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UNDERSTANDING THE BREAST CANCER EXPERIENCE OF WOMEN: A QUALITATIVE STUDY OF AFRICAN AMERICAN, ASIAN AMERICAN, LATINA AND CAUCASIAN CANCER SURVIVORS

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Abstract

Breast cancer is the most common form of cancer in American women across most ethnic groups. Although the psychosocial impact of breast cancer is being studied, there is little information on women from diverse ethnic and socioeconomic backgrounds.

We conducted a qualitative study with breast cancer survivors (BCS) of various ethnicities. A total of 102 BCS participated in focus group interviews (24 African Americans, 34 Asians, 26 Latinas and 18 Caucasians); 20 health professionals participated in key informant interviews. Important ethnic differences in type of treatment were noted, Asians and Latinas were more likely to receive mastectomies and African American BCS were least likely to receive adjuvant therapies, including radiation and chemotherapy. These BCS enjoyed a fairly good overall health-related quality of life (HRQOL) with some persistent concerns. The prevailing concerns among all women included overall health, moderate physical concerns, cancer recurrence or metastases, psychosocial concerns related to worry about children and burdening the family, and body image and sexual health concerns.

Additional challenges included: lack of knowledge about breast cancer; medical care issues such as insurance, cost and amount of time spent with physician; cultural sensitivity of providers, language barriers, cultural factors related to beliefs about illness, gender role and family obligations (e.g. self-sacrifice). These BCS, particularly the women of color, voiced that their spiritual beliefs and practices are central to their coping. This study accomplishes two goals; it adds to the sparse literature concerning the psychosocial sequelae of breast cancer among women of color, and it increases our knowledge of specific cultural influences (e.g. dietary practices, coping) and socio-ecological factors

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on HRQOL. More importantly, the study addressed areas that have not been studied before, specifically, an in-depth study on BCS QOL comparing multiple ethnic groups in the US. The results of this investigation will provide preliminary information to survivors and health-care providers about the impact of culture and socio-ecological contexts on survivorship.

Among women of all major ethnic groups, breast cancer is the most common form of cancer and the second leading cause of cancer death (American Cancer Society (ACS), 2002). In 2002, over 203,000 women in the United States will be diagnosed with breast cancer (ACS, 2002). Ethnic disparities exist for cancer stage, diagnosis, survival, morbidity and mortality. In general, ethnic minority women are diagnosed with more advanced disease and experience greater morbidity and mortality (Haynes & Smedley, 1999; Miller *et al.*, 1996; Ries *et al.*, 2000; Shinagawa, 2000).

In general, increases in survival rates have prompted greater interest in the quality of life (QOL) of breast cancer survivors (BCS) over the past two decades. Additionally, the QOL of cancer survivors from diverse ethnic, cultural and socioeconomic backgrounds is an emerging priority area for studies on survivorship research and clinical care (Haynes and Smedley, 1999; National Cancer Institute (NCI), 2002; President's Cancer Panel, 2000).

QUALITY OF LIFE

Health-related quality of life (HRQOL) is a multidimensional concept that assesses physical, functional, psychological/emotional, and social wellbeing in relation to health (Ware, 1984; Cella and Tulsy 1993). Studies that include ethnic minority women (specifically African American) have found that breast cancer and its treatments result in physical, economic and employment problems, familial and marital relationships challenges, and concerns with body image and sexuality (Ashing-Giwa *et al.*, 1999; Ashing-Giwa and Ganz, 1997). One study reported that compared to age-matched healthy women, BCS had favorable health outcomes, but greater role functioning concerns (e.g. Bower *et al.*, 2000). Further, these concerns affect women's QOL and can persist in long-term survivors (Dorval *et al.*, 1998; Ashing-Giwa *et al.*, 1999).

A multi-ethnic cancer study that included Latinas, non-Latina whites, and African Americans found significantly higher concerns about pain, survival and sexuality among Latinas (Spencer *et al.*, 1999). Additionally, studies investigating Latino cancer patients' QOL found that cultural beliefs, family and religion had significant influences on QOL, including pain expression and management (Juarez *et al.*, 1998a, b). Cultural beliefs regarding family role, women's roles, perceptions of spousal support, and concepts of self-image differentially impacted Asian American and Caucasian women's experiences with cancer (e.g. lower help-seeking and social support in Asian American women, greater medical concerns in Chinese Americans) (Kagawa-Singer *et al.*, 1997; Wellisch *et al.*, 1999; Kagawa-Singer and Wellisch, 2003; Ashing-Giwa *et al.*, 2003).

To address issues relevant to the increasing numbers of diverse women with breast cancer, research studies need to include larger samples of these women. Also important are studies that allow in-depth understanding of the experiences of BCS from diverse groups. Through qualitative approaches, we can better understand cultural and contextual factors of cancer survivorship. This study explores experiences and concerns of BCS from diverse ethnic and socioeconomic backgrounds. The results of this investigation will provide preliminary information to survivors and health-care providers about the impact of cultural influence (e.g. dietary practices, coping, spiritual practices) and socio-ecological contexts (e.g. life stress, neighborhood, social support) on survivorship. The research question addressed in this study is: How do culture and socio-ecological factors impact HRQOL and psychosocial experiences among women who have survived breast cancer?

METHODS AND PROCEDURES

Due to the paucity of information about the breast cancer experiences of women from various ethnicities in the US, we used qualitative methodology to guide the investigation and explore the research question. These methods allow for a deeper, richer understanding of the survivorship experience via open dialogue between the researcher and target population. Qualitative methods can enhance HRQOL and psychosocial research by identifying additional relevant variables, generating new hypotheses, and by strengthening conceptual validity (Gilchrist, 1993; Waxler-Morrison *et al.*, 1995; Strass and Corbin, 1990). This study describes the cancer experiences of African American, Latina, Asian and Caucasian women.

UCLA IRB approval was obtained. Key informant and focus group interviews were conducted with participants in the Los Angeles area by bilingual research assistants (RAs) with at least 3 years cancer-related research experience, and basic training in qualitative methodology and psychosocial oncology.

The key informant interviews

The purpose of the key informant interviews was to gather information about the breast cancer experiences from knowledgeable, community health professionals and advocates working with diverse populations. The interview structure and questions were guided by Dr Ashing's previous work and the breast cancer literature. The domains addressed included: impact of breast cancer, health care access, culture (for example, role of health beliefs, acculturation, religion), socio-ecological factors (for example, SES, education), barriers to health care and psychosocial care, role of the health care system, patient-physician relationship and medical adherence.

Leaders in the African American ($n = 5$), Asian American ($n = 5$), Caucasian ($n = 4$) and Latina ($n = 6$) communities were recruited from community health clinics, cancer-related organizations (e.g. American Cancer Society and the Wellness Community) and hospitals. Informants were contacted by telephone, and all but two agreed to participate in a 1 h, face-to-face, audio-taped interview discussing the status of breast cancer in the communities they worked with. The informants included physicians, nurses, community health educators, social workers and health care administrators who worked in cancer prevention, control and treatment. Some had personal family experiences with breast cancer. Signed informed consents were obtained, and the interviews followed a semi-structured, open-ended format.

Focus groups interviews

The *focus group interview* provides a facilitative, non-threatening group environment in which to explore the perceptions and personal experiences regarding a specified issue or topic. Detailed narrative data is collected (Knafl and Howard, 1984). The purpose of the focus groups for this study was: (1) to obtain information directly from women who had a breast cancer diagnosis, and (2) to further explore the issues identified in the key informant interviews. Groups discussed attitudes, beliefs, and knowledge about breast cancer, health care issues, quality of the patient–doctor relationship, and cultural and socio-ecological issues (Table 1).

A convenience sample of 102 BCS participated: 19 Asian, 24 African American, and 13 Caucasian women recruited from cancer support groups, and 15 Asian, 26 Latina, and 5 Caucasian women contacted through hospitals and community health clinics. Groups were organized according to homogeneous ethnic and/or linguistic groupings. Support group leaders, hospital and clinic directors were first contacted by telephone to assess interest and willingness to involve their group members or patients in a focus group meeting. Subsequently, these BCS were sent written invitations from the agencies describing the focus group format

and proposed incentives for participants. Fliers were posted at the agencies and focus group sites. Participants were recruited via a telephone call from the agency representative or via fliers posted at the agency. Agency personnel did not record refusals. Therefore, it is not possible to calculate the percent who agreed to participate in the focus groups.

Focus group size ranged from 4 to 13 women and took place at the recruitment sites to provide a familiar environment. All focus groups were conducted by trained RAs, except the Korean group, which was conducted by the support group leaders. Each audio-taped focus group lasted about two hours. Participants took part in a meal, during which they were oriented to the study. They were encouraged to respond to all the issues raised by the facilitator, but were informed that they had the right to not respond to any issue. Signed informed consent was obtained. Women sat in a circle to encourage participation and foster openness. At the end of the session, women were thanked for their participation and given a \$10 grocery voucher.

RESULTS

Analysis

A detailed summary of each audio taped interview was conducted and select quotes were transcribed verbatim. Armenian, Chinese, Korean and Latina focus group discussions were translated into a detailed summary in English before conducting further analyses. Content and theme analyses were conducted using a tabulated matrix of the major issues identified (Appendix A). The matrix allowed for comparative analyses across ethnic group. Results from the key informant and focus group interviews are discussed separately to fully present the information.

Key informant demographics

Twenty female key informants participated: African American ($n = 5$), Asian American ($n = 5$), Caucasian ($n = 4$) and Latina ($n = 6$). On average, they had 11 years of cancer-related work experience (range: 3–25 years). The majority held clinical and administrative responsibilities, including medical, psychosocial, or educational patient care. All worked with diverse ethnic communities representing varying SES, language abilities, length of time in the US, and immigration status.

FINDINGS FROM THE KEY INFORMANT INTERVIEWS

Health professionals' perceptions about patient cancer knowledge and health beliefs

The key informants reported that specific beliefs about breast cancer etiology and disease course exist in African American, Asian and Latina communities, particularly among older and less acculturated women (e.g. recent immigrants, non-English monolingual individuals). For example, some women believe that cancer is contagious, that breast trauma or the use of wired bras will lead to breast cancer, or that breast cancer almost always results in loss of breasts. The informants felt that many women have fatalistic attitudes towards cancer in general, and that cancer is viewed as a death sentence by many members of these communities. There are often strong spiritual beliefs, for example, that the diagnosis is willed by God, a punishment from God, or that one's fate including the outcome of the illness is in God's control. Further, informants noted that recent immigrants, those with lower SES, lower education and the uninsured, lack awareness about breast cancer and the available resources, treatments, and are not as proactive about seeking medical care. In general, Asian American and Latina women have less knowledge about their bodies and lack awareness about the benefits of screening and early detection; while African American women lack awareness of the benefit of regular screenings. For Latinas and Asians, cultural taboos against talking about or touching one's body can often result in the avoidance of self-exams and screenings. Educated and/or

acculturated women of color are more aware of screening and early detection benefits and have better access to care. The key informants reported that women may rely more on alternative medicine (e.g. shark fin and herbs) rather than Western medicine for treatment, and on word-of-mouth rather than doctors' recommendations. Further, informants noted that the seeking of medical care in communities of color is often delayed due to beliefs that the lack of symptoms or pain implies good health.

Health professionals' perceptions about patient psychosocial functioning and social support

Key informants indicated that women's responses to breast cancer often include fear, worry and denial. However, particularly among older women of color and more recent immigrants, cultural beliefs may deter their accessing psychosocial care, since they may be reluctant to discuss emotional problems and personal feelings with mental health professionals. They view psychological assistance as primarily for the mentally ill. Instead, these women cope with psychosocial problems by engaging in activities for distraction, such as cleaning and cooking.

The informants cited the family as often being the primary resource for support for BCS, particularly for Asians and Latinas. The church family is often a part of African American BCS' fictive kin support network. These women depend on their families to help cope with their diagnosis, treatment and recovery. One Asian key informant noted, 'The Oriental way of thinking [is] placing the role of mother above the role of woman. [This] plays a big role in their attitude. The primary concern is to survive for the children, not be a beautiful woman for their husband.' The key informants believed that the significance of the family in communities of color and more recent immigrants results in the family being prioritized over one's health and may delay seeking screening, treatment and health care. Key informants believed that family support is beneficial for women's medical adherence, although some women of color may not share their diagnosis with their family to avoid family disruption.

Health professionals' perceptions about patient spirituality issues

Spirituality is a belief in God or a higher power who has authority over life and the universe. Key informants highlighted spirituality as a very important component of many women's cancer experience. These communities, particularly African American, Asian and Latina, hold firm religious and spiritual beliefs and practices (e.g. they may perceive the outcome of their illness being completely in God's hands). Many have an unshakable belief in the power of prayer and place more importance on spirituality or their religious beliefs than on health care providers.

Health professionals' perceptions about barriers to patients' access and quality of care

Socioeconomic and cultural factors, as well as systemic problems in the health care system, were discussed by the key informants as the most significant barriers to access and quality care among women of color. Socioeconomic barriers include lack of insurance, lack of transportation, and financial concerns, for example long, inflexible work hours that inhibit their ability to seek early care. Cultural issues include beliefs (e.g. the immobilizing fear of cancer) and language barriers. Women of color, particularly Asian and Latinas, often do not seek second opinions or question the physician's advice. This is based on cultural values of respect for the doctor's status as an authority figure. They also lack the wherewithal to obtaining second opinions from leading treatment centers that remain inaccessible to the economically challenged. Moreover, key informants viewed the health care system as contributing to treatment delays, such as delaying referral to specialists. These realities perpetuate the unfamiliarity of and lack of trust in the health care system. Additionally, due to societal status, the key informants all agreed that members of the African-, Asian- and Latino American communities perceive that they have less control over their medical care than the mainstream

society, and are consequently less inclined to cross the line to inclusion and participation as health care consumers.

Summary of key informant interviews

The informants stressed the need for more affordable and accessible care. Additionally, communities must be educated about breast cancer and how to maximize their use of available resources, including the treatment and recovery process. Additionally, these community members felt that it is the responsibility of the health care system to become more culturally responsive by increasing staff diversity, knowledge about community resources and psychosocial service partnership or programs. Programs must be culturally and linguistically appropriate, such as community based support groups. Key informants emphasized that these systemic responses will benefit survivors and their loved ones as well as the society by promoting greater physical and psychological and familial recovery.

Focus group participant demographics

A total of 102 BCS participated in 11 focus group interviews: a Korean group ($n = 10$), Chinese (Cantonese) group ($n = 11$), mixed Asian group including Thai, Chinese, Filipina and Japanese women ($n = 9$), Filipina group ($n = 4$), two Caucasian groups ($n = 12$), Armenian group ($n = 5$), two African American groups ($n = 24$) and two Latina groups ($n = 26$). The Korean, Chinese, Armenian and Latina groups were comprised of less acculturated, monolingual women and were thus conducted in the women's native languages. The Filipina and mixed Asian groups were bilingual and more acculturated, and were conducted in English. Due to the small number in the Filipina group and similarity in acculturation (determined by ability to understand and speak English competently) to the mixed Asian group, results from these two groups were combined.

Table 2 lists the participants' medical and demographic characteristics. Mean age at diagnosis is late forties to early fifties. The mean number of years since diagnosis for Korean women was 1, Chinese women 5, for Latinas and Bilingual Asians 4 years, for African Americans 3 years, and for Caucasians and Armenians 2 years. The majority of African American, Korean, Bilingual Asian, and Armenian women were diagnosed with Stage 0, I or II cancer. One in four Caucasians and almost a fifth of Latinas had a Stage III diagnosis. However, half of the Chinese women and over a third of the African Americans and Latinas did not know their cancer stage.

Variations in breast cancer treatment existed across groups. At least half of the African Americans and more than half of Korean, Chinese, bilingual Asian, Armenian and Latina women received mastectomies. For some groups, for example, Chinese, Armenian and Latina, this proportion was almost 70% or greater. In contrast, half of African Americans and Caucasians received lumpectomies. African Americans were least likely to receive adjuvant therapies including chemo- and radio-therapies, and Chinese women were least likely to receive hormone treatments or Tamoxifen. A small percent of Latinas did not report receiving treatment.

Group differences in obtaining a second opinion existed; about 1 in 2 women across all ethnic groups received a second opinion but Asian women, including bilingual women, were least likely to receive a second opinion (about 1 in 7). Groups also varied in family history of cancer. The majority of African Americans, Koreans, Chinese, Bilingual Asians and Armenians reported no such history. However, half of Caucasians and more than half of Latinas had a family history.

The current age of the women was early to mid-50s. The majority of the monolingual women (Korean, Chinese, Armenian, Latina) were married, while the African American, Caucasian, bilingual Asian groups were comprised of similar proportions of married and single women (including divorced or widowed). Although income and education was not directly assessed, it is estimated that most of these BCS were lower-middle to lower income.

FINDINGS FROM THE FOCUS GROUPS

A summary of the major issues identified in the focus groups is presented in Appendix A.

Recovery and coping

Although family support, spirituality, and support groups were all very important to the women's recovery and coping, Caucasian BCS stressed the importance of the support groups; African American, Asian American, and Latina BCS emphasized the salience of spirituality and prayer. Overall, receiving support from others, whether it be family, friends, and/or in the context of a support group, was emphasized as key in the recovery and coping process. Additionally, Caucasian women commented on doctor assistance (e.g. western and alternative medicine), pets, and exercise as important factors. Asian Americans and Latinas discussed how keeping busy with activities distracted them from feeling emotionally overwhelmed. Asian American survivors also felt that a positive attitude, educating oneself about the illness, and taking medication were beneficial to recovery. The African American women spoke of gaining resilience from the strength of the African American community.

Family support

Family support was identified as important for all women. In particular, many married Caucasian women identified their husbands as providing the greatest support. Ethnic minority women discussed the salience of support from immediate and extended family to emotional well-being and treatment adherence:

At times when I didn't want to take my medication, I believe that cooperation and love from family and husband have helped me a lot. He would encourage with love by saying, 'You can do it.' (Korean)

I am very fortunate to have my family support, especially my daughter who always accompanies me to my appointments and supports me in any way. Her support is very important to me and has helped me to cope with the disease. (Latina)

It's your immediate family that help you through—through the physical, through your condition, and also, believe it or not, through your mental condition. Because, you know, as Black women we aren't as outspoken as a lot of other women, we don't share our problems with everybody. We keep it within ourself or we keep it within a close-knit group of our own family who we trust to talk on a one to one basis. (African American)

For many Latinas and Asians, family was the main source of support; their roles included accompanying the women to medical visits. Some African Americans expanded their definition of family to include friends who accompanied them to doctor visits and served as caregivers.

However, the family was also a source of strain for some Asian American, Armenian, and Latina women. They expressed concern about disclosing their illness and burdening family:

Even though I'm not that great myself, I keep telling others to think positively. I'm a parent. I can't just give up. I can't just cry in front of my children or husband whenever I feel like it. It'll be harder on them, they'll feel more helpless. You have to behave in such a manner so that they forget you are ill. (Armenian)

As a parent, it is very hard to express your feelings when you see your children are getting affected. You don't want them to see you down and worry about you, and then you pretend everything is under control. (Latina)

Some Caucasians and African Americans reported that family members' own coping difficulties impaired the provision of needed support. One African American commented on half of her family being in denial about her illness and on her husband's inability to provide emotional support:

When it comes to helping me, being there for me, he's there. But when it comes to discussing the situation, he will not discuss it. (African American)

A Caucasian survivor compensated for lack of family support by attending support groups. Another spoke of family members' challenges adjusting to new roles of being caregivers and her difficulty in reversing roles with her family:

Women are always being the caregivers. When tables are turned and we need to be taken care of, our family doesn't know how to do it. It was hard for me to even let my family do it because I wanted to be strong, a superwoman. I realized that I was robbing them of the chance to be able to help, to give. It was hard for my husband to switch to my needing the help. That's why support groups are great, my family doesn't know what it's like. (Caucasian)

Family expectations about the woman's functioning after treatment was a concern expressed by some Asian Americans and Latinas:

I felt a lot of stress from my family with expectations to be the same person and work as hard. It hurt me a lot for them not to understand what I'm going through. (Korean)

Since I decided to stop working, my husband pressures me to get a job and tells me he is not going to provide for me while I just stay home being lazy. I'm scared because if he leaves me, I probably won't be able to provide for my children. (Latina)

A number of Chinese survivors reported that they performed daily chores themselves even during treatments, rather than receiving help from their families.

Social support

Support groups provided women with an additional resource, specifically the theme of feeling understood and encouraged by other survivors. In addition, support groups provided a means of obtaining valuable information regarding treatment and recovery:

...Although my family loves me and took care of me, when I came to the support group and I saw that there were so many women who were going through the same thing that I was going through, it just made a great change in my life. I figured they're 'living, they're doing things, I can do the same thing. The support group has been my greatest support'. (African American)

One day someone invited me to come to the support group. I was shy—ashamed because of the loss of my hair, but I was very surprised when I heard participants talking about their hair growing back as if they were talking about something very natural. Then I realized I wasn't alone and neither was I the only one suffering from this disease. Since then I thank God for showing me the way to get here, and have met such nice people. They have been very important and have helped me to understand and express my feelings spontaneously. (Latina)

It is most important to be with people with same disease. Because we understand each other in physical and psychological states. Families don't understand these. They

(family members) say they understand, but they expect us to be the same people as before the disease. (Korean)

Asian American and Latina survivors also considered health care providers to be important sources of support. Additionally, some Latinas and African Americans felt that close family friends were important in offering comfort and in serving as confidants.

Spirituality

Spirituality was highlighted as a fundamental component of the healing process. Although many acknowledged initial fear upon hearing the cancer diagnosis, spirituality served as a source of comfort, enhanced confidence, and lessened fears. In particular, survivors noted that their faith and God's direction over the doctors healed them:

The doctor does what he has to do, but if you have faith, God also helps the doctor's hands and your mental stability. (Caucasian)

Mental stability was frequently described as a spiritual awakening or reconnection by women in the African American groups:

I came out here [to California] and the Doctor told me, I said what! This can't be. I said I have to go to my God. I think that God was doing the makeover from the inside out. I didn't just lose my hair, I started rebuilding my spirit, because I was a beaten up person when I got here. It just happened that cancer allowed me to be recreated, I think. Being able to accept God before I found out about the cancer is what saved me. I had gotten a spiritual awakening. (African American)

Ethnic minority women stressed the significance of spirituality and prayer on their recovery. These women considered God an important source of support.

A number of Asian American and Latina survivors felt that the outcome of the illness and their fate was ultimately controlled by God, regardless of their actions:

I know that whatever happens will be God's will, because even when you have all your family support, if you don't have God, you don't have anything. (Latina)

We all know cancer is a non-curable disease, if we follow up treatment we can get better, but not cured. So who else can decide if we are making it or not, if it's not God? It is only Him who has the last word, and if He decides time has come, no matter what I do, my time is over. (Latina)

I just trust God. Everything trust to God and He will give us miracle. You cannot do anything if you already have cancer. God is the one to give us life, he is the one to get our life. (Asian American)

While spirituality offered women a great deal of support, some survivors were disappointed in the lack of conjunctive support from those around them. For example, one African American referred to the historical cultural mistrust of doctors:

If we didn't have God to lean on—the doctor's don't care. It's either God or nothing. (African American)

Handling a major illness, participation in medical treatments

African Americans and Caucasians attributed having an overall attitude of survival and the need to fight the illness:

If you give up, you will die. When I first got out of the hospital, it was very hard to accept help from other people (helping me dress, shower, etc). As soon as I could, I

would do things for myself. Told my daughter not to make me an invalid. The more we do for ourselves, the better—helps extend life. (Caucasian)

A cultural tradition of surviving severe obstacles was noted by one African American survivor as a testimony of having the strength to also fight cancer:

Every time I have come across a sister with it, I am very proud to say that whatever things that we have went through, we handle it. I think that honestly, it is in our genes. It is in our ancestry. We do this. We get diagnosed with cancer; we have our moments, because I have fallen apart, but we pull ourselves together like a puzzle... I believe that we just have that stamina. We get back up, and dust yourself off and do this kind of thing. (African American)

Religious beliefs that influence health practices were deemed essential to handling an illness by African Americans, Latinas and less acculturated Asian American survivors.

How we take care of this temple (one's body) has a lot to do with the QOL and health. If we abuse the temple, then we will suffer the consequences. We can control the longevity of our lives by how we take care of our bodies. From my past experience I haven't taken care of my body the way I should. (African American)

A few Latinas and Caucasians, however, were disillusioned by the failure of their healthy lifestyles to prevent cancer:

I have been a vegetarian all my life. I always thought that would keep me healthy and not catch any major diseases, and here I'm diagnosed with cancer. So I think food doesn't have much to do with getting the disease, but I don't know where it comes from and how I got it because I don't have a family history of cancer. (Latina)

I watched my food for many years, considered myself very fit, walked 4 miles every day. I was shocked when diagnosed. I was somewhat angry because I had done all the right things with diet, I didn't drink or smoke. (Caucasian)

Some women also discussed the importance of minimizing stress:

...Stress irritates whatever is vulnerable and if it is something that can become cancer, it will. We give ourselves cancer and we can rid ourselves of it. It is really important for women to take control of their lives and to look out for their own health. (Caucasian)

I think that's why we got the cancer. Holding things all the time, worry all the time, worry about many things, small things. (Asian American)

The more acculturated Asian American women cited avoidance of isolation, avoidance of dwelling on the illness, and having a positive attitude. In general, the Asian Americans noted the importance of accepting the illness.

While women from all groups agreed on the importance of following medical advice, African Americans, Caucasians and more acculturated Asian Americans also stressed becoming proactive in their medical treatment by taking responsibility for their care. Educating oneself by seeking additional information and asking questions, timely follow-up with medical treatment, documenting physical response to medical treatment, obtaining a second opinion, and engaging in a healthy diet and taking exercise were emphasized:

When they told me that I had cancer but no active cancer, I questioned what it meant. It's a whole new language I had to learn. Things are written in medicalese. Women really need to know a lot more than they do about taking care of themselves, and what should be done. The patients have to take responsibility for themselves. (Caucasian)

Ask for a second opinion. Keep track of everything yourself. The doctor might be more alert knowing that you're keeping track of your own body too. (African American)

However, the less acculturated Asian Americans indicated that while they participated in the decision-making, they depended on their doctors for the final treatment decision. Further, some women preferred that the doctor decide the treatment. A few Latinas admitted putting other priorities ahead of their health, but altered their attitudes toward health after cancer recurrence.

Fear and anxiety

Across ethnicity, survivors expressed similar fears regarding recurrence, death, pain, and suffering (often identified as a larger fear than dying), but focused on specific areas. For several Caucasians, apprehensions about incapacitation and loss of autonomy were greater than fears about death:

I'm not afraid of dying...I'm afraid of being bedridden because I have been an independent person all my life. (Caucasian)

Well, you know, just lying there, being ill for a long time. You're not dead, but you're suffering. Then, it's better to die quickly. (Armenian)

Women from different groups discussed the uncertainty about recurrence and survival:

As a cancer survivor, one of my biggest fear is the 5 year waiting period, to find out if we are going to survive or not. That creates suspense, fear, and negative emotions. Five years is a lot and I never know if I'll be the one winning the battle. I feel like I'm standing on a balance just waiting to see which way it is going to go. (Latina)

It is not the pain, but it is the anxiety, the fear of it becoming positive. The anxiety is worse than the pain. Pain, I can deal with it. When you're given pain medication, it's relieved. But anxiety, it sticks in your mind. (Asian American)

They give surgery, they give you treatments, they say, 'we got it all'. But you feel a pain, you wonder what is going on, or you feel dizzy. I try not to obsess about it. But I feel it's a legitimate fear. The fact that it might come back and I might have to physically suffer. (African American)

Concerns about the illness affecting their roles as caregivers and the impact on their families were mentioned by African American, Asian American and Latina women:

As caregivers, we worry about those who depend on us because if something happens to us, who would care and provide for our family, children, parents, etc. who totally depend on us? (Latina)

All I want to do is to make sure my child grows up and that I'm there for her. She is six years old. I want to be here until she's 18. After that, you can take me. (African American)

I feared the most the pains that I have seen others suffering. I wasn't afraid of death, but the pain...I didn't want to show myself screaming from pain to my family. (Korean)

African American and Latina survivors also held fears that female relatives will also develop with breast cancer.

Along with fears about changes in body image and scarring, some Asian American and Latina women discussed worries about the effects chemotherapy and surgery. This was a major

concern for many Latinas who felt that doctors often favored performing more radical surgeries:

We consider them as butchers, who like to mutilate people, because even when some women only had a little dot (of cancer) they cut the whole breast. (Latina)

African American women expressed additional fears related to unfamiliarity with breast cancer, inability to attend to one's own health, and racism within the health care system:

Ignorance about the disease. Women are so busy with their lives that they forget that they have to take care of themselves. Women are too busy being wives and mothers and working where they're totally lost. By the time they're diagnosed with the cancer, they're so consumed with everything else, some of them don't even have the strength to fight to live. Since being diagnosed, it made me stop and consider myself, whereas before I put everyone before myself. It made me stop and say, what about you. (African American)

My greatest fear is to know if I'm being treated differently than other patients with cancer. (African American)

Doctors' involvement in patient adherence and doctor-patient relationship

Almost all the Asian Americans and Latinas, and half the Caucasians reported doctor recommendations of healthier diet and/or exercise to aid recovery. Additionally, Asian Americans received advice regarding relaxation and avoiding worry. Most followed doctor recommendations. Caucasians who did not, discontinued medication due to side effects and researched treatments to make their own decisions. Pain was mentioned most frequently by Asian Americans and Latinas as a barrier to adhering to exercise recommendations. Childcare was another barrier for Asian Americans. Latinas discussed making lifestyle changes regardless of doctor recommendations, including eating healthier, increasing exercise and relaxation, and decreasing worry.

Overall, Caucasian, Latina, and Asian American BCS characterized their doctors as providing sufficient support for following recommendations:

My doctor's whole office is supportive—quick to call back if anything going on, help me with insurance problems, even called me when I was in the hospital. (Caucasian)

However, the more acculturated Asian Americans were disappointed with what they perceived to be doctors' limited scope in recommendations, such as lack of spiritual and mental support, and holistic or alternative treatments.

In contrast, the majority of the African American BCS did not express receiving significant support for recovery. Most did not receive recommendations from their doctors beyond those relating to medical treatment, although one survivor's doctor advised her to 'enjoy life', and another urged one survivor to inform female relatives to increase awareness of breast cancer risk.

Several of these women felt the doctors really did not care about them and noted that they were treated disrespectfully for asking questions:

If you ask questions, they make you feel like you're a problem. They won't listen. They make you feel like there's something wrong with you in your head, to be asking questions. (African American)

One African American, however, spoke of receiving good support:

My surgeon had a lady come from the Cancer Society come to my room before the surgery and after. He was concerned about it; he tried to reassure me. My surgeon was very nice. (African American)

Overall, Asian American, Latina and Caucasian survivors described positive relationships with their doctors. Asian Americans and Latinas felt their doctors were sensitive and sufficiently communicated with them despite language barriers. Trust and good communication were viewed as essential components of a good doctor–patient relationship for these two groups of survivors. The majority of Latinas, in particular, felt that as authority figures, their doctors have been very helpful. However, these survivors also expressed concern over insufficient time with their doctors:

He is very, very good doctor, but too busy everyday with patients. So I wait, we saw him only few minutes. He has no time to talk to you, but I still trust him because I know he is a very good doctor. (Asian American)

It could be better if they could only spend more time talking to us or answering any questions we may have either about breast cancer or any other medical concerns we may have at the time. (Latina)

The doctor was too busy to talk to me, but there is a responsible person who talked to me before my surgery. That person also taught me what to do after my surgery. (Chinese)

The majority of the African American survivors described negative relationships, such as doctors discounting their concerns:

Every time I get a pain, I wonder what is happening to me there. I told my doctor I have a pain, he said it's nothing. (African American)

African Americans and Latinas also mentioned the lack of doctor sensitivity in listening to their concerns or in relaying the diagnosis:

When I went to the doctor, a staff member was very rude to me...she was the one who gave me my diagnosis and was not sensitive at all. She even asked me why I wasn't crying like others she had given the diagnosis to. I am sure that my ignorance, legal status and also color of my skin had to do with her rejection. (Latina).

The more acculturated Asians expressed worries about trust and disclosure of information:

You have to ask them what you want to know because they don't come out and tell you everything. (Asian American)

Additionally, the less acculturated Asian Americans who were primarily treated in public/county hospitals were concerned about the lack of continuity in their care.

Access to care

A number of the African American, Asian American, Latina, and Armenian women experienced barriers and/or discriminatory treatment in accessing care. Economic barriers were particularly salient for African American and Latina survivors. Economic-related discrimination was a major concern for many of the African Americans:

The only thing that made it different was the fact that I walked in saying I had no money. And that made a difference. A big difference. I've come to the opinion that this is big business, as far as the doctors are concerned. They don't care. They just want—the money. They're glad to see you coming. And they're glad to see you go if you say, I have no money. (African American)

Over half of the Latinas and some of the monolingual Asian Americans found it difficult to follow and meet requirements for treatment-related financial assistance. In particular, Asian Americans discussed not qualifying for public assistance, yet having insufficient coverage through their health insurance. Thus, many have significant medical debts:

I had postponed my breast cancer surgery because I'm hoping I would get my Medi-Cal. However, my doctor said, 'Don't wait anymore' because he's worried that the cancer would spread. After 2 months, my application was denied. I had to pay the doctor \$4,000 and each doctor visit was \$70. I had been paying monthly payment of \$100 to my doctor until I am 65 years old. (Chinese)

I had to pay my doctor fee at one time. There's no monthly payment. The doctor made me pay. He said if I didn't have money, I could use credit cards. I didn't have credit cards. Then he said, 'Use your daughter's credit cards.' (Chinese)

Our economic situation wasn't good and financial help was denied, so we had to borrow money in order for me to start treatment. Unfortunately it wasn't enough, so we had to sell our belongings so I could continue with treatment. As time went by, my application for financial help was accepted, and our economic situation is now getting better. (Latina)

We are aware that there are clinics and hospitals that...offer free care for low income, but the problem is not getting there, or not speaking the language, the problem is to qualify for the program.... My experience on that...is not good, because no matter what paper work I presented, I never qualify. The person(s) who decide who is eligible or not seem to have a problem with low-income Latino people, because I have known many others who have better financial situations than I do and they do receive free care. That is frustrating and keeps me from getting care. I struggle and got the care I needed, but I am still afraid of what I may confront while I'm under medical care. (Latina)

Several African American and Latina survivors also mentioned disparate treatment due to ethnicity:

Your race has got a lot to do with it...about 90%. It [race] has a lot to do with how you're treated. (African American)

I was in the doctor's the other day, she was giving me my six-month check-up. This white lady and her husband walked in. No appointment...it made me so angry to know that I have to wait two or three weeks to get an appointment and I'm in a lot of pain, and these people can walk in and be treated, and be taken care of. (African American)

At the time of diagnosis, I had to deal with an insensitive translator who was in a hurry and did not take the time to explain to me what cancer was. Then on my next visit, the personnel made me feel even worse, they looked at me as if I was a leper, maybe because of my poor clothing and make me feel very uncomfortable. I waited for hours, people who had appointment later than mine went in and out....I approached the front desk person, but she was very rude and shouted at me to sit and wait, which I did without saying a thing. At the end of the day, she finally called me to tell me that the doctor had an emergency and had left and sent me to make another appointment. I asked her why she did not mention that earlier so I could go home, but all the response was that the doctor has more important things to do and that we as immigrants think that we are important but all that we are is a bunch of intruders and freeloaders. (Latina)

Insurance status was another factor resulting in discriminatory treatment mentioned by Caucasians and Latinas. For example, a survivor described suffering in relation to not being able to afford procedures and prescriptions:

I applied for Medi-Cal, but was told that I can't get Medi-Cal 'cause I'm too young. But there are blood tests we need and don't have the money to afford that. Supposedly, you can only qualify for it when you're already near death. What help is that? We don't need that Medi-Cal. We need it now, in the earlier stages to take care of us.
(Caucasian)

Additionally, two Caucasian survivors described difficulties in enrollment (e.g. denial of coverage) or in receiving payments from an 'accelerated life insurance' plan (i.e. life insurance payments for those who will die from a terminal illness within 1 year). Latinas believed that lack of insurance often resulted in limited access to treatment and neglect by medical staff.

Language barriers by Latinas and Armenians were cited as interfering with obtaining information and care:

...When you don't know English, some of the hospital staff, such as nurses, don't treat you like the Americans. Since they know you don't know the language, you don't know the procedures or your rights as well, so they kind of neglect you." (Armenian)

Barriers to quality health care

Women from all ethnic groups felt that financial status was an important determinant in the quality of care received. In general, having financial means and private insurance were equated with a better quality of care. Due to their status as immigrants receiving financial assistance, Latinas were concerned that medical staff at county hospitals provided inferior treatment. They believed that the staff did not view them as deserving of public assistance, and as a result received delays in diagnosis or indifference to their condition.

The Latinas acknowledged that lack of education complicated their ability to access and receive information and care. The Asian Americans and Caucasians believed that one's attitude and motivation was more important than educational level per se in receiving quality care:

Even if you are educated, if you don't get involved, nothing will come out of it. When you are active, it doesn't matter whether you are high school graduate or you have a PhD. (Asian American)

Educational level is not as important as how willing and able a person is to take charge and find out information for themselves. If you're educated, but don't know what the doctor is talking about and don't do anything about it, it doesn't make any difference.
(Caucasian)

The women noted that the quality of care received is based upon assumptions that others make about education level. In particular, Latinas believed that medical staff made assumptions based on inability to speak English and manner of dress, and Asian American survivors felt that medical staff gave more information to those who were more educated about the disease. One African American survivor, was aware of differential treatment based on lack of education, educated herself on breast cancer using the Internet to prepare questions.

Language was also important in receiving quality care for Latinas, Asian Americans and Armenians. Being able to communicate with the health care provider was essential in order to relay one's concerns and to understand the doctors' advice. Monolingual Asian American and Armenian women were also concerned that brochures were not available in their native language:

...I can't read or understand English well. It's hard that educational literature for us breast cancer survivors is not available in Armenian. I wished it was. It's available in Spanish, but not in Armenian. (Armenian)

Further, monolingual Asian Americans and Latinas expressed the difficulties experienced in obtaining or utilizing interpreters in the health care system:

It's very inconvenient. I had friends going with me, but they had to spend the whole day in the hospital. They could only go once or twice. It's like a burden to them. There were times that I had no one to go with me to help with translation. I was asked to come back next time. I already paid a fee for doctor visit, but I couldn't see him. (Chinese)

African Americans and some monolingual Asian Americans were also concerned with Medicare and HMO insurance limitations on hospital stay. Many were dissatisfied that the insurance only covered hospital stay for one night (if even that), and many African Americans felt that the care they received from medical staff was sub-par.

When you stay overnight they treat you like you shouldn't be there. (African American)

When a woman goes in the hospital for breast surgery, it shouldn't be overnight. That's a major surgery. That's your breast that's removed, and they're only giving you a few hours to get back to normal or be able to leave the hospital. If you take an extra day, they're going to charge you. And then they put this drain there...most times you're going to have to go back in six or seven days to the emergency room because of that drain. And why can't they just keep us in the hospital another day or so and check that to make sure that it's okay? It just doesn't make sense to me. (African American)

Some of the Asian Americans and Armenians felt that had they been in their native country, the outcome of their disease would probably have been worse. In particular, some Asian American women related how many in their home country do not receive mammograms and those diagnosed with cancer often cannot afford the treatments.

Health socialization; traditions and values affecting cancer

Most women recalled that cancer was not openly discussed in the family during their childhood. Some Asian and Latina survivors believed this was in part due to lack of knowledge about cancer, particularly in their home countries. To some extent, women believed that it was regarded taboo to talk about having cancer. One African American noted that she first learned of other BCS within her family while informing family members about her condition. The silence and shame regarding cancer was particularly more common in the past and in certain cultures:

African Americans if they were diagnosed, they didn't discuss it; we are a people who think it's a disgrace to have such a disease as cancer. Not knowing that—it's not my fault that I have cancer, but back then they did think so. I think that a lot of my family had cancer and they kept it a secret. (African American)

During childhood, people died, but we had never heard of cancer...Back then, they either didn't know about it or it was considered taboo, a subject no one was allowed to talk about. (Latina)

Chinese people like to hold everything inside. They don't like other people to know. But I had a lot of my [American] friends who were breast cancer survivors who were very open to telling others that they had the surgery. Here in America, people are much more open-minded. (Chinese)

Women recalled learning primarily about practices and beliefs related to general health. The adverse effect of stress on health and the importance of a positive attitude were taught to the Caucasians and Asian Americans as children. In particular, Caucasians emphasized laughter and having patience, and the mind-body connection was discussed by the Asian Americans:

Be happy and think happy. The mind has to be happy in order to be physically well.
(Korean)

Healthy eating practices and nutrition was also mentioned by women from the different groups as having a strong link to well-being. All women discussed decreasing fats and red meats. The Latinas and Asians decreased pork, and some Chinese women described beliefs about avoiding certain foods (e.g. egg and shellfish particularly during illness). Exercise was also an important lesson for African Americans and Asian Americans.

However, some women questioned whether certain traditional beliefs or behaviors might have contributed to cancer or the severity of the illness. For example, Latinas cited the common view of preferring overweight to thin bodies:

As children we were encouraged to eat well, and back then that signified to eat everything without any limitations. The heavier you were, the healthier you were considered to be. Now I think all that possibly has something to do with getting the disease. (Latina)

Some Latinas felt that ambivalent or negative attitudes toward screening exams and religious beliefs about seeking healing from God rather than from medicine contributed to the late detection or worsening of their cancer. Some African Americans also spoke of the hazards of self-medication practices, such as herbal remedies:

...Don't try to do it yourself. Down in Texas where I was raised, a lot of people used to try to cure things with a lot of... herbs. We're losing too many women in our race because we decide... I'll take this herb my grandmother took many years ago and was healed, so I'll heal myself. And by the time you decide to go to the doctor, you're in late stages and it's too late to be treated. (African American)

Body image

Women from all groups spoke of difficulties in adjusting to physical changes from cancer. Several Caucasian survivors expressed anger and disappointment of developing cancer despite a healthy lifestyle:

I felt like my body let me down. I had a really healthy lifestyle, but it didn't do any good. I took herbs and vitamins for years. (Caucasian)

Many survivors described negative feelings about their bodies after breast cancer and its treatments. Common sentiments include decreased self-worth and attractiveness, feeling deformed, inadequate, sad, embarrassed, frustrated, and/or a sense of loss:

You know you get your hair back, but your body is missing something. You'll never be the same. You feel as if you're beneath others, you don't feel as worthy. (Caucasian)

It makes you not as pretty as you used to be. I have a deformity on my chest. (African American)

The majority of us feel degraded as women as we see ourselves in the mirror and wonder, 'If we cannot accept ourselves, how can our husbands or partners?' (Latina)

Cancer to me, is like a stigma. Once you have it, it's always hanging until they find the cure. And then I always have the scar to remind me of that. (Asian American)

Further, some Asians avoided looking in the mirror and dressed to disguise their bodies (e.g. wearing vests). Weight gain was particularly problematic for Latinas in affecting their body image.

However, some Asian Americans reported that cancer did not negatively affect their body image, and some African American women expressed particularly self-affirming comments:

My breast cancer has nothing to do with my femininity. I am a woman, and I don't allow anyone to make me feel less a woman because I had breast cancer. If I have one breast or two breasts, I'm still a mother, I'm still a wife, I'm still a woman. And nobody can take that from me. I walk the same walk today that I did then. (African American)

I feel better about myself now, because I take better care of myself now. (African American)

You keep going on. Just because I had my breast removed, it doesn't make me less.... I'm still a woman. My husband still loves me, he still wants me. (African American)

African American, Asian American, and Latina survivors noted that self-acceptance is more difficult for younger women, as there is more emphasis on physical appearance and concern about breast reconstruction. Effect on body image for older women was less problematic:

We're more mature, we're more accepting and adaptable to change. We tend to have more courage. I don't believe we put so much on the body, how it looks, as we did, say ten years ago. (African American)

Intimate relationships

In general, older women (50 years and older) experienced less or no negative impact on their sex life and relationships compared to younger women. Latinas and Asian Americans attributed this in part to abstinence before diagnosis. Others cited common experiences with declining health due to age and older individuals' perceptions about the body and relationships.

Decreased or lack of sexual desire after treatment was a common problem for the Caucasians, African Americans and Asian Americans. In conjunction with painful intercourse, decrease in desire negatively impacted women's relationships. Some Korean survivors reported feeling obligated to satisfy their partners' desires despite their lack of desire.

A number of the Latinas' husbands did not accept them after their illness and treatments. Seven were abandoned after being diagnosed:

Latino men are brought up as machos.... To them, a woman is not considered as a complete woman if she's missing a body part, and in this case it's more pronounced because the missing part is considered to them a part of femininity. They consider us only as the mother of their children or a housekeeper, but not as a wife, and end up leaving us alone. (Latina)

He didn't understand my disease and obviously he didn't want to deal with it...so he chose the easiest way and left me. (Latina)

However, a number of women across ethnicity had supportive and accepting partners:

It's more difficult for me, not for my husband. He doesn't care if I have one breast, or two breasts. (Caucasian)

Before cancer, I had long hair and lost it during chemo. I was worried that my husband would not find me attractive anymore after my hair fell out, but he told me that I was still pretty. My husband is very nice, I have all these other conditions, diabetes, cancer,

high blood, everything! But my husband just says it comes with the package. (Asian American)

...After treatment I gained a lot of weight. I felt bad and cried a lot, not only because of my missing breast, but also because I looked huge. I avoided my husband...the only thing I was expecting from him was rejection but he turned out to be the most understanding person. He consoled me and told me he loved me for the person who I am and not for my physical appearance. (Latina)

Reservations about dating were discussed by single African American, Latina and Asian American survivors. Disclosure to potential partners was a major concern for some African Americans and Asian Americans. One African American detailed her struggle with feeling that she had a 'duty' to inform her dates about having had cancer. An Asian American survivor expressed feeling hesitant about dating because of uncertainty about cancer recurrence and not wishing to be a burden to someone. Another survivor described the challenges in dating relationships:

Some of the men that I have gone out with—you really find out the people who are really in your corner...One friend of mine, after I told him I was diagnosed, I seldom heard from him. I told him, cancer is not contagious, and I hung up the phone. He never offered, may I take you to the doctor, if you're nauseated may I bring you some ginger ale, nothing. (African American)

Latinas whose spouses had left them after the cancer diagnoses and treatments expressed lack of interest in getting involved in another relationship to avoid rejection and betrayal.

Overall effect of breast cancer

These BCS discussed both negative and positive impact of breast cancer. Some women commented on the negative physical and psychological effects of breast cancer and its treatments on QOL, including decreased appetite, increased fatigue, recurring pain, loss of physical strength, emotional/psychological side effects (e.g. increased irritability, depression), and memory loss.

Many survivors reported experiencing significant anxiety about recurrence around the time of their annual exams. One African American noted a distrust of mammograms:

They tell the women, go get the mammogram. But when you find out that the mammogram didn't pick it up, and I found the lump myself, why is that? (African American)

While the survivors did not minimize their painful experiences, they reported that overall breast cancer had a positive effect on their lives. They identified improvements in the quality of relationships with loved ones and a heightened appreciation and purpose of life:

First, I was depressed, but later when I accept it, I see things differently. I enjoy my son and I talk to him, spend time with him. I don't know how long I can be with him, how long I have. And I am nicer to my husband. Before we argue a lot. But now, just let it go. (Asian American)

...Before I had breast cancer I was thinking, 'What am I living for?' Like there's no purpose, nothing. Then when my life was threatened with this disease, it hit me that I love my life and I want to live. It kind of make me realize, appreciate life more than before. So now, I become more positive. I still get angry, but I don't keep it in me. And then I don't worry a lot. (Asian American)

The way I see life now has changed a lot. Now I appreciate my family, parents, children, more. Before, I knew they were there if I needed them but I didn't value them as much as I do now. Cancer has shown me to value what I have. (Latina)

I'm looking at everything, just appreciating everything on a daily basis. My kids used to stress me out. They're little and I'm older, but I have a lot of tolerance and patience for them. I'm feeling like this is today, and I do not know about tomorrow. (African American)

Breast cancer has made me change my whole life priority. I am very selective and particular about how I spend my time. (Caucasian)

After my diagnosis, I learned to see things different. Before I was superficial and only saw others' defects. Now I have learned to appreciate and value life and others more. I thank God for that and also because it was me who was diagnosed and not my children or other members of my family. (Latina)

As a result, some women have changed their lifestyles, such as decreasing stress levels and workload, and taking better care of themselves:

I used to be a stressful person, I used to worry about everybody but myself. I used to go to work, come home, have dinner, cook, clean. I don't do it now. My children have told me that I have become very selfish. I told them I have become self-full...After God, I'm supposed to come first, then I can take care of everybody. (African American)

I manage my life in a relaxed way since the most difficult part had passed. Every day I live my life happily. One shouldn't think of cancer. (Chinese)

Breast cancer made me re-evaluate and slow down my life a lot. Gave me more empathy for what people might be going through. I'm taking better care of my body—getting enough sleep, not pushing myself to do everything. It was like a wake-up call. (Caucasian survivor)

Effect of neighborhood

Among most survivors, current neighborhood did not impact stress levels or ability to cope with cancer. However, two Caucasians reported that loud noise in their neighborhood was stressful. One African American survivor also acknowledged the neighborhood where she lived prior to diagnosis was stressful. Some Asians and Latinas felt uncomfortable and stressed when neighbors asked questions after noticing the side effects of treatment, such as hair loss and fatigue. The majority of Asian American survivors did not report receiving support from their neighborhoods, primarily because they did not know their neighbors very well. A few of the Korean women indicated that their mostly Korean neighborhood had a positive impact:

The neighborhood has been so kind. Every time I see them, they ask me how I'm doing. I feel so thankful. They care about my health. Each time, they tell me that I look better. (Korean)

Additionally, although some Latinas reported that they had disclosed their diagnoses and received support from their neighbors, many preferred to keep their diagnosis within their family:

As Latinos we have learnt from our parents to respect privacy and keep personal issues within the family. The less people know about it the better. That prevents people from asking questions and getting into your business. (Latina)

Employment issues

Breast cancer and its treatments had varying effects on women's employment. Most Caucasian survivors either were not working at the time of diagnosis or had stopped working due to residual pain from treatment. Self-employed Asian American survivors did not have concerns about employment. Most Asians who disclosed their diagnosis in their work environment reported receiving support from employers and co-workers, while others received no support and felt pressured to leave their job. Many reduced their workload. African American women reported side effects such as low energy and difficulties focusing on the work, but also continued employment. The majority of African Americans disclosed their condition to supervisors and co-workers, and all who disclosed received support. Some attempted to educate co-workers as well:

I work with a bunch of ladies. I didn't feel like I needed to hide anything, but I hope I'm educating them at the same time. Maybe by my telling them different things that they'll be more inclined to do more breast self-examination and go tell their friends and tell their families. It's an educational thing for me and it helps me to talk about it. (African American)

In contrast, employment was a major concern for Latinas. Few maintained their positions, six lost their jobs as a result of missing work or change in performance due to the cancer and treatment, another eight changed or lost their jobs after treatment due to inability to continue functioning at the same level. Unfortunately, some did not attend all treatment in order to avoid termination. These women worried about being unable to financially support their families, and felt that cancer had a significant effect on their employability. A few who disclosed their diagnoses to their employer reported receiving support, but some expressed much discomfort in their supervisor or co-workers finding out about their diagnosis. Several women chose instead to change jobs or stop working to avoid disclosure of their cancer diagnosis:

I was embarrassed, I didn't want my boss to know about my cancer diagnosis so I moved on to another job so I wouldn't feel obligated to respond to questions from curious people. If I would have chosen to stay and not tell anyone I would have had to take time off to go to treatment and its side effects are pretty obvious. Then I would feel obligated to tell them, so it was better for me to move on and I did. (Latina)

I work in sales, but after the mastectomy I decided to stop working. I don't feel confident. Cancer has affected me emotionally and physically and I think my appearance will affect my dividends. Besides, that is not the image I want to present to my clients. They will probably start asking me questions and I will feel obligated to give them an explanation, which is something I don't want to do. (Latina)

SUMMARY AND DISCUSSION

Summary of key findings

Specific noteworthy findings: (1) African American, Asian and Latina BCS welcomed and actively participated in support groups that were culturally and linguistically appropriate; (2) spirituality is significant to the QOL for BCS, (3) many of these BCS, particularly African American and Latinas, acknowledged profound health care and physical concerns; (4) there is an urgent need for health care providers to become more culturally sensitive, (5) significant ethnic differences in type of treatments were noted, Asians and Latinas were more like to receive mastectomies and African Americans were the least likely to receive adjuvant therapy, (6) body image and sexual concerns were common issues for women across all ethnic groups, and (7) the financial burden of breast cancer is noted; Latinas in particular experienced serious job disruptions and financial hardships due to cancer and its treatments. This study accomplishes many goals: (1) it adds to the sparse literature about women of color and breast

cancer, (2) it enhances our understanding of the psychosocial impact, (3) it increases our knowledge of specific cultural influences (e.g. dietary practices, coping) and socio-ecological factors and suggests areas that need further systematic research. More importantly, the study addressed areas that have not been adequately studied before.

Limitations

This study offers important contributions to the literature, however there are important limitations that affect external validity, particularly generalizability: (1) the small sample size; (2) many of the participants were Christians; and (3) about 55% were support group members in urban centers (while this may have increased openness, it may have resulted in potential bias). Further, the convenience sampling employed in this study may have resulted in the selection of a specific subset of BCS and may not capture the extent of the diversity of BCS' experiences.

Overall, we found this diverse group of BCS were satisfied with overall recovery, felt purposeful in their role functioning and optimistic about their health. These survivors enjoyed a fairly good HRQOL because they benefitted from cultural healing practices (e.g. traditional medicine, specific diet, supportive family/friends/others) and resilience built on spiritual faith and practices and reliance on inner strength.

However, common persistent HRQOL concerns were identified: (1) psychosocial issues related to worry about children and burden to the family; (2) health concerns about the causes and management of breast cancer; (3) medical care issues such as cost and amount of time with physician, treatment and hospital practices, and language barriers; (4) marital and relational issues, (5) financial and work challenges and (6) body image and sexual health concerns.

Many women revealed that they did not want to burden their families and children with their cancer. On the other hand, some Asian and Latina survivors discussed feeling stressed and upset over their partners' and family's expectations that they continue their role and functioning as before the cancer. Moreover, regarding work and employment, many Latinas experience serious job disruptions (e.g. terminations) due the cancer and its treatments. These findings corroborate a multi-ethnic study that found that women endorsed greater self-care independence, worry about burdening family members, and financial concerns as a result of their cancer (Greimel *et al.*, 1998). These gender-specific, cultural factors may contribute to unmet social support needs (Kagawa-Singer & Wellisch, 2003).

Moreover, most women accepted their cancer diagnosis as well as the pain and suffering that may accompany this fate. Thus, their coping responses illustrate common human characteristics, yet there were profound cultural differences. Spirituality was essential to all women and the use of spiritual or religious practices were very common. The African American and Latinas relied heavily on their prayers and the prayers and support of their faith community, and the Asian and Latinas on faith. These prayers offered intercession for healing and strength in response to the cancer and increased faith in their relationship with God. The women of color primarily relied on religion-based spirituality while many of the Caucasian women used various spiritual practices. All women in this study embodied resilience; many of the African American women drew from the long legacy of resilience and survivorship history of African Americans; the majority of the Asians and Latinas relied on inner strength and an emotional response of displacement (e.g. focusing their energy on their families and their household responsibilities); most of the Caucasian women used a sense of personal empowerment, individual responsibility and knowledge as their source of resiliency.

Many women across ethnicities believed that the illness is caused in part by a stressful life (chronic distress) and is contained by having a positive attitude. This positive attitude is

essential to overcoming the cancer, and has various cultural manifestations. The African American BCS talked about self-care (e.g. personal style) and self-determination (survivor instinct), the Asian women shared beliefs about mental control, the Latinas discussed attitudes of gratitude and faithfulness, and the Caucasian BCS spoke of perseverance and control.

Additionally, many women reflected some dissatisfaction with the quality of the relationship with their doctors. Moreover, these women expressed concerns about their inclusion in the treatment decision-making process and expressed desire for greater involvement. Treatment decision-making issues are complex, the interaction among personal (e.g. SES, cancer knowledge, individual choice), sociocultural (e.g. support, health beliefs particularly about cancer and its treatments) and systemic factors (e.g. best practices, insurance, discrimination) are not well understood. Future studies must examine cultural, family, and the health care system in addition to individual-level factors to address treatment options and quality of care.

Finally, regarding body image and sexual health concerns—a number of women expressed trauma, loss of body esteem, a sense of flawed femininity, as well as negative relational effects. Caucasians and Latinas were particularly vulnerable to experiencing a sense of damaged womanhood. Furthermore, many women revealed significant decreases in sexual desire and activity. This preliminary, qualitative study has resulted in some important discoveries regarding the relationship between breast cancer and sexual health for all women including women of color. These findings draw attention to the fact that Asian and Latino women are affected by body image and sexuality concerns after breast cancer. The relationship between breast cancer and sexual health is multifarious, involving personal as well as partnership issues. Therefore, studies should include women and their partners to decrease body image and relational issues among BCS.

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APPENDIX A. MAJOR THEMES FROM CONTENT ANALYSIS OF FOCUS GROUPS

The major themes are presented in Table 3.

Table 1

Focus group interview domains

Domain	Sample question
Health beliefs	What are things that have helped your recovery or coping the most?
Health socialization	What is the best way or ways to handle a major illness?
Relationships	Thinking back to childhood, what were some of the things you learnt about health?
Quality of care	Who gave you the most support to help cope with breast cancer?
Socio-economic status	Tell me about your relationship with your breast cancer doctors.
Socio-ecological factors	What did your doctors tell you to do to get well?
	What are things that may affect the quality of treatment a person gets from the medical staff or doctor?
	How has your local neighborhood or community affected your coping with breast cancer?
	What type of support do you receive from your supervisor? Co-workers?

Table 2

Focus group demographics

	African American N = 24	Korean Monolingual N = 11	Chinese Monolingual N = 10	Asian Bilingual N = 13	Caucasians N = 12	American Monolingual N = 5	Latina N = 26
Age (years)							
Mean (range)	56 (42–79)	56 (31–78)	56 (42–81)	53 (40–65)	55 (43–72)	54 (37–67)	56 (40–73)
Marital status							
Single	4 (17%)	1 (9%)	0 (0%)	2 (15%)	3 (25%)	0 (0%)	5 (19%)
Married	9 (38%)	8 (73%)	8 (80%)	6 (46%)	4 (33%)	4 (80%)	14 (54%)
Divorced	6 (25%)	1 (9%)	0 (0%)	4 (31%)	5 (42%)	1 (20%)	2 (8%)
Widowed	5 (20%)	1 (9%)	2 (20%)	1 (8%)	0 (0%)	0 (0%)	5 (19%)
Age at diagnosis							
Mean (range)	51 (30–74)	53 (31–75)	49 (41–71)	49 (40–60)	53 (51–72)	52 (35–65)	52 (28–70)
Stage of cancer							
0	4 (17%)	1 (9%)	0 (0%)	0 (0%)	2 (17%)	1 (20%)	0 (0%)
I	3 (13%)	4 (36%)	4 (40%)	4 (31%)	0 (0%)	1 (20%)	5 (18%)
II	7 (29%)	5 (46%)	1 (10%)	5 (39%)	4 (33%)	3 (60%)	7 (27%)
III	1 (4%)	0 (0%)	0 (0%)	2 (15%)	3 (25%)	0 (0%)	5 (18%)
IV	0 (0%)	0 (0%)	0 (0%)	1 (8%)	1 (8%)	0 (0%)	0 (0%)
Unknown	9 (37%)	1 (9%)	5 (50%)	1 (8%)	2 (17%)	0 (0%)	9 (37%)
Treatment ^a							
Lumpectomy	12 (50%)	4 (36%)	2 (20%)	6 (46%)	6 (50%)	1 (20%)	8 (31%)
Mastectomy	12 (50%)	7 (64%)	8 (80%)	7 (54%)	5 (42%)	5 (100%)	18 (69%)
Radiation	4 (17%)	5 (46%)	4 (40%)	8 (62%)	8 (67%)	2 (40%)	13 (50%)
Chemotherapy	7 (29%)	6 (56%)	5 (50%)	9 (69%)	9 (75%)	3 (60%)	16 (62%)
Hormone	1 (4%)	0 (0%)	0 (0%)	7 (54%)	1 (8%)	4 (80%)	8 (31%)
Tamoxifen	9 (38%)	9 (86%)	1 (10%)	6 (47%)	6 (50%)	3 (60%)	8 (31%)
None reported	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	3 (11%)
Family history of BC							
Yes	8 (33%)	1 (10%)	1 (10%)	6 (46%)	6 (50%)	1 (20%)	16 (62%)
No	16 (67%)	10 (90%)	9 (90%)	7 (54%)	6 (50%)	4 (80%)	10 (38%)
Obtained second Opinion							
Yes	14 (58%)	2 (18%)	1 (11%)	4 (44%)	6 (50%)	2 (40%)	15 (58%)
No	10 (42%)	9 (82%)	8 (89%)	9 (69%)	6 (50%)	3 (60%)	11 (42%)

^a Respondents may report more than one treatment.

Table 3

	African American	Asian American	Caucasian	Latina
Factors helping recovery, coping	<ul style="list-style-type: none"> Spirituality, prayer Family support Emotional support lacking Survivor instinct in African American ancestry Self-care affects quality of life, longevity Changes in diet, drinking Participate in care Some view the mastectomy site as a deformity Ugliness of scar 	<ul style="list-style-type: none"> Faith, prayer Family support (spouse, kids, siblings, in-laws) Accept illness God ultimately in control Attitude affects recovery Participation important; less acculturated prefer doctor to make decisions Feel self-conscious Feel inadequate, lose self-confidence Cancer is a stigma Sex life negatively affected Feel obligation to fulfill spouse's sexual desire Doctors are supportive Language barriers Confidentiality important Need more time w/ doctor Insurance status Good attitude more important than education Fatigue Decreased quality of life Increased concern about own needs Most felt working environment supportive 	<ul style="list-style-type: none"> Support groups Partners and friends Spirituality Perseverance, attitude, knowledge Don't let cancer control life Diet, nutrition, stress More active involvement in health care Disappointed with body Shocked Fear partner's feelings about them after surgery Decreased desire, frequency of sex Doctors do not have time to listen Some were satisfied with their treatment Financial state Insurance status Ability, willingness to seek information Slower pace, reduce stress Enjoy life Selective about how time is spent Some felt working environment supportive 	<ul style="list-style-type: none"> Prayer, accept God's will Family, friends' support God has ultimate control Healthy diet, no excess Vulnerability to illness due to unhealthy habits Participation in health care important Embarrassed, sad, frustrated Feel incomplete Feel ugly, self-conscious Afraid partners may not consider them complete women Language barriers Need more time w/ doctor Different treatment based on ethnicity, insurance, class and legal status Language barriers Legal status Education Medical assistance process difficult Loss of breast is stressful Treatment side effects=difficulty with activities Fear of losing job so delay seeking care
Control over illness, participation in treatment				
Feelings about body, intimate relationships				
Relationship with doctor	<ul style="list-style-type: none"> Some feel doctors do not provide support or care about them Concern about doctor sensitivity 			
Factors affecting quality of treatment	<ul style="list-style-type: none"> Type of insurance Educational level Health care system 			
Overall stress/effect of BC	<ul style="list-style-type: none"> Lack of energy 			
Work, career issues	<ul style="list-style-type: none"> Some working in female environments 			

African American	Asian American	Caucasian	Latina
feel coworkers are supportive	• Self-employed: no work concerns		• Concerns about ability to provide for their family