%)	6 (5.9%)	<5 (8.7%)	<5 (3.2%)	25 (4.9%)	
Surgical treatment, N(%)								
BCS, no radiation	21 (10.5%)	11 (17.7%)	7 (17.5%)	11 (10.8%)	6 (13.0%)	5 (7.9%)	61 (11.9%)	
BCS, radiation	110 (55.0%)	31 (50.0%)	17 (42.5%)	44 (43.1%)	17 (37.0%)	37 (58.7%)	256 (49.9%)	
Mastectomy	68 (34.0%)	17 (27.4%)	14 (35.0%)	45 (44.1%)	21 (45.7%)	21 (33.3%)	186 (36.3%)	p=0.08
Other/unknown	<5 (0.5%)	<5 (4.8%)	<5 (5.0%)	<5 (2.0%)	<5 (4.3%)	<5 (0.0%)	10 (1.9%)	
Hormone therapy, N(%)								
No	77 (38.5%)	31 (50.0%)	19 (47.5%)	41 (40.2%)	29 (63.0%)	29 (46.0%)	226 (44.1%)	
Yes	116 (58.0%)	31 (50.0%)	21 (52.5%)	59 (57.8%)	17 (37.0%)	32 (50.8%)	276 (53.8%)	p=0.13
Unknown	7 (3.5%)	<5 (0.0%)	<5 (0.0%)	<5 (2.0%)	<5 (0.0%)	<5 (3.2%)	11 (2.1%)	
YOST SES quintile, N(%)								
Q1-low SES	<5 (1.0%)	5 (8.1%)	<5 (5.0%)	<5 (2.0%)	<5 (2.2%)	<5 (0.0%)	12 (2.3%)	
Q2	<5 (2.0%)	9 (14.5%)	6 (15.0%)	<5 (3.9%)	<5 (6.5%)	<5 (6.3%)	30 (5.8%)	
Q3	16 (8.0%)	15 (24.2%)	13 (32.5%)	15 (14.7%)	5 (10.9%)	<5 (6.3%)	68 (13.3%)	p<0.01
Q4	41 (20.5%)	20 (32.3%)	7 (17.5%)	30 (29.4%)	10 (21.7%)	22 (34.9%)	130 (25.3%)	
Q5-high SES	137 (68.5%)	13 (21.0%)	12 (30.0%)	51 (50.0%)	27 (58.7%)	33 (52.4%)	273 (53.2%)	

[1] Data from EBCC survey

[2] percentage doesn't add up to 100% because respondents could report more than one type

-- Statistics cannot be calculated

Table 5. Percent reporting discrimination experiences by race/ethnicity, Equality in Breast Cancer Care (EBCC) Study, Greater San Francisco Bay Area, 2006-2009

Discrimination Experiences	Race/Ethnicity[1]							Chi-Square Test P-value
	Non-Hispanic White	African American	Hispanic	Chinese	Filipino	Other	Total	
	n=200	n=62	n=40	n=102	n=46	n=63	n=513	
INTERPERSONAL DISCRIMINATION								
Medical Discrimination (% Any)[2]								
treated with less respect than other people	23 (11.5%)	12 (19.4%)	7 (17.5%)	30 (29.4%)	6 (13.0%)	9 (14.3%)	87 (17.0%)	p<0.01
receive poorer service than others	33 (16.5%)	12 (19.4%)	10 (25.0%)	31 (30.4%)	11 (23.9%)	13 (20.6%)	110 (21.4%)	p=0.14
someone from your health care team act as if he or she thinks you are not smart	23 (11.5%)	9 (14.5%)	8 (20.0%)	21 (20.6%)	4 (8.7%)	8 (12.7%)	73 (14.2%)	p=0.23
someone from your health care team act as if he or she is better than you	27 (13.5%)	8 (12.9%)	5 (12.5%)	24 (23.5%)	9 (19.6%)	14 (22.2%)	87 (17.0%)	p=0.16
someone was not listening to what you were saying	64 (32.0%)	13 (21.0%)	13 (32.5%)	38 (37.3%)	9 (19.6%)	16 (25.4%)	153 (29.8%)	p=0.14
someone make inappropriate comments to you or about you	27 (13.5%)	8 (12.9%)	2 (5.0%)	20 (19.6%)	2 (4.3%)	8 (12.7%)	67 (13.1%)	p=0.11
wait longer than other people to be seen by your health care team	27 (13.5%)	17 (27.4%)	12 (30.0%)	39 (38.2%)	12 (26.1%)	23 (36.5%)	130 (25.3%)	p<0.01
you were denied a test or treatment	18 (9.0%)	4 (6.5%)	4 (10.0%)	17 (16.7%)	2 (4.3%)	7 (11.1%)	52 (10.1%)	p=0.17
you had to insist on receiving a test or treatment	30 (15.0%)	7 (11.3%)	6 (15.0%)	27 (26.5%)	4 (8.7%)	15 (23.8%)	89 (17.3%)	p=0.03
Summary % Any	88 (44.0%)	24 (38.7%)	19 (47.5%)	64 (62.7%)	17 (37.0%)	28 (44.4%)	240 (46.8%)	p=0.01
Attribution[3]								
Racial/ethnic[4]	2 (2.3%)	10 (41.7%)	6 (31.6%)	8 (12.5%)	2 (11.8%)	1 (3.6%)	29 (12.1%)	p<0.01
Immigration[5]	0 (0.0%)	0 (0.0%)	4 (21.1%)	14 (21.9%)	4 (23.5%)	5 (17.9%)	27 (11.3%)	p<0.01
Other[6]	82 (93.2%)	17 (70.8%)	18 (94.7%)	52 (81.3%)	11 (64.7%)	26 (92.9%)	206 (85.8%)	p<0.01
None[7]	6 (6.8%)	2 (8.3%)	1 (5.3%)	3 (4.7%)	3 (17.6%)	1 (3.6%)	16 (6.7%)	p=0.51
Global measure of medical discrimination due to race/ethnicity (% Any)[2]	4 (2.0%)	11 (17.7%)	5 (12.5%)	21 (20.6%)	6 (13.0%)	7 (11.1%)	54 (10.5%)	p<0.01
Personal experiences (% reporting any concern)[7]	4 (2.0%)	19 (30.6%)	12 (30.0%)	28 (27.5%)	10 (21.7%)	8 (12.7%)	81 (15.8%)	p<0.01
Group experiences (% reporting any concern)[7]	15 (7.5%)	41 (66.1%)	23 (57.5%)	46 (45.1%)	17 (37.0%)	24 (38.1%)	166 (32.4%)	p<0.01
Provider Mistrust (% Any)[8]								
difficult to trust doctors	24 (12.0%)	12 (19.4%)	6 (15.0%)	14 (13.7%)	8 (17.4%)	8 (12.7%)	72 (14.0%)	p=0.74
difficult to trust nurses	19 (9.5%)	11 (17.7%)	5 (12.5%)	14 (13.7%)	9 (19.6%)	7 (11.1%)	65 (12.7%)	p=0.36
doctor has made references to your race/ethnicity or skin color when it did not seem important	1 (0.5%)	4 (6.5%)	2 (5.0%)	11 (10.8%)	0 (0.0%)	3 (4.8%)	21 (4.1%)	p<0.01
trust your doctor's advice because you were treated at a very prestigious/well-known medical facility	92 (46.0%)	31 (50.0%)	17 (42.5%)	36 (35.3%)	13 (28.3%)	21 (33.3%)	210 (40.9%)	p=0.13
because of your insurance status, you are happy to receive any medical treatment you can get[9]	14 (30.4%)	7 (46.7%)	10 (55.6%)	21 (70.0%)	6 (50.0%)	7 (50.0%)	65 (48.1%)	p=0.56
GENERAL DISCRIMINATION								
Lifetime Discrimination (Summary % Any)	173 (86.5%)	57 (91.9%)	30 (75.0%)	87 (85.3%)	31 (67.4%)	53 (84.1%)	431 (84.0%)	p<0.01
Attribution[3]								
Racial/ethnic[4]	21 (12.1%)	45 (78.9%)	14 (46.7%)	46 (52.9%)	16 (51.6%)	26 (49.1%)	168 (39.0%)	p<0.01
Immigration[5]	6 (3.5%)	5 (8.8%)	9 (30.0%)	43 (49.4%)	16 (51.6%)	15 (28.3%)	94 (21.8%)	p<0.01
Other[6]	158 (91.3%)	37 (64.9%)	27 (90.0%)	74 (85.1%)	26 (83.9%)	41 (77.4%)	363 (84.2%)	p<0.01
None[7]	12 (6.9%)	2 (3.5%)	0 (0.0%)	2 (2.3%)	0 (0.0%)	1 (1.9%)	17 (3.9%)	p=0.17
Recent Everyday Discrimination (Summary % Any)	126 (63.0%)	42 (67.7%)	23 (57.5%)	68 (66.7%)	30 (65.2%)	41 (65.1%)	330 (64.3%)	p=0.81
Attribution[3]								
Racial/ethnic[4]	6 (4.8%)	31 (73.8%)	4 (17.4%)	21 (30.9%)	14 (46.7%)	13 (31.7%)	89 (27.0%)	p<0.01
Immigration[5]	2 (1.6%)	1 (2.4%)	3 (13.0%)	23 (33.8%)	11 (36.7%)	9 (22.0%)	49 (14.8%)	p<0.01
Other[6]	87 (69.0%)	21 (50.0%)	12 (52.2%)	54 (79.4%)	18 (60.0%)	32 (78.0%)	224 (67.9%)	p<0.01
None[7]	37 (29.4%)	6 (14.3%)	11 (47.8%)	5 (7.4%)	6 (20.0%)	4 (9.8%)	69 (20.9%)	p<0.01
Usual responses to discrimination experiences (% Yes)[3]								
try to do something about it	57 (45.2%)	16 (38.1%)	5 (21.7%)	24 (35.3%)	9 (30.0%)	14 (34.1%)	125 (37.9%)	p=0.06
accept it as a fact of life	65 (51.6%)	26 (61.9%)	10 (43.5%)	51 (75.0%)	17 (56.7%)	28 (68.3%)	197 (59.7%)	p=0.25
work harder to prove them wrong	42 (33.3%)	16 (38.1%)	2 (8.7%)	24 (35.3%)	14 (46.7%)	13 (31.7%)	111 (33.6%)	p=0.21
believe that you brought it on yourself	7 (5.6%)	1 (2.4%)	1 (4.3%)	17 (25.0%)	2 (6.7%)	9 (22.0%)	37 (11.2%)	p<0.01
talk to someone about how you were feeling	82 (65.1%)	24 (57.1%)	9 (39.1%)	47 (69.1%)	17 (56.7%)	30 (73.2%)	209 (63.3%)	p=0.05
express anger or get mad	53 (42.1%)	23 (54.8%)	5 (21.7%)	37 (54.4%)	13 (43.3%)	20 (48.8%)	151 (45.8%)	p=0.92
pray about the situation	37 (29.4%)	28 (66.7%)	4 (17.4%)	25 (36.8%)	19 (63.3%)	16 (39.0%)	129 (39.1%)	p<0.01
Global measure of recent discrimination due to race/ethnicity (% Any)[2]	9 (4.5%)	32 (51.6%)	5 (12.5%)	40 (39.2%)	13 (28.3%)	18 (28.6%)	117 (22.8%)	p<0.01
INSTITUTIONAL DISCRIMINATION								
Hospital Mistrust								
Summary % Any	181 (90.5%)	51 (82.3%)	32 (80.0%)	75 (73.5%)	29 (63.0%)	44 (69.8%)	412 (80.3%)	p<0.01
Summary Score (0-5), Mean (SD)	2.5 (1.3)	2.7 (1.7)	2.4 (1.7)	1.8 (1.4)	1.5 (1.5)	1.6 (1.6)	2.2 (1.5)	p[10]<0.01
Cronbach's alpha	0.61	0.76	0.78	0.68	0.71	0.72	0.69	--
Dissimilarity Index & racial/ethnic composition (residential segregation measure of evenness)[11]								
low segregation, low composition	--	4 (6.5%)	11 (27.5%)	16 (15.7%)	11 (23.9%)	--	42 (8.2%)	
low segregation, high composition	--	0 (0.0%)	9 (22.5%)	42 (41.2%)	22 (47.8%)	--	73 (14.2%)	
high segregation, low composition	--	28 (45.2%)	6 (15.0%)	7 (6.9%)	3 (6.5%)	--	44 (8.6%)	p<0.01
high segregation, high composition	--	29 (46.8%)	14 (35.0%)	35 (34.3%)	10 (21.7%)	--	88 (17.2%)	
Segregation missing or composition missing	--	1 (1.6%)	0 (0.0%)	2 (2.0%)	0 (0.0%)	--	266 (51.9%)	
Isolation Index & racial/ethnic composition (residential segregation measure of exposure)[11]								
low segregation, low composition	--	4 (6.5%)	17 (42.5%)	0 (0.0%)	0 (0.0%)	--	21 (4.1%)	
low segregation, high composition	--	0 (0.0%)	23 (57.5%)	0 (0.0%)	0 (0.0%)	--	23 (4.5%)	
high segregation, low composition	--	28 (45.2%)	0 (0.0%)	23 (22.5%)	14 (30.4%)	--	65 (12.7%)	p<0.01
high segregation, high composition	--	29 (46.8%)	0 (0.0%)	77 (75.5%)	32 (69.6%)	--	138 (26.9%)	
Segregation missing or composition missing	--	1 (1.6%)	0 (0.0%)	2 (2.0%)	0 (0.0%)	--	266 (51.9%)	

[1] Data, including race/ethnicity, from EBCC survey except for segregation measures (US Census Bureau)

[2] Any=rarely, sometimes, often

[3] Only among those who reported any discrimination, percentage doesn't add up to 100% because respondents could report more than one type

[4] Racial/ethnic attribution—race/ethnicity and skin color

[5] Immigration attribution—way you speak English) and birthplace

[6] Other attributions—health insurance, gender, age, religion, height and weight, sexual retention, education, how much money you have, a physical disability, appearance, all other reasons reported in answers to open-ended questions

[7] Report No/Refused/DK to all of the attribution questions

[8] Report % agree/strongly agree except for trust your doctor's advice because you were treated at a very prestigious/well-known medical facility (report % disagree/strongly disagree)

[9] only among those who reported having MediCal, MediCare, other government sponsored health insurance, or no health insurance

[10] P value for ANOVA test

[11] For Chinese and Filipina, measures for Asian Americans were used; For Non-Hispanic Whites and Other race/ethnicity, measures not available

-- Statistics cannot be calculated

Table 6. Resources/coping styles by race/ethnicity, Equality in Breast Cancer Care (EBCC) Study, Greater San Francisco Bay Area, 2006-2009

Resources/coping styles	Race/Ethnicity[1]							ANOVA Test P-value
	Non-Hispanic	African American	Hispanic	Chinese	Filipino	Other	Total	
	n=200	n=62	n=40	n=102	n=46	n=63	n=513	
D9. Active Coping (John Henryism)								
Summary score (12-48), Median	23.0	21.0	21.5	24.0	21.0	22.0	23.0	--
Summary score (12-48), Mean(SD)	22.3 (4.0)	20.3 (4.4)	20.9 (4.4)	24.4 (3.8)	20.6 (4.3)	22.1 (4.8)	22.2 (4.4)	p<0.01
Cronbach's alpha	0.78	0.82	0.79	0.76	0.85	0.85	0.82	--
S11. Perceived Stress Scale								
summary score (0-40), Mean(SD)	15.1 (7.8)	14.6 (6.9)	14.6 (7.6)	17.1 (8.7)	15.5 (7.0)	16.1 (7.3)	15.5 (7.7)	p=0.26
Cronbach's alpha	0.92	0.78	0.85	0.91	0.84	0.86	0.89	
N2. Neighborhood cohesion/ collective efficacy								
Summary score (5-20), Mean(SD)	9.9 (3.6)	9.3 (3.2)	8.2 (3.4)	7.5 (3.2)	6.3 (3.5)	8.6 (3.5)	8.7 (3.6)	p<0.01
Cronbach's alpha	0.86	0.78	0.78	0.81	0.83	0.83	0.85	--

[1] All data, including race/ethnicity, from EBCC survey

-- Statistics cannot be calculated

Table 7. Distribution of quality of life (QOL) variables and internal consistency reliability of QOL scales by race/ethnicity, Equality in Breast Cancer Care (EBCC) Study, Greater San Francisco Bay Area, 2006-2009

Quality of life scales	Non-Hispanic White n=200	African American n=62	Hispanic n=40	Chinese n=102	Filipino n=46	Other n=63	Total n=513	ANOVA Test P-value
Race/Ethnicity[1]								
PROMIS Global Items[2]								
Global Item #1: general health (1-5), Mean (SD)	2.3 (1.1)	2.8 (1.1)	2.5 (1.2)	2.8 (1.1)	2.9 (1.2)	2.6 (1.1)	2.5 (1.1)	p<0.01
Global Item #2: quality of life (1-5), Mean (SD)	2.1 (1.0)	2.5 (1.0)	2.3 (1.0)	2.7 (1.0)	2.4 (1.0)	2.4 (1.1)	2.3 (1.1)	p<0.01
Global Item #3: physical health (1-5), Mean (SD)	2.4 (1.1)	2.8 (1.1)	2.5 (1.1)	2.8 (1.1)	2.9 (1.1)	2.6 (1.1)	2.6 (1.1)	p<0.01
Global Item #4: mental health (1-5), Mean (SD)	2.3 (1.0)	2.5 (1.1)	2.6 (1.2)	2.8 (1.1)	2.4 (1.0)	2.5 (1.1)	2.5 (1.1)	p<0.01
Global Item #5: social satisfaction (1-5), Mean (SD)	2.2 (1.0)	2.5 (1.2)	2.3 (0.9)	2.7 (1.1)	2.3 (0.9)	2.4 (0.9)	2.4 (1.0)	p<0.01
Global Item #6: social activities (1-5), Mean (SD)	2.1 (1.0)	2.4 (1.1)	2.4 (1.1)	2.7 (1.0)	2.4 (1.0)	2.5 (1.0)	2.4 (1.0)	p<0.01
Global Item #7: physical activities (1-5), Mean (SD)	1.7 (1.0)	1.9 (1.2)	1.7 (1.0)	1.8 (1.0)	1.8 (1.0)	1.7 (1.0)	1.7 (1.0)	p=0.60
Global Item #8: emotional problems (1-5), Mean (SD)	2.4 (1.0)	2.3 (1.0)	2.5 (1.0)	2.5 (1.1)	2.5 (1.2)	2.3 (1.0)	2.4 (1.1)	p=0.84
Global Item #9: fatigue (1-5), Mean (SD)	2.2 (0.8)	2.5 (1.0)	2.4 (0.8)	2.5 (0.9)	2.5 (0.8)	2.2 (0.9)	2.3 (0.9)	p=0.03
Global Item #10: pain (0-10), Mean (SD)	2.5 (2.5)	4.0 (3.1)	3.3 (2.8)	2.9 (2.7)	3.7 (3.1)	3.1 (2.7)	3.0 (2.7)	p<0.01
Summary Score (9-55) , Mean (SD)	22.2 (8.4)	26.3 (8.7)	24.5 (8.3)	26.0 (9.0)	25.7 (8.9)	24.4 (8.2)	24.2 (8.7)	p<0.01
Cronbach's α	0.91	0.88	0.88	0.91	0.90	0.90	0.90	--
PROMIS Psychosocial Positive Illness Impact[3]								
You are comfortable with who you are								
Before diagnosis (1-5), Mean (SD)	4.3 (1.0)	4.5 (0.9)	4.1 (1.0)	3.9 (1.1)	3.8 (1.5)	4.2 (1.0)	4.2 (1.1)	p<0.01
After diagnosis (1-5), Mean (SD)	4.1 (1.0)	4.2 (1.2)	4.0 (1.1)	3.8 (1.2)	3.7 (1.5)	4.0 (1.2)	4.0 (1.1)	p=0.01
You realize who your real friends are								
Before diagnosis (1-5), Mean (SD)	4.2 (1.0)	4.5 (1.0)	4.3 (1.0)	3.6 (1.3)	4.5 (0.9)	3.9 (1.3)	4.1 (1.1)	p<0.01
After diagnosis (1-5), Mean (SD)	4.6 (0.8)	4.6 (0.9)	4.5 (0.9)	3.9 (1.3)	4.5 (0.8)	4.2 (1.1)	4.4 (1.0)	p<0.01
You can adjust to things you cannot change								
Before diagnosis (1-5), Mean (SD)	3.8 (1.1)	3.9 (1.3)	4.2 (0.9)	3.6 (1.1)	4.1 (1.0)	3.7 (1.2)	3.8 (1.1)	p=0.04
After diagnosis (1-5), Mean (SD)	4.1 (1.0)	4.1 (1.2)	4.4 (0.8)	4.0 (1.1)	4.1 (1.0)	4.0 (1.1)	4.1 (1.0)	p=0.41
Your life is meaningful								
Before diagnosis (1-5), Mean (SD)	4.3 (0.8)	4.4 (1.0)	4.6 (0.7)	4.1 (1.0)	4.5 (0.8)	4.1 (1.0)	4.3 (0.9)	p<0.01
After diagnosis (1-5), Mean (SD)	4.4 (0.9)	4.3 (1.0)	4.7 (0.7)	4.2 (1.0)	4.6 (0.6)	4.4 (1.0)	4.4 (0.9)	p=0.02
Summary Score (range)								
Before diagnosis (4-20), Mean (SD)	16.5 (2.9)	17.3 (3.2)	17.1 (2.9)	15.0 (3.4)	15.9 (4.0)	15.2 (4.0)	16.1 (3.3)	p<0.01
After diagnosis (4-20), Mean (SD)	17.2 (2.9)	17.2 (3.6)	17.5 (2.9)	15.5 (3.4)	15.9 (3.9)	15.9 (4.1)	16.6 (3.4)	p<0.01
Cronbach's α								
Before diagnosis	0.71	0.73	0.76	0.73	0.45	0.64	0.70	--
After diagnosis	0.75	0.87	0.81	0.71	0.41	0.70	0.74	--
FACT-B Breast Cancer Subscale[4]								
Self-conscious about way you dress (1-5), Mean (SD)	1.9 (1.1)	1.7 (1.1)	1.8 (1.0)	2.7 (1.4)	1.8 (1.2)	2.1 (1.4)	2.0 (1.2)	p<0.01
Swollen/tender arms (1-5), Mean (SD)	1.4 (0.8)	1.6 (1.0)	2.1 (1.2)	1.8 (1.2)	1.6 (1.0)	1.5 (0.9)	1.6 (1.0)	p<0.01
Felt sexually attractive (1-5), Mean (SD)	2.5 (1.1)	2.6 (1.3)	2.3 (1.3)	1.9 (1.1)	2.5 (1.1)	2.2 (1.1)	2.3 (1.2)	p<0.01
Bothered by weight change (1-5), Mean (SD)	1.9 (1.2)	2.2 (1.3)	2.3 (1.4)	1.9 (1.3)	2.4 (1.5)	2.0 (1.2)	2.0 (1.3)	p=0.06
Bothered by treatment side effects (1-5), Mean (SD)	2.0 (1.3)	2.4 (1.3)	2.3 (1.4)	2.1 (1.3)	2.5 (1.3)	2.5 (1.3)	2.2 (1.3)	p=0.06
Worried about risk of cancer in family members (1-5), Mean (SD)	2.1 (1.2)	2.1 (1.4)	2.7 (1.4)	1.9 (1.2)	3.0 (1.4)	2.0 (1.1)	2.1 (1.3)	p<0.01
Summary Score (6-30) , Mean (SD)	11.7 (3.3)	12.5 (3.5)	13.3 (4.6)	12.3 (3.5)	13.5 (4.5)	12.2 (3.6)	12.3 (3.7)	p=0.03
Cronbach's α	0.29	0.21	0.63	0.23	0.50	0.41	0.33	--

[1] All data, including race/ethnicity, from EBCC survey

[2] Lower score indicates better quality of life; higher score, worse quality of life

[3] Higher score indicates high agreement with statement (better QOL); lower score, lower agreement (worse QOL)

[4] Higher score indicates high agreement with statement (worse QOL); lower score, lower agreement (better QOL)

-- Statistics cannot be calculated

Table 8. QOL subscale scores by type of discrimination experience, Equality in Breast Cancer Care (EBCC) Study, Greater San Francisco Bay Area, 2006-2009

Discrimination experiences	PROMIS Global QOL Summary Score	PROMIS Psychosocial Summary Score (before diagnosis)	PROMIS Psychosocial Summary Score (after diagnosis)	FACT-B Breast Cancer Subscale Summary Score
	Mean (SD)[2, 3]	Mean (SD)[2, 4]	Mean (SD)[2, 4]	Mean (SD)[2, 5]
INTERPERSONAL				
Medical Discrimination				
None	23.3 (8.4)	16.6 (3.2)	16.8 (3.3)	11.9 (3.6)
Any	25.2 (8.9)	15.6 (3.5)	16.4 (3.5)	12.7 (3.6)
T test	p=0.01	p<0.01	p=0.11	p<0.01
Attribution[6]				
Racial/ethnic	29.8 (9.3)	15.5 (4.1)	15.3 (4.6)	13.3 (3.6)
Non-racial/ethnic	24.6 (8.7)	15.7 (3.3)	16.6 (3.2)	12.7 (3.6)
T test	p<0.01	p=0.77	p=0.15	p=0.42
Immigration	29.6 (8.5)	13.0 (4.1)	13.7 (4.2)	12.8 (4.1)
Non-immigration	24.7 (8.8)	15.9 (3.3)	16.6 (3.3)	12.7 (3.6)
T test	p<0.01	p<0.01	p<0.01	p=0.99
Other	25.0 (9.0)	15.8 (3.3)	16.6 (3.3)	12.7 (3.5)
Non-other	26.5 (8.2)	14.4 (4.4)	14.7 (4.2)	12.9 (4.5)
T test	p=0.36	p=0.09	p<0.01	p=0.79
No attribution specified	25.2 (7.2)	14.3 (4.2)	15.3 (4.2)	13.8 (5.8)
Any attribution specified	25.2 (9.0)	15.7 (3.4)	16.4 (3.4)	12.6 (3.4)
T test	p=0.98	p=0.14	p=0.21	p=0.46
Global measure of medical discrimination due to race/ethnicity				
None	23.6 (8.5)	16.2 (3.3)	16.8 (3.3)	12.1 (3.6)
Any	29.1 (8.5)	15.0 (3.6)	15.1 (4.0)	13.5 (3.9)
T test	p<0.01	p=0.01	p<0.01	p=0.01
Lifetime Discrimination				
None	24.7 (9.6)	16.2 (3.9)	16.4 (3.9)	11.6 (4.0)
Any	24.1 (8.6)	16.1 (3.2)	16.7 (3.3)	12.4 (3.6)
T test	p=0.57	p=0.90	p=0.54	p=0.10
Attribution[6]				
Racial/ethnic	24.9 (8.1)	16.2 (3.4)	16.4 (3.6)	12.6 (3.7)
Non-racial/ethnic	23.5 (8.8)	16.1 (3.1)	16.8 (3.0)	12.3 (3.5)
T test	p=0.11	p=0.81	p=0.25	p=0.47
Immigration	25.7 (8.4)	14.9 (3.9)	15.5 (3.8)	12.9 (4.2)
Non-immigration	23.6 (8.6)	16.5 (3.0)	17.0 (3.0)	12.3 (3.4)
T test	p=0.04	p<0.01	p<0.01	p=0.14
Other	24.0 (8.7)	16.1 (3.1)	16.8 (3.2)	12.4 (3.6)
Non-other	24.8 (7.9)	16.1 (3.8)	16.1 (3.8)	12.2 (3.6)
T test	p=0.47	p=0.97	p=0.20	p=0.63
No attribution specified	24.2 (8.4)	15.9 (3.3)	16.0 (3.2)	12.9 (4.3)
Any attribution specified	24.1 (8.6)	16.1 (3.2)	16.7 (3.3)	12.4 (3.6)
T test	p=0.97	p=0.75	p=0.38	p=0.57
Recent Everyday Discrimination				
None	23.0 (9.2)	16.4 (3.6)	16.9 (3.6)	11.5 (3.6)
Any	24.8 (8.4)	16.0 (3.2)	16.5 (3.3)	12.7 (3.6)
T test	p=0.03	p=0.25	p=0.28	p<0.01
Attribution[6]				
Racial/ethnic	26.5 (8.9)	16.0 (3.7)	16.3 (3.9)	13.7 (3.9)
Non-racial/ethnic	24.2 (8.4)	15.7 (2.9)	16.3 (3.0)	12.6 (3.3)
T test	p=0.04	p=0.52	p=0.88	p=0.02
Immigration	27.4 (8.9)	14.4 (4.1)	14.7 (4.1)	13.3 (3.6)
Non-immigration	24.4 (8.5)	16.0 (2.9)	16.6 (3.1)	12.9 (3.6)
T test	p=0.03	p=0.01	p<0.01	p=0.41
Other	25.5 (8.9)	15.6 (3.1)	16.2 (3.3)	13.1 (3.6)
Non-other	22.6 (6.9)	16.3 (3.5)	16.5 (3.5)	12.5 (3.4)
T test	p=0.01	p=0.16	p=0.66	p=0.33
No attribution specified	24.2 (8.4)	15.9 (3.3)	16.0 (3.2)	12.9 (4.3)
Any attribution specified	24.1 (8.6)	16.1 (3.2)	16.7 (3.3)	12.4 (3.6)
T test	p=0.97	p=0.75	p=0.38	p=0.57
Global measure of recent discrimination due to race/ethnicity				
None	23.6 (8.6)	16.3 (3.2)	16.8 (3.2)	12.0 (3.5)
Any	26.3 (8.6)	15.7 (3.6)	16.0 (3.8)	13.2 (4.0)
T test	p<0.01	p=0.08	p=0.04	p<0.01
INSTITUTIONAL				
Hospital Mistrust				
None	25.6 (9.3)	16.4 (3.2)	16.6 (3.3)	11.8 (3.7)
Any	23.9 (8.5)	16.1 (3.3)	16.6 (3.4)	12.4 (3.6)
T test	p=0.07	p=0.46	p=0.85	p=0.13
Segregation index (Dissimilarity Index & racial/ethnic composition)[1]				
low segregation, low composition	24.9 (8.6)	16.6 (3.1)	16.8 (3.2)	12.8 (3.5)
low segregation, high composition	25.1 (8.6)	15.4 (3.5)	15.8 (3.6)	12.5 (3.7)
high segregation, low composition	25.5 (9.1)	17.0 (3.5)	17.1 (3.5)	12.1 (3.6)
high segregation, high composition	26.8 (8.7)	15.9 (3.5)	16.3 (3.4)	13.0 (4.3)
ANOVA test	p=0.56	p=0.07	p=0.19	p=0.56
Segregation index (Isolation Index & racial/ethnic composition)[1]				
low segregation, low composition	23.1 (7.3)	16.9 (3.5)	17.4 (3.5)	12.3 (3.4)
low segregation, high composition	25.5 (8.6)	17.0 (2.5)	17.1 (2.9)	14.4 (5.1)
high segregation, low composition	25.9 (9.2)	16.8 (3.3)	16.8 (3.3)	12.4 (3.6)
high segregation, high composition	26.1 (8.7)	15.4 (3.6)	15.9 (3.6)	12.5 (3.8)
ANOVA test	p=0.54	p=0.02	p=0.09	p=0.15

[1]NH Whites and Others were excluded for the analysis

[2]Missing values were not used to compute the mean and standard deviation estimates

[3]Lower score indicates better quality of life; higher score, worse quality of life

[4]Higher score indicates high agreement with statement (better QOL); lower score, lower agreement (worse QOL)

[5]Higher score indicates high agreement with statement (worse QOL); lower score, lower agreement (better QOL)

[6]Means and standard deviations are caculated only among those who report any discrimination

Table 9. Bivariate associations between discrimination experiences and surgical treatment outcomes among early-stage breast cancer survivors [1], Equality in Breast Cancer Care (EBCC) Study, Greater San Francisco Bay Area, 2006-2009

Discrimination experiences	BCS, no radiation	BCS, radiation	Mastectomy	Total[2]	P-value
	n=48	n=217	n=97	n=364	
	N(%)	N(%)	N(%)	N(%)	
INTERPERSONAL					
Medical Discrimination					
None[4]	18 (37.5%)	128 (59.0%)	49 (50.5%)	195 (53.6%)	p=0.02
Any[4]	30 (62.5%)	89 (41.0%)	48 (49.5%)	169 (46.4%)	
Attribution[3]					
Racial/ethnic[4]	6 (20.0%)	10 (11.2%)	6 (12.5%)	23 (13.6%)	p=0.30
Non-racial/ethnic[4]	24 (80.0%)	78 (87.6%)	41 (85.4%)	144 (85.2%)	
Immigration[4]	3 (10.0%)	11 (12.4%)	7 (14.6%)	21 (12.4%)	p=0.89
Non-immigration[4]	27 (90.0%)	77 (86.5%)	41 (85.4%)	147 (87.0%)	
Other[4]	28 (93.3%)	78 (87.6%)	40 (83.3%)	147 (87.0%)	p=0.22
Non-other[4]	2 (6.7%)	10 (11.2%)	8 (16.7%)	21 (12.4%)	
No attribution specified	0 (0.0%)	6 (6.7%)	3 (6.3%)	9 (5.3%)	p=0.53
Any attribution specified	30 (100.0%)	83 (93.3%)	45 (93.8%)	160 (94.7%)	
Global measure of medical discrimination due to race/ethnicity					
None[4]	42 (87.5%)	196 (90.3%)	86 (88.7%)	325 (89.3%)	p=0.23
Any[4]	6 (12.5%)	19 (8.8%)	11 (11.3%)	37 (10.2%)	
Lifetime Discrimination					
None[4]	3 (6.3%)	30 (13.8%)	18 (18.6%)	51 (14.0%)	p=0.23
Any[4]	45 (93.8%)	183 (84.3%)	79 (81.4%)	309 (84.9%)	
Attribution[3]					
Racial/ethnic[4]	25 (55.6%)	71 (38.8%)	33 (41.8%)	130 (42.1%)	p=0.24
Non-racial/ethnic[4]	20 (44.4%)	112 (61.2%)	46 (58.2%)	179 (57.9%)	
Immigration[4]	12 (26.7%)	37 (20.2%)	17 (21.5%)	66 (21.4%)	p=0.70
Non-immigration[4]	33 (73.3%)	146 (79.8%)	62 (78.5%)	243 (78.6%)	
Other[4]	36 (80.0%)	152 (83.1%)	67 (84.8%)	257 (83.2%)	p=0.83
Non-other[4]	9 (20.0%)	31 (16.9%)	12 (15.2%)	52 (16.8%)	
No attribution specified	2 (4.4%)	8 (4.4%)	3 (3.8%)	13 (4.2%)	p=0.99
Any attribution specified	43 (95.6%)	175 (95.6%)	76 (96.2%)	296 (95.8%)	
Recent Everyday Discrimination					
None[4]	9 (18.8%)	76 (35.0%)	38 (39.2%)	123 (33.8%)	p=0.07
Any[4]	38 (79.2%)	136 (62.7%)	59 (60.8%)	235 (64.6%)	
Attribution[3]					
Racial/ethnic[4]	13 (34.2%)	36 (26.5%)	11 (18.6%)	61 (26.0%)	p=0.35
Non-racial/ethnic[4]	21 (55.3%)	72 (52.9%)	39 (66.1%)	133 (56.6%)	
Immigration[4]	7 (18.4%)	17 (12.5%)	9 (15.3%)	33 (14.0%)	p=0.83
Non-immigration[4]	27 (71.1%)	91 (66.9%)	41 (69.5%)	161 (68.5%)	
Other[4]	27 (71.1%)	89 (65.4%)	43 (72.9%)	161 (68.5%)	p=0.77
Non-other[4]	7 (18.4%)	20 (14.7%)	7 (11.9%)	34 (14.5%)	
No attribution specified	7 (18.4%)	32 (23.5%)	11 (18.6%)	50 (21.3%)	p=0.71
Any attribution specified	31 (81.6%)	104 (76.5%)	48 (81.4%)	185 (78.7%)	
Global measure of recent discrimination due to race/ethnicity					
None[4]	30 (62.5%)	165 (76.0%)	74 (76.3%)	269 (73.9%)	p=0.02
Any[4]	15 (31.3%)	43 (19.8%)	20 (20.6%)	80 (22.0%)	
INSTITUTIONAL					
Hospital Mistrust					
None[4]	6 (12.5%)	28 (12.9%)	27 (27.8%)	61 (16.8%)	p<0.01
Any[4]	42 (87.5%)	188 (86.6%)	70 (72.2%)	302 (83.0%)	
Segregation index (Dissimilarity Index & racial/ethnic composition)[5]					
low segregation, low composition	7 (23.3%)	12 (13.3%)	16 (29.1%)	36 (20.3%)	p=0.05
low segregation, high composition	7 (23.3%)	20 (22.2%)	21 (38.2%)	48 (27.1%)	
high segregation, low composition	4 (13.3%)	22 (24.4%)	5 (9.1%)	31 (17.5%)	
high segregation, high composition	12 (40.0%)	34 (37.8%)	13 (23.6%)	60 (33.9%)	
Segregation index (Isolation Index & racial/ethnic composition)[5]					
low segregation, low composition	4 (13.3%)	7 (7.8%)	6 (10.9%)	17 (9.6%)	p=0.98
low segregation, high composition	4 (13.3%)	8 (8.9%)	6 (10.9%)	18 (10.2%)	
high segregation, low composition	7 (23.3%)	27 (30.0%)	15 (27.3%)	50 (28.2%)	
high segregation, high composition	15 (50.0%)	46 (51.1%)	28 (50.9%)	90 (50.8%)	

[1]Inclusion criterion used here: SEER summary stage: Localized

[2]Total included 2 patients with unknown surgical treatment information

[3]Percentages are caculated only among those who report any discrimination

[4]Percentages may not add up to 100% since the missing categories are not presented in the table

[5]NH Whites and Others were excluded for the analysis. Percentages may not add up to 100% since the missing categories are not presented in the table

Table 10. Bivariate associations between discrimination experiences and use of hormone therapy, Equality in Breast Cancer Care (EBCC) Study[1], Greater San Francisco Bay Area, 2006-2009

Discrimination experiences	Never had hormone therapy n=154 N(%)	Ever had hormone therapy n=270 N(%)	Total[2] n=435 N(%)	Chi-square Test P-value
INTERPERSONAL				
Medical Discrimination				
None[4]	85 (55.2%)	144 (53.3%)	233 (53.6%)	p=0.48
Any[4]	69 (44.8%)	126 (46.7%)	202 (46.4%)	
Attribution[3]				
Racial/ethnic[4]	7 (10.1%)	11 (8.7%)	18 (8.9%)	p=0.67
Non-racial/ethnic[4]	62 (89.9%)	114 (90.5%)	183 (90.6%)	
Immigration[4]	3 (4.3%)	17 (13.5%)	21 (10.4%)	p=0.12
Non-immigration[4]	66 (95.7%)	108 (85.7%)	180 (89.1%)	
Other[4]	64 (92.8%)	107 (84.9%)	177 (87.6%)	p=0.33
Non-other[4]	5 (7.2%)	18 (14.3%)	24 (11.9%)	
No attribution specified	2 (2.9%)	11 (8.7%)	13 (6.4%)	p=0.22
Any attribution specified	67 (97.1%)	115 (91.3%)	189 (93.6%)	
Global measure of medical discrimination due to race/ethnicity				
None[4]	138 (89.6%)	245 (90.7%)	392 (90.1%)	p=0.50
Any[4]	16 (10.4%)	23 (8.5%)	41 (9.4%)	
Lifetime Discrimination				
None[4]	18 (11.7%)	46 (17.0%)	66 (15.2%)	p=0.31
Any[4]	135 (87.7%)	221 (81.9%)	365 (83.9%)	
Attribution[3]				
Racial/ethnic[4]	50 (37.0%)	86 (38.9%)	138 (37.8%)	p=0.59
Non-racial/ethnic[4]	84 (62.2%)	135 (61.1%)	226 (61.9%)	
Immigration[4]	24 (17.8%)	52 (23.5%)	76 (20.8%)	p=0.13
Non-immigration[4]	110 (81.5%)	169 (76.5%)	288 (78.9%)	
Other[4]	115 (85.2%)	185 (83.7%)	309 (84.7%)	p=0.38
Non-other[4]	19 (14.1%)	36 (16.3%)	55 (15.1%)	
No attribution specified	5 (3.7%)	10 (4.5%)	15 (4.1%)	p=0.76
Any attribution specified	130 (96.3%)	211 (95.5%)	350 (95.9%)	
Recent Everyday Discrimination				
None[4]	55 (35.7%)	85 (31.5%)	145 (33.3%)	p=0.48
Any[4]	96 (62.3%)	180 (66.7%)	282 (64.8%)	
Attribution[3]				
Racial/ethnic[4]	26 (27.1%)	45 (25.0%)	74 (26.2%)	p=0.38
Non-racial/ethnic[4]	56 (58.3%)	102 (56.7%)	160 (56.7%)	
Immigration[4]	13 (13.5%)	26 (14.4%)	40 (14.2%)	p=0.93
Non-immigration[4]	69 (71.9%)	121 (67.2%)	194 (68.8%)	
Other[4]	68 (70.8%)	122 (67.8%)	195 (69.1%)	p=0.59
Non-other[4]	14 (14.6%)	26 (14.4%)	40 (14.2%)	
No attribution specified	18 (18.8%)	41 (22.8%)	60 (21.3%)	p=0.71
Any attribution specified	78 (81.3%)	139 (77.2%)	222 (78.7%)	
Global measure of recent discrimination due to race/ethnicity				
None[4]	119 (77.3%)	198 (73.3%)	325 (74.7%)	p=0.61
Any[4]	30 (19.5%)	63 (23.3%)	96 (22.1%)	
INSTITUTIONAL				
Hospital Mistrust				
None[4]	34 (22.1%)	45 (16.7%)	79 (18.2%)	p=0.12
Any[4]	120 (77.9%)	221 (81.9%)	352 (80.9%)	
Segregation index (Dissimilarity Index & racial/ethnic composition)[5]				
low segregation, low composition	8 (11.1%)	26 (20.8%)	34 (17.1%)	p=0.39
low segregation, high composition	27 (37.5%)	32 (25.6%)	60 (30.2%)	
high segregation, low composition	12 (16.7%)	26 (20.8%)	38 (19.1%)	
high segregation, high composition	24 (33.3%)	40 (32.0%)	65 (32.7%)	
Segregation index (Isolation Index & racial/ethnic composition)[5]				
low segregation, low composition	4 (5.6%)	13 (10.4%)	17 (8.5%)	p=0.45
low segregation, high composition	8 (11.1%)	9 (7.2%)	17 (8.5%)	
high segregation, low composition	16 (22.2%)	39 (31.2%)	55 (27.6%)	
high segregation, high composition	43 (59.7%)	63 (50.4%)	108 (54.3%)	

[1]Inclusion criterion used here: ER+ or PR+

[2]Total included 11 patients with unknown hormone therapy information

[3]Percentages are caculated only among those who report any discrimination

[4]Percentages may not add up to 100% since the missing categories are not presented in the table

[5]NH Whites and Others were excluded for the analysis. Percentages may not add up to 100% since the missing categories are not presented in the table

Table 11. Bivariate associations between stage at diagnosis and type of discrimination experience, Equality in Breast Cancer Care (EBCC) Study, Greater San Francisco Bay Area, 2006-2009

Discrimination experiences	Early Stage (Stage Localized) n=364 N(%)	Late Stage (Stage Regional/Remote) n=148 N(%)	Total[1] n=513 N(%)	Chi-square Test P-value
INTERPERSONAL				
Medical Discrimination				
None[3]	195 (53.6%)	78 (52.7%)	273 (53.2%)	p=0.56
Any[3]	169 (46.4%)	70 (47.3%)	240 (46.8%)	
Attribution[2]				
Racial/ethnic[3]	23 (13.6%)	6 (8.6%)	29 (12.1%)	p=0.50
Non-racial/ethnic[3]	144 (85.2%)	64 (91.4%)	209 (87.1%)	
Immigration[3]	21 (12.4%)	6 (8.6%)	27 (11.3%)	p=0.64
Non-immigration[3]	147 (87.0%)	64 (91.4%)	212 (88.3%)	
Other[3]	147 (87.0%)	58 (82.9%)	206 (85.8%)	p=0.59
Non-other[3]	21 (12.4%)	12 (17.1%)	33 (13.8%)	
No attribution specified	9 (5.3%)	7 (10.0%)	16 (6.7%)	p=0.40
Any attribution specified	160 (94.7%)	63 (90.0%)	224 (93.3%)	
Global measure of medical discrimination due to race/ethnicity				
None[3]	325 (89.3%)	130 (87.8%)	456 (88.9%)	p=0.85
Any[3]	37 (10.2%)	17 (11.5%)	54 (10.5%)	
Lifetime Discrimination				
None[3]	51 (14.0%)	25 (16.9%)	76 (14.8%)	p=0.64
Any[3]	309 (84.9%)	121 (81.8%)	431 (84.0%)	
Attribution[2]				
Racial/ethnic[3]	130 (42.1%)	38 (31.4%)	168 (39.0%)	p=0.11
Non-racial/ethnic[3]	179 (57.9%)	81 (66.9%)	261 (60.6%)	
Immigration[3]	66 (21.4%)	28 (23.1%)	94 (21.8%)	p=0.79
Non-immigration[3]	243 (78.6%)	92 (76.0%)	336 (78.0%)	
Other[3]	257 (83.2%)	105 (86.8%)	363 (84.2%)	p=0.49
Non-other[3]	52 (16.8%)	15 (12.4%)	67 (15.5%)	
No attribution specified	13 (4.2%)	4 (3.3%)	17 (3.9%)	p=0.89
Any attribution specified	296 (95.8%)	117 (96.7%)	414 (96.1%)	
Recent Everyday Discrimination				
None[3]	123 (33.8%)	50 (33.8%)	173 (33.7%)	p=0.77
Any[3]	235 (64.6%)	94 (63.5%)	330 (64.3%)	
Attribution[2]				
Racial/ethnic[3]	61 (26.0%)	27 (28.7%)	89 (27.0%)	p=0.33
Non-racial/ethnic[3]	133 (56.6%)	54 (57.4%)	187 (56.7%)	
Immigration[3]	33 (14.0%)	16 (17.0%)	49 (14.8%)	p=0.77
Non-immigration[3]	161 (68.5%)	65 (69.1%)	227 (68.8%)	
Other[3]	161 (68.5%)	63 (67.0%)	224 (67.9%)	p=0.08
Non-other[3]	34 (14.5%)	18 (19.1%)	53 (16.1%)	
No attribution specified	50 (21.3%)	19 (20.2%)	69 (20.9%)	p=0.86
Any attribution specified	185 (78.7%)	75 (79.8%)	261 (79.1%)	
Global measure of recent discrimination due to race/ethnicity				
None[3]	269 (73.9%)	109 (73.6%)	379 (73.9%)	p=0.72
Any[3]	80 (22.0%)	37 (25.0%)	117 (22.8%)	
INSTITUTIONAL				
Hospital Mistrust				
None[3]	61 (16.8%)	36 (24.3%)	97 (18.9%)	p=0.10
Any[3]	302 (83.0%)	109 (73.6%)	412 (80.3%)	
Segregation index (Dissimilarity Index & racial/ethnic composition)[4]				
low segregation, low composition	36 (20.3%)	6 (8.3%)	42 (16.8%)	p=0.28
low segregation, high composition	48 (27.1%)	25 (34.7%)	73 (29.2%)	
high segregation, low composition	31 (17.5%)	13 (18.1%)	44 (17.6%)	
high segregation, high composition	60 (33.9%)	27 (37.5%)	88 (35.2%)	
Segregation index (Isolation Index & racial/ethnic composition)[4]				
low segregation, low composition	17 (9.6%)	4 (5.6%)	21 (8.4%)	p=0.50
low segregation, high composition	18 (10.2%)	5 (6.9%)	23 (9.2%)	
high segregation, low composition	50 (28.2%)	15 (20.8%)	65 (26.0%)	
high segregation, high composition	90 (50.8%)	47 (65.3%)	138 (55.2%)	

[1]Total included 1 patients with unknown SEER summary stage information

[2]Percentages are caculated only among those who report any discrimination

[3]Percentages may not add up to 100% since the missing categories are not presented in the table

[4]NH Whites and Others were excluded for the analysis. Percentages may not add up to 100% since the missing categories are not presented in the table

Table 12. EBCC test-retest agreement table

Survey Item	N[1]	% Missing[2]	% Agreement[3]
MEDICAL DISCRIMINATION			
M1. While getting medical care for breast cancer, did you feel you were treated unfairly by having any of the following things happen to you?			
a. were you treated with less respect than other people	102	0.0%	86.3%
b. did you receive poorer service than others	102	0.0%	81.4%
c. did someone from your health care team act as if he or she thinks you are not smart	102	0.0%	89.2%
d. did someone from your health care team act as if he or she is better than you	102	0.0%	83.3%
e. did you feel like someone was not listening to what you were saying	102	0.0%	78.4%
f. did someone make inappropriate comments to you or about you	102	0.0%	90.2%
g. did you have to wait longer than other people to be seen by your health care team	102	0.0%	76.5%
h. did you feel that you were denied a test or treatment	102	0.0%	89.2%
i. did you feel that you had to insist on receiving a test or treatment	102	0.0%	85.3%
M2. Please tell me which of these may be the reasons why you were treated unfairly while getting medical care for breast cancer? **(1=Yes, 2=No, 88=Refused, 99=D/K)** **Only answered if any discrimination reported in M1**			
Race/ethnicity			
e. Your race/ethnicity	58	0.0%	58.6%
i. Your skin color	58	0.0%	58.6%
Partial agreement	58	0.0%	58.6%
Immigration			
b. The way you speak English	58	0.0%	56.9%
c. Your birthplace	58	0.0%	58.6%
Partial agreement	58	0.0%	55.2%
Other			
a. Your health insurance (or lack of)	58	0.0%	58.6%
d. Your gender	58	0.0%	60.3%
f. Your age	58	0.0%	51.7%
g. Your religion	58	0.0%	60.3%
h. Your height or weight	58	0.0%	58.6%
j. Your sexual orientation	58	0.0%	60.3%
k. Your education	58	0.0%	60.3%
l. How much money you have	58	0.0%	62.1%
m. A physical disability	58	0.0%	58.6%
n. Your appearance on a given day	58	0.0%	56.9%
o. Other specified	58	0.0%	44.8%
M3. In general, how concerned are you that you may be treated unfairly because of your race/ethnicity when seeking medical care? **(1=Not at all concerned, 2=A little concerned , 3=Somewhat concerned, 4=Extremely concerned, 88=Refused, 99=D/K)**	102	0.0%	82.4%
M4. In general, how concerned are you that people of your same race/ethnicity may be treated unfairly because of their race/ethnicity when seeking medical care? This could include a family member, friend, or someone you do not know personally. **(1=Not at all concerned, 2=A little concerned , 3=Somewhat concerned, 4=Extremely concerned, 88=Refused, 99=D/K)**	102	0.0%	70.6%
M6. For the next items, please tell me how much you agree with each one. **(1= Strongly Agree, 2=Agree, 3=Disagree, 4=Strongly Disagree, 88=refused, 99=D/k)**			
a. In general, you find it difficult to trust doctors.	102	0.0%	72.5%
b. In general, you find it difficult to trust nurses.	102	0.0%	70.6%
c. Your doctor has made references to your race/ethnicity or skin color when it did not seem important.	102	0.0%	70.6%
d. You trust your doctor's advice because you were treated at a very prestigious/well-known medical facility.	102	0.0%	58.8%
e. Because of your insurance status, you are happy to receive any medical treatment you can get.	20	4.9%	50.0%
GENERAL DISCRIMINATION (in the past 12 months)			
D4. Over the past 12 months, how often have any of the following things happened to you in your day-to-day life? **(1=Never, 2=Rarely, 3=Sometimes, 4=Often, 88=refused, 99=D/K)**			
a. have you been treated with less respect than other people?	102	0.0%	69.6%
b. have you received poorer service than other people at restaurants or stores?	102	0.0%	70.6%
c. have people acted as if they think you are not smart?	102	0.0%	73.5%
d. have people acted as if they are afraid of you?	102	0.0%	78.4%
e. have people acted as if they think you are dishonest?	102	0.0%	89.2%
f. have people acted as if they're better than you?	102	0.0%	65.7%
g. have you been called names or were insulted?	102	0.0%	77.5%
h. have you been threatened or harassed?	102	0.0%	85.3%
i. have you been followed around in stores?	102	0.0%	91.2%
D5. Please tell me which of these may be the reasons why you were treated unfairly over the past 12 months? **(1=Yes, 2=No, 88=Refused, 99=D/K)** **Only answered if any discrimination reported in D4**			
Race/ethnicity			
e. Your race/ethnicity	76	1.0%	38.2%
i. Your skin color	76	1.0%	40.8%
Partial agreement	77	0.0%	39.0%
Immigration			
b. The way you speak English	76	1.0%	43.4%

	N	%missing	%agreement
c. Your birthplace	76	1.0%	48.7%
Partial agreement	77	0.0%	44.2%
Other			
a. Your health insurance (or lack of)	76	1.0%	47.4%
d. Your gender	76	1.0%	40.8%
f. Your age	76	1.0%	39.5%
g. Your religion	76	1.0%	48.7%
h. Your height or weight	76	1.0%	47.4%
j. Your sexual orientation	76	1.0%	50.0%
k. Your education	76	1.0%	43.4%
l. How much money you have	76	1.0%	43.4%
m. A physical disability	76	1.0%	43.4%
n. Your appearance on a given day	76	1.0%	31.6%
o. Other specified	76	1.0%	35.5%
GENERAL HEALTH (over the past 4 weeks)			
Q1: For the next section, please think about your general health over the past 4 weeks. **(1=Excellent, 2=Very Good, 3=Good, 4=Fair, 5=Poor, 88=Refused, 99=D/K)**			
a. In general, over the past 4 weeks, would you say your health was:	102	0.0%	56.9%
b. In general, over the past 4 weeks, would you say your quality of life was:	102	0.0%	58.8%
c. In general, over the past 4 weeks, how would you rate your physical health?	102	0.0%	63.7%
d. In general, [over the past 4 weeks], how would you rate your mental health, including your mood and your ability to think?	102	0.0%	48.0%
e. In general, [over the past 4 weeks], how would you rate your satisfaction with your social activities and relationship?	102	0.0%	59.8%
f. In general, [over the past 4 weeks], please rate how well you carried out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)	102	0.0%	56.9%
Q7. Now I'd like you to think about the future. Next year, at this time would you predict that your overall health will be better, about the same, or worse? **(1=Better, 2=About the same, 3=Worse, 88=Refused, 99=D/K)**	102	0.0%	73.5%
How your breast cancer diagnosis has affected you, please rate how true these statements were for you before your breast cancer diagnosis and again now, since your breast cancer diagnosis. **(1=Not at all, 2=A little bit, 3=Somewhat, 4=Quite a bit, 5=Very much, 88=Refused, 99=D/K)**			
Q8. You are comfortable with who you are:			
a. How true was this before your breast cancer diagnosis?	102	0.0%	51.0%
b. How true is this now since your breast cancer diagnosis?	102	0.0%	57.8%
Q9. You realize who your real friends are:			
a. How true was this before your breast cancer diagnosis?	102	0.0%	55.9%
b. How true is this now since your breast cancer diagnosis?	102	0.0%	62.7%
Q10. You can adjust to things you cannot change:			
a. How true was this before your breast cancer diagnosis?	102	0.0%	52.0%
b. How true is this now since your breast cancer diagnosis?	102	0.0%	52.0%
Q11. Your life is meaningful			
a. How true was this before your breast cancer diagnosis?	102	0.0%	60.8%
b. How true is this now since your breast cancer diagnosis?	102	0.0%	66.7%
BREAST CANCER TREATMENT			
T5. Did you have surgery for your breast cancer? By surgery we mean a procedure in which breast tissue was removed. **(1=Yes, 2=No, 88=REFUSED, 99=D/K)**	102	0.0%	99.0%
P8. If you could choose, would you prefer to be treated by doctors of your own racial/ethnic group, another racial/ethnic group, or do you NOT have a preference? **(1=Your own racial/ethnic group , 2=Another racial/ethnic group, 3=No preference, 88=REFUSED, 99=D/K)**	102	0.0%	89.2%
P9. Why would you prefer to have a doctor who is of the same race/ethnicity as you? **(Y=Yes, N=No)** **Only answered if answer to P8 is 1 (Your own racial/ethnic group)**			
1. She or he would understand your disease better than others (that is, the type of cancer you have, your biology or physiology)	16	0.0%	31.3%
2. She or he would be able to speak your language	16	0.0%	50.0%
3. She or he would understand your cultural beliefs	16	0.0%	43.8%
4. She or he would be able to relate to you better	16	0.0%	37.5%
5. You feel you would be more involved in making decisions about your care	16	0.0%	43.8%
6. Other: please specify	11	4.9%	18.2%
Partial agreement	16	0.0%	50.0%
P11. OVERALL, on a scale of 1 to 10 where 1 is the worst health care possible and 10 is the best health care possible, what number would you use to rate the breast cancer care you have received ? (write down number, 88=REFUSED, 99=D/K)	102	0.0%	55.9%
SUPPORT NETWORK (within the FIRST YEAR of your breast cancer diagnosis) **(0=None, 1=1 or 2, 2=3 to 5, 3=6 to 9, 4=10 or more, 88=Refused, 99=D/K)**			
S1a. How many close relatives did you have? (By close we mean people you felt at ease with, could talk to about private matters, and could call on for help?	102	0.0%	55.9%
S1b. How many close friends did you have (who were not relatives)?	102	0.0%	60.8%
S2. How many of these friends and/or family members did you see or talk to at least once a month? **Only answered if 1-4 reported for either of S1a or S1b**	101	0.0%	58.4%

[1] Number of patients answered this question (excluding those who skipped the question per skip pattern as described above, and the missings)

[2] %missing was calculated using only people who should have completed the question as the denominator. The question had to be missing/blank in both test and retest to be

[3] %agreement was calculated using N as denominator (excluding those who skipped the question per skip pattern as described above, and the missings)

Appendix E

Open-ended responses to the attribution questions

Table 13. Open-ended responses for other attributions among participants reporting experiences of medical discrimination (EBCC Survey Item M2O)

1=Longer wait because chemo appts typically delayed at facility / MD running late / office too busy / too many patients--sometimes patients took too long w/ doctor
2=Medical personnel not well trained
3=Had to insist on a diagnostic test
4=Believes in integrated/alt medicine and was looked down upon
5=Communication issues / was not given complete information / lacked information
6=Participant having a bad day
7=Other people's / MDs personalities / attitudes / egos / incompetencies
8=Nurses overworked
9=Not sure why treated unfairly (as opposed to don't know IF other reasons why)
10=Was not feeling well (vomiting) and nurse would not let her see MD b/c she did not have an appt.
11=Some pts have to wait longer - just the way it is
12=Lack of awareness and sensitivity
13=Wanted to get treated right away, but was put off
14=Difference in medical findings between respondent and doctor based on respondent's research / Her level of education - ready with a lot of questions
15=Doctor/patient "hierarchy" / doctor knows best attitude; physician's old fashioned views - used to making all decisions w/o input from pt. / doctor resented ppt for asking questions and did not like being interrupted / asked too many questions, talked too much / doctor just didn't want to listen
16=Her docs explained the treatments before she asked for them; she needed to discuss the treatment options w/the doc
17=Respondent didn't agree to tx choices originally offered
18=Language barrier on doctor's end
19=scheduling for bx took a long time
20=Doctors are in a hurry/busy schedule/not enough time to listen
21=Ppt having a bad day
22=Denied tests because the docs don't think they're necessary
23=The hospital was very busy and circumstances that couldn't be controlled. Ex: something happened to the previous patient. / too busy, gives care to whom needed more urgently
24=mammography and physician - lack of knowledge in imaging-wrong dx at first time-rec her to come back in 6 months but she decided to have a biopsy to confirm
25=doc (oncologist) uncertain about the situation
26=People may think she was overreacting because she had cancer, i.e., worry too much
27=It's just the way people act - she said she doesn't really pay attention to this. Sometimes it can be people are just too busy.
28=Respondent had to insist on double mastectomy; wanted this because of family history; 2 blood relatives ended w/double mastectomy
29=Didn't believe results; want to confirm the cancer diagnosis
30=MD (oncologist) didn't listen to her   [70327-Wanted her to go on a clinical trial she was not interested in participating in; 73212-combo of meds on clinical trial causing bowel problem, MD dismissed].
31=Had an issue with one MD and switched to another
32=Told them that she had depression so they didn't take what she said seriously
33=Had to deal with her more b/c her case was complicated. But always acted on her behalf
34=responded "rarely" b/c didn't want team to sound "perfect"
35=Sees her type of case all the time. Felt like her case was "run of the mill"

36=	Respondent seemed less fragile and stronger than she really felt. Saw other patients more fragile and seemed to get more attention. Respondent only appeared to be doing well.
37=	Had stage 0 and had to insist on mastectomy - MDs wanted her to have lumpectomy
38=	Staff distracted; seemed like some tension between technicians
39=	Involved w/computer, no eye contact
40=	I think I was disrespected when they did radiation because random people barged into the room while I was lying naked from the waist up - it was very upsetting when office staff, a woman, came in without even knocking.
41=	Treating others who had cancer, sometimes a long wait
42=	Had infection and was not taken seriously by doctors and was ignored, didn't get prompt care, then doctor and nurse tried to blame her for incidence
43=	A medical tech suggested she should have had a mastectomy because her friend did / an opinion unasked for
44=	They were just busy. / people tend to get busy
45=	Said she just had different opinion with doctor / not treated unfairly, but different opinion than doctors
46=	Dr based on western training and decided that tx is not needed (recommended by Chinese medicine doctor)
47=	Nurses are too busy. Also, they don't have knowledge to answer her questions which she is supposed to ask her doctor.
48=	Office was too busy. Staff knew she can wait longer because familiar and friend with her.
49=	Primary care doctor always told her to refer to the BC doctor for any BC questions
50=	Oncologist can give more info - too busy
51=	Surgeon didn't pay enough attention, didn't give her details for follow-up procedures after the treatment
52=	Doc's interpretation of mammogram--thought it was negative
54=	Husband was trying to have subject's tx data included in a research study on this rare tumor, rad. oncol. Was unwilling and uncooperative. Rad oncol. cancelled appt, unilateral decision w/o any notice.
55=	Biopsy tested negative but she wanted to remove the lump and it turned out it was in fact cancer
56=	Left alone in exam room for an hour, forgot about her
57=	Too busy, impatient-- delayed by others and docs
58=	Some people may have a bad day, bad mood, bad attitude
59=	Ignored by the staff in the hospital
60=	Staff are too busy
61=	Her condition was not as serious as others
62=	"Doc prescribed may not be right for her (ppt was in emergency room)"
63=	At one of the chemo therapy sessions something came up so appt was delayed by 1/2 hour, but this was a small matter
64=	Insisted on having hereditary gene test and had to pay out of pocket for it
65=	When being marked to go into surgery, it was very uncomfortable and I don't know if that was due to lack of experience
66=	Doctor didn't want to believe that she had a problem
67=	Her surgeon at El Camino Hospital: communication skill was poor; didn't explain enough; insensitive; didn't give enough time/details
68=	County hospitals probably have a rule book so there were limitations, e.g. she had the axillary node dissection instead of the sentinel node and also no option other than saline implants
69=	Bureaucracy / I had to be pushy to get a 2nd opinion at a teaching institution where the research is being done--longer waits to get in

70=The doctor's insensitivities	
71=Had to wait for a month for the surgery to be done	
72=The doctor stated she wanted to do a chest can but ppt wanted to do a full body scan. Then the doctor said yes.	
73=They though the MRI wasn't necessary and told her might even have side effect	
74=Miscommunication	
75=Respondent had own views of tx because of family history of breast cancer and did not feel heard	
76=Had a hard time drawing blood, was called a "pin cushion"	
77=I was too proactive	
78=She just didn't seem like she listened (1st oncologist), she was from a different culture (Indian) and perhaps this was just a cultural difference	
79=Some people were not always polite/understanding in the hospital setting	
80=Doctor was not diligent in following up on side effects ppt was experiencing during chemo winding up in 5 day hospital stay	
81=Her own inability to describe, communication skills, don't know how to ask questions	
82=I just felt like one of the oncologists was not warm - she had made up her mind about my treatment and did not take my feelings into account	
83=My sister-in-law (a radiologist) thought I should an MRI because my particular breast cancer was high risk in opposite breast to occur and Kaiser ordinarily doesn't do the MRI - It was nice to have a health professional in the family to act as an advocate.	
84=Only because somebody had an appointment before me	
85=Maybe it was something personal and that caused the radiologist to make the experience unpleasant - maybe she had a bad day	
86=They thought they knew better than her and so she should listen to them. They didn't respect her viewpoint on treatment since it was different from theirs.	
87=Surgeon had poor interpersonal skills, had a sort of "superior" attitude (changed surgeons)	
88=RN did not respect subject's decision on not taking Tamoxifen. Felt it was inappropriate for nurse to call twice at home and share RN's personal experience with objective of having subject take hormone treatment.	
89=Oncologist had "high and mighty" attitude, oncologist didn't like being questioned	
90=Subject was having symptoms of eye loss and frequent urination during chemo treatment, doctor didn't seem diligent in doing appropriate testing to diagnosis diabetes. Ended up in a 5-day hospital stay.	
91=A postoperative mammogram looked suspicious so I had to have an ultrasound and one of the oncologists said "we weren't meant to live this long". I guess she was very busy and stressed out but I'd never heard, in 50 years of nursing, a doctor say such a thing.	
92=Something about the surgeon - felt the incision healed awkwardly.	
93=ppt didn't understand the medical condition	
94=Logistics/ policies of hospital	
95=MD was on vacation and gave her the runaround	
96=Used medical terminology that was hard to understand	
97=Felt doctors are of course better than her	
98=Insensitive	
99=Ppt requested shot once/wk instead of once/day b/c it made her sick, but they ignored her.	
100=MD lazy	

Table 14. Open-ended responses for other attributions among participants reporting experiences of lifetime or recent everyday discrimination (EBCC Survey Items D2O and D5O)

D2O & D5O

1=Other people's personalities / attitudes / egos / incompetencies
3=Boyfriend's ex-wife confrontational
6=Not sure why treated unfairly (as opposed to don't know IF other reasons why)
7=Human imperfections
8=Co-workers impatient with side effects from her health history (poor short term memory)
9=Executive position at work and inherent decisions that go along with it not taken well by others.
10=People didn't like her / maybe they just didn't like me
11=Kids
12=Co-Worker saying untrue things about her
13=At work, people may not know whole situation and treat differently
14=Spouse incarcerated
15=Has a perfectionist personality
16=Differences in work ethic
17=Works with teens at a high school and kids can have a bad attitude
18=Didn't feel she was given enough info, wanted more details
19=Respondent's personality/attitude
20=Being adopted
21=Working environment/work politics
22=Misunderstanding/miscommunication
23=On pain meds from surgery, which made her appear incompetent. Family/friends watching her closely
24=Spouse's race (Filipino)
25=Attractiveness / not pretty
26=Respondent having a bad day / had bad mood herself
27=Breast cancer, treatment costs too much from employer's contribution, sick time off (ppt got laid off in 2009 after returning to work after treatment)
28=Health situation
29=Expectation from others to perform the same as before after BC treatment, can't be 100% after BC treatment
30=Confliction/ dispute or disagreement
32=Fear of their jobs (?)
33=Bad supervisor - didn't quite get along
34=Family problems - violence
35=Outspoken
36=Parents were killed violently. When she was in school - spread rumors at school - not accepted.
37=Can't lift things at work because of lymphedema so they fired me
38=Prior breast cancer
39=Work/school: teacher/bosses have "favorites"
40=Not a good test taker
41=Did not feel heard by the police during a situation w/neighbor
42=Family background
43=Police wanted to give ticket / rec'd ticket, did not think it was fair

44=Kids just like to pick on me at school, DK why
45=political affiliation / political
47=Americans are very out there and forceful and I'm more reticent/mousy and don't stick for self, people can trample over me
48=Ability to sing because I am a singer
49="It goes with the territory of living in a crowded area"
50=Does not speak or understand Cantonese
51=Stutters at times
52=Because of school she attended
53=Job status
54=People treated her differently because of her depression
55="craziness with kids" ??
56=Favoritism (in classroom, at work)
57=Always new kid at school b/c moved a lot
58="don't want to say"
59=Sometimes this world is not fair
60=No job openings
62="Human experiences"
63=Relationship with ex-husband (work together)
64=Nature of her work
65=society issues / way society-community is / people don't treat people as nice as they used to-- service not as good as it once was
66="Laws are unfair was victim of violence offender was considered for parole every 1 or 5 5 years. Respondent has had to fight for this."
67=Was not given enough attention at school
68=Respondent seemed less fragile and stronger than she really felt. Saw other patients more fragile and seemed to get more attention. Respondent only appeared to be doing well.
69=Is a business owner, younger employees sometimes seem intimidated when interacting
70=Subject had filed a sexual harassment complaint, was treated unfairly because of it
71=Competition
73=being a single mom (refers to housing question)
74=Co-worker's attitudes / teamwork issue
75=Says it's subjective, doesn't know why
76=Brother says she has a mental disability
77=Supervisor had preconceived idea about what her job should entail. Respondent a social worker. Supervisor thought her job should be done by RN.
78=Personality clash led to unfair treatment at work/school
79=Some customers at the grocery store get favoritism because they shop there more often
81=House - small
82=Police just discriminating - want to show their authority
83=General discrimination existed, just understated
84=General thinking, people are always better in certain things
85=Hard to get a house because the house was assigned by government in China
89=Don't understand their culture (American)
90=We just had different values.
91=Her own attitude
92=People in a bad mood that day. / Some people just have bad days

93=Different opinions of co-workers
94=Reverse discrimination
95=Being a cancer patient
97=Boss doesn't like her
98=I talked/socialized too much in elementary school--got in trouble
99=The stigma after divorce
100=Work issues as a woman dealing with men's club type atmosphere and particularly men from other cultures who are not comfortable doing business with women
101=Place/ people are busy
102=husband/ kid (just normal family interaction)
103=Jealousy from others
104=Immigration - Chinese government wanted to get money from her (corruption)
105=Family doc - didn't give her help when needed, always made her go back for few times for only one thing; also delayed her BC surgery
106=Estranged by daughter who was away from her for many years
107=Different dialects (Cantonese vs. Mandarin)
108=Too capable of doing a job-->pushed w/ more responsibility than other co-workers
110=Unpleasant supervisor and mean to women
111=Random occurrences at school and court and difficult to refinance or get a mortgage
112=Rude customers / bad attitudes from customers
113=Having breast cancer people showing suspicious attitude due to her BC
115=Police wanted to make money
116=Not enough staff to do work
117=Teenage children just act that way
118=Teacher's problems
119=Family origin (not referring to race--just because of her family)
120=She's too nice, so other take advantage of this fact
121=Restaurants just have poor service
122=Bullied by kids because she was skinny
123=Unfair treatment at work because people are stressed out
124=I do not know why people act the way they do--I try not to pass judgments
125=Workers' compensation did not want to do MRI for back issues because of "cost"
127=Respondent stood her ground on a job that needed to be done, other person did not agree to rules and called names/ threatened
128=Their personality or they actually know more than me
129=Higher authority - persons thought they are at higher authority, so they think they know better
131=Work position (seniority)
132=Because of neighborhood location (discrimination at school)
133=Because of breast cancer diagnosis (discrimination at work)
134=Merger of workplace and new employees act is they knew more
135=The other person who treated her unfairly had a mental illness
136=I have a learning disability and was in special ed
137=Being too proactive and would question things
138=I'm sure that it happens to everyone at one time or another that a person is treated with less respect for no apparent reason
139=Sometimes people have their own issues and problems and take it out another person as a scapegoat

140=Don't know, just ignore other people, just the way people act, attitude
141=Cultural revolution in China
142=People preference for partiality
143=work environment - just the way people act - ego
144=from co-worker - ego attitude
145=from sibling - didn't get credit for suggesting something that works
146="Due to the longevity I'd been at the position" (referring to unfair treatment on a job)
147=Wrong judgment by police
148=Bad service at restaurant
149=Just the way people get along
150=I had a couple of asshole teachers so I did learn how to fight for myself
151=When I was young my father was alcoholic and the kids at school were mean and teased me
152=I quit a job and they withheld sales commissions
153=Teased in school about her name
154=Probably my personality or thinking about school days, kids teased me because I was shy
155=Subject commented possibly because of her interpretation and cultural/value belief system thought of these situations as rude or disrespect
156=Because I'm in management, I sometimes must take responsibility for things outside of my control
157=General inconsiderateness, people don't think about how their behavior affects others
158=Has no idea for credit question
159=Was robbed but not because of these attributions. Random act.
160=Different situations in life - didn't want to elaborate, subject commented: "I don't want to go into all that"
161=In my job, I answer the phone a lot and I feel people treat me disrespectfully on the phone sometimes
162=Unfairness at work was due to getting a promotion when others thought they were more deserving. She thought this demonstrated professional jealousies immaturity.
163=It was part of growing up - school and not playing sports that well
164=Minority group - not enough influence
165=Medical oncologist nurse who suggested she look for a cure when she asked for something to help with her hair falling out.
167=Newcomer at work (treated unfairly by those with seniority)
168=Social status in China
169=Thinks she was rude to people first and that's why they don't treat her well

NOTE: 167, 168, and 169 are unique to D2O.

Table 15. Upcoded open-ended responses for other attributions among participants reporting experiences of medical, lifetime, and recent everyday discrimination (EBCC Survey Items M2O, D2O andD5O)

	Pre-coded responses in EBCC survey	Specific responses from Other for upcoding
b.	The way you speak English -immigration	D2o/D5o. 109=Can't speak English
c.	Your birthplace-immigration	D2o/D5o. 130=New immigrants
d.	Your gender-other	D2o/D5o. 114=Possibly because I'm a woman and I'm a rancher, so I'm the last one at the lumberyard the guy will offer to help (bc I'm a woman) D2o/D5o. 166=Because of being a woman – other people think women lack of intelligence
e.	Your race/ethnicity-race	D2o/D5o. 4=having Hispanic surname D2o/D5o. 46=prejudice/ "because white people feel superior to blacks" D2o/D5o. 96=Different areas not having racial tolerance
k.	Your education-other	D2o/D5o. 31=overqualify on top of the pay scale, they are trying to get rid of me D2o/D5o. 72=qualifications might not be enough for their job (?) D2o/D5o. 80=Boss-lower paid than minimum wage for new immigrants – no knowledge D2o/D5o. 88=There are things I feel about myself and part of it is I'm around people with advanced degrees D2o/D5o. 126=had to change oncology physician who was Asian with blue eyes and had cleavage showing, and stilettos; gave me the impression I was stupid; she was also head of the department
l.	How much money you have-other	M2o. 53=reverse discrimination – were not informed about some services she's entitled to have because of high income D2o/D5o. 61=had a foreclosure
m.	A physical disability-other	D2o/D5o. 86=I use a cane and it makes me look less healthy
n.	Your appearance on a given day-other	D2o/D5o. 2=insulted by boyfriend's ex-wife because she wears a wig D2o/D5o. 5=Hair texture (very curly) D2o/D5o. 87=Kids teased her about her eyes because her eyes protruded – they called her "banjo eyes"