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THE IMPACT OF CERVICAL CANCER AND DYSPLASIA: A QUALITATIVE, MULTIETHNIC STUDY

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Abstract

Study purpose—Cervical cancer (CCA) remains a health challenge nationally and globally. In the US, more than 12 000 women are diagnosed each year with invasive cervical cancer and more than 220 000 are living with a history of this diagnosis (ACS, 2003). This qualitative study aims to examine health related quality of life (HRQOL) from a culturally consistent framework.

Methods—Key-informant interviews (*N*=23) and focus group interviews (*N*=51) were conducted with a multiethnic sample of cervical cancer survivors (CCS) recruited from hospitals and clinics.

Analyses and results—Content and theme analyses were conducted. Findings indicate that cultural and family factors often promote coping and well-being, but may foster delay in care seeking and self-deprecation, particularly among Latina and Asian CCS. Faith in God was relied on for comfort, strength and healing by many survivors, especially the African Americans and Latinas. Overall, our participants reported moderate HRQOL. However, persistent concerns included treatment side-effects; difficulties accessing quality care; inadequate health insurance, barriers to good physician-patient relationship such as language and doctors' time constraints; insufficient knowledge about CCA due to limited information from medical staff; lack of control over treatments; social support, family well-being, functional and work issues; and sexuality and relationship concerns. Socioeconomic status, ethnicity, cultural beliefs and practices, age and family support dictated the level of cancer-related burden.

Conclusion—Invasive CCA is primarily a cancer of women who are economically disenfranchised. Women with a CCA diagnosis are disproportionately challenged by lack of resources including quality, affordable health care and psychosocial services. CCS experience persistent medical, psychological, social, and relational concerns. Information concerning CCS is needed, particularly in Spanish, Vietnamese and Korean. There is an urgent need for further research to understand the risk factors, and the social and cultural mediators of cancer-related HRQOL for CCS.

Cervical cancer (CCA) remains a national and global health challenge. An estimated 12 000 women nationally and 1600 women in California will be diagnosed with invasive CCA this

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year (ACS, 2002, 2003). SEER incidence rates for invasive CCA among African American, Asian, Latino, and Caucasian women are 11.2, 12.1, 15.3, and 7, respectively, per 100 000 (NCI-SEER, 2001). Almost 4 200 US and 500 California women die each year due to CCA. California has the highest CCA rate: over 11% of the cases in the US (ACS, 2002) Among Caucasians, incidence and mortality rates have declined by approximately 60% over the past two decades, but regrettably, the mortality rate for African Americans has risen almost 10% between 1976 and 1997. The 5-year survival rate is lower for ethnic minority women: 72% for Caucasian and 58% for African Americans (ACS, 2002; NCI-SEER, 2001). Among Latinas and Asian Americans, incidence and mortality have increased in the past 5 years.

CCA, or cancer of the cervix uteri, is one of the more easily detected (via the Pap test) and highly treatable cancers. One of the major causes of CCA is malignant cell change resulting from untreated human papilloma virus (HPV) infection. Many more women are affected with this illness than are diagnosed with cancer. The primary cancer preventive strategies are early diagnosis and timely, appropriate medical care. Yet, each year thousands of women fall through the net of care and are diagnosed with invasive CCA or in situ CCA (stage 0 or CIN III) because the system poses such barriers to access and health education, particularly among underserved women. Invasive CCA is most prevalent among the socio-economically disadvantaged and medically underserved (Krieger *et al*., 1999; Liu *et al*., 1998). In the US and California, ethnic minorities are over-represented among the poor; a significant number of African Americans (23%), Asian/Pacific Islanders (10%), Latinos (21%) and Native Americans (32%) live below the poverty level (US Census Bureau, 2000). Although ethnic minority groups are the fastest-growing populations in California and the US (US Census, 2000), and experience greater incidence, greater morbidity and lower five-year survival rate, there is a paucity of cancer control research with ethnic minority and under-served patients (Aziz and Rowland, 2002), especially in the area of health-related quality of life of cancer survivors.

HEALTH RELATED QUALITY OF LIFE (HRQOL) WITH CERVICAL CANCER PATIENTS

The body of literature on HRQOL and CCA is limited. Studies report data with mostly Caucasian women (samples typically 90% Caucasian), include various gynecological cancers in the samples and focus primarily on sexual functioning (Andersen, 1996; Schover, 1989; Shingleton and Orr, 1995; Thranov and Klee, 1994; Yeo and Perera, 1995). Padilla *et al*.'s (1992) HRQOL study with 100 women with gynecological cancers (including 38 with CCA) reported that identified mood states, ambiguity about illness-wellness state, danger-focused appraisal and mastery were key predictors of HRQOL scores. Some studies document persistent physical symptoms (pain, bowel and bladder problems) (Klee *et al*., 2000a) and psychosocial concerns (worry, depression, anxiety, inadequate social support) (Eisemann and Lalos, 1999; Klee *et al*., 2000b; Lambley, 1993) after CCA treatment, particularly radiation therapy. However, research on CCA specifically is insufficient, particularly with multi-ethnic and underserved samples. Most studies on ethnic minorities and CCA have focused on epidemiological issues (e.g. incidence, mortality) and screening (Morgan *et al*., 1996; Thomas *et al*., 1995). A few studies have explored health beliefs and/or QOL issues with diverse groups of cervical cancer survivors (CCS). A recent study with 50 Latina CCS found significantly higher levels of depression than in other cancer patients and community samples of Mexican-Americans and non-Hispanic Whites (Meyerowitz *et al*., 2000). Social support, general stress, family issues, relational and sexual issues, physical symptoms associated with treatments, and barriers to obtaining treatment are common concerns (Li *et al*., 1999; Meyerowitz *et al*., 2000; Nair, 2000; Ohaeri *et al*., 1998), particularly for ethnic minorities. Further, most participants wanted additional access to cancer-related support (support groups or individual psychotherapy) and additional information about CCA and treatments. Perceived social support from multiple family members was significantly associated with better adjustment. (Meyerowitz *et al*., 2000).

METHODS AND PROCEDURES

This qualitative study was designed to describe the cancer experience in a diverse sample of CCS: African American, Latina, Asian American and Caucasian women. UCLA IRB approval was obtained. Key informant and focus group interviews were conducted in the Greater Los Angeles area by bilingual research assistants with at least 3 years cancer-related research experience, and basic training in qualitative methodology and psychosocial oncology.

The key informant interviews

Twenty-three key informants were interviewed to gather information about CCA from health professionals who work with diverse ethnic communities. Interviews were guided by Dr Ashing-Giwa’s previous work and a review of the CCA literature. Domains addressed included attitudes, beliefs, and knowledge about cancer, health-care system issues, and cultural and socio-ecological factors that influence the HRQOL outcomes of women with CCA (Table 1).

Informants were physicians, nurses, and health-care administrators knowledgeable about and involved with diverse cancer patients, and were recruited from community hospitals, health clinics, and cancer-related organizations. Informants were contacted by telephone and all agreed to participate in a 1 h, face-to-face, audio-taped interview to discuss the status of CCA in the communities they serve. Informed consents were obtained and the interviews followed a semi-structured, open-ended format.

Focus groups interviews

Fifty-one women from four major ethnic groups participated in focus groups to (1) document women’s cancer experiences and (2) further explore the issues identified in the key informant interviews. Topics included attitudes, beliefs, and knowledge about CCA, health-care issues, quality of doctor-patient relationship, and cultural and socio-ecological issues (Table 2).

Groups were organized according to homogeneous ethnic and/or linguistic groupings. Hospital and community health clinic directors were first contacted by telephone to assess interest and willingness to involve their group members or patients for a special focus group meeting. Individuals were sent written invitations from the agencies describing the focus group format and proposed incentives. Participants were recruited via a personal telephone call from agency representatives or via fliers posted at the agency. It was not possible to calculate participation or refusal rates as agency personnel did not record refusals.

Focus group size ranged from 4 to 10 individuals. Each audio-taped group lasted about 2 h and was held at the recruitment site to provide a familiar environment. The informed consent process and participant orientation were conducted during a meal. Women were encouraged to respond to all the issues raised, but were informed that they had the right to not respond to any issue. Participants sat in a circle to foster openness. At the end of the session, women were thanked for their participation and given a $20 grocery voucher.

Detailed summaries of each key informant interview and focus group discussion were conducted and selected quotes were transcribed verbatim. Discussions conducted in Spanish and Chinese were translated into English for analyses. Comprehensive content analysis was conducted using a tabular matrix pre-established from the domains of the questions.

RESULTS

Major themes were identified (see Appendix). Results from key informant interviews and focus group discussions will be discussed separately in order to fully present the information.

Key informant demographics

Twenty-three key informants (7 African American, 6 Asian American, 6 Latina, and 4 Caucasian) participated: 3 men and 20 women. On average, informants were 50 years old (range of 25–70 years) and had 19 years of cancer-related work experience (ranging from 2 to 35 years). Most held positions with administrative and clinical responsibilities (medical, psychosocial, or educational patient care). All had worked with diverse ethnic communities with varying socioeconomic status (SES), language abilities and length of time in the US.

Findings from the key informant interviews

Impact of cervical cancer—The key informants described CCA's impact on women's lives as multifaceted. First, CCA and its treatments often profoundly affect women's overall health via infertility, morbidity, and mortality. Latinas were believed to bear the greatest burden, in that more Latinas are diagnosed, particularly at younger ages and more advanced stage, in part due to inadequate healthcare. Additionally, many patients experience negative psychosocial reactions, e.g. fear, shock, denial, anxiety, depression, anger, and shame due to the perception that CCA is associated with sexually transmitted diseases and promiscuity. When left unaddressed, the informants warned that these reactions may likely impact treatment-seeking behaviors, especially among women of color. Finally, some CCA treatments have left women burdened by infertility, negative body image, and feeling flawed as a woman and sexually undesirable. Unfortunately, these concerns are rarely voiced and addressed, as patients often feel uncomfortable and embarrassed. The informants agreed that a consistent, trusting relationship with their doctors must be established in order for CCS to present these concerns.

Socio-ecological factors affecting the experience—The primary socio-ecological factors were SES and language. Women of lower SES and limited English fluency, many of whom are recent immigrants and heads of households, have similar issues across ethnicity: less access to care, less knowledge about CCA and resources, more likely to be uninsured or under-insured, more likely to view the diagnosis as a death sentence, and to equate asymptomatic state with good health. For many, family and finances are prioritized over their own health. These factors create barriers to screening, care and treatment. Lower SES women have difficulty keeping treatment and follow-up care due to transportation problems, work circumstances (inability to take time off, threat of job termination, loss of wages), or lack of childcare. Frequent change of residence is another challenge to promoting timely treatment and follow-up care. Moreover, one African American informant noted that stigma associated with government assisted healthcare plans (e.g., MediCal) has turned African Americans away from utilizing such plans.

Social support—Social support was identified as another key socio-ecological factor. According to the key informants, Caucasian CCS view support from friends as most important, followed by family and spousal support. Also essential is balancing social support with independence (i.e. not becoming too dependent on the family/caregiver). For African American CCS, social support from family and friends is very important. However, many African American CCS are unpartnered and thus have one less source of support. Informants who work with Latina and Asian American CCS noted that these women view spousal support as essential; support from other family members and friends is also important. Family provides support through doctor's visits, transportation and medical compliance. For all CCS, children often provided powerful motivation to get well. However, family problems may also delay treatment seeking.

Role of culture—Most key informants agreed that beliefs in communities of color that CCA is a contagious, sexually transmitted disease stigmatizes those with the illness. Some cultural beliefs and practices may increase women's vulnerability to gynecologic illness (e.g. douching after intercourse to prevent pregnancy and infection). Additionally, CCA screening (e.g. yearly pap-smears) are shunned by some Latina and Asian women because it is unacceptable to expose women's genitalia or discuss sexual health concerns.

Culture also affects how CCS cope with the illness. Key informants observed that African-, Asian- and Latina- American CCS, particularly the less acculturated, often do not question doctors about diagnosis or treatment. Beliefs in the superiority of alternative medicine (i.e. home remedies, herbs) over Western modern medicine exists across some ethnic groups, particularly with older, lower SES and/or more recently immigrated women. An increasing number of women across ethnicity incorporate complimentary and herbal medicines into their treatment. Across ethnicity, spirituality and religion are also important. Use of prayer to cope with CCA is very common. However, informants suggested that religious beliefs could also impose undue burden on CCS (e.g. belief among many Latina and Asian American CCS that cancer results from divine punishment). Among the very religious, the idea that God will heal them without medical support was prevalent, leading to serious negative outcomes.

Healthcare system and provider-patient relationship—Another barrier to healthcare identified was the doctor-patient relationship. Informants reported that people of color as a whole harbored substantial distrust of providers and disenchantment with services due to history, personal experiences (e.g. lack of continuity of care) and others' negative experiences. An African American informant noted, 'A lot of African American women are aware that racism impacts the quality of care received.' Latina key informants reported that older Latinas feared being used as 'guinea pigs' by the medical establishment. Informants believed language and communication problems contributed to this sentiment, as patients often feel intimidated by doctors and embarrassed about asking questions. They are not usually encouraged to ask questions nor are they actively involved in the treatment decision-making. Communication barriers, lack of cultural sensitivity, and limited time spent with patients created impediments to care and treatment adherence for ethnic minority women. Informants urged doctors to treat CCS with dignity and coordinate care with other providers to increase compliance.

Summary of key informants interviews

The consensus among the key informants was that cultural factors and socio-ecological contexts influenced women's HRQOL and how they define and cope with CCA. Informants agreed that poverty was the main contributor to CCA diagnoses and poor outcomes. Poverty dictated several risk factors including lack of knowledge about CCA and treatments, uninsured or underinsured status, and limited access to timely, appropriate healthcare. Informants noted that many patients, particularly ethnic minority and underserved, often lack empowerment, knowledge and time to navigate the complex health care system. Informants identified support as a major buffer against stress for all CCS, and emphasized the need to increase support structures (patient advocates, social workers) within the health care system. They acknowledged the major role of religious beliefs and practices in coping, both positively and negatively, especially among ethnic minorities. Finally, they highlighted the need for the health care system to enhance cultural sensitivity and employ bilingual staff to improve quality of care.

Focus group participant demographics

The 51 CCS participated in 7 different focus group meetings: Chinese group (*n*=6); mixed Asian group including 3 Thai and 1 Japanese women (*n*=4); Caucasian group (*n*=5); African American group (*n*=10); and three Latina groups (*n*=26; 8–9 per group). The Chinese and Latinas groups were comprised of less acculturated, monolingual women and were thus conducted in the women's native languages.

Table 3 describes participants' demographic and diagnostic characteristics. All the African Americans were diagnosed with cervical dysplasia; all Caucasians, 80% of Latinas and 50% of Asian Americans had CCA. A third of Asian Americans and almost 40% of Latinas did not know the stage at diagnosis. The African Americans were the youngest (mean age of 33 years) and Caucasians the oldest (mean age of 56 years). Almost all Asian Americans were married versus less than half of Latina, 20% of African American, and 40% of Caucasian CCS.

Findings from the focus group discussion

Table 2 lists the domains covered in the focus group discussions. Major themes are also presented in the Appendix.

Recovery and coping—The women discussed various strategies to recovery. African Americans stressed timely medical care and trust in God. Asian American CCS cited religious faith, family support, complying with doctors' recommendations, attending check-ups, and sustaining normal routines as most important in recovery and coping. Proper surgery and treatment were most important for survival for the Latina CCS. They were motivated to get well through a positive attitude, religious faith, family support, and the desire to see their children grow up. However, some had great difficulty coping with the diagnosis. One Latina stated:

> At first I refused to accept the diagnosis and I went to Mexico to get a second opinion and saw three different doctors but unfortunately they all gave me the same diagnosis. It took time for me to accept it but I wanted to make sure of the diagnosis and the results were not a mistake.

Caucasian CCS spoke of being educated about the illness and proactive in the treatment. Also helpful was enlisting support from doctors and other CCS, and maintaining normal routines:

> After my gynecologist called me and said that I had cancer, I immediately asked for a second opinion. I had my tissue samples from the biopsies reviewed. Then, I went on the internet and got as much information as I could get, talked to other doctors and friends that were doctors that knew about cancer. I kind of knew what to do and it also… psychologically gave me something else to focus on rather than feel despair.

Social support—Participants across ethnicity expressed the importance of support from immediate and extended family. Mothers, spouse/partners, and children were the principal sources of support. Family members frequently accompanied patients to appointments and performed household chores. A Japanese survivor recalled:

> My mother was really there for me. She cooked a lot of meals and went with me to my appointments even a year later.

Many Latina survivors were dependant on their spouses for providing emotional as well as financial stability. This was poignantly stated by one woman:

> I'm very fortunate to have my husband's support emotionally and with family care. Without him I'm sure I wouldn't be feeling as I feel today… me siento segura (assured and secure) or talking with others about my cancer experience.

However, one African American woman was reluctant to go to her family for support:

> I don't say much to family because I don't want them to know much particularly when I didn't get that much information from doctors. My family can't help me so I don't want sympathy. Why tell people? Keep it to yourself.

Moreover, friends were important sources of emotional support and information for Caucasians.

Spirituality and religiosity—All the African Americans agreed on the importance of (a) prayer and of seeking God's guidance and assistance in coping with the illness, and (b) doctors as God's instruments in healing. One patient explained that both are involved in healing:

> A lot of people think that they shouldn't go to the doctor. They do things such as take herbs or steam treatments instead. It's important to use prayer and ask God for assistance… put it in His hands either way it goes. God knows the end result before you do.

Similarly, faith was a significant means of coping with the illness and pain for the Asian American CCS. One Chinese survivor explained, 'You can tell God when you are in pain, and you get support from Him.'

Latina CCS found support and relief through church and religious faith. They likewise experienced comfort and peace in prayers. Latina and Asian American CCS held a strong sentiment that the condition is beyond their control and in God's hands. Thus, they were able to feel at peace by turning the situation over to God and accepting God's will. One Latina stated:

> If He doesn't want me to be here on earth anymore there is nothing I can do about it and I will accept God's decision whatever it'll be.

Many Caucasian CCS also discussed the importance of spirituality, support from clergy, as well as practicing visualization and relaxation to promote healing.

Handling a major illness, control over illness, participation in medical treatments—While the African Americans believed in the importance of seeking prompt medical care for any body changes, they indicated that many in their community tolerate severe symptoms before seeking medical attention. They stressed that patients need to speak up for themselves because doctors often do not provide much information. They also believed that they have some control over their body and illness by practicing cleanliness and disinfecting behaviors (e.g. douching):

> You do have control over things when you notice things are different about your body. You don't want to ignore this. It is important to take care of this by going to the doctor and get medication. [However], no one has total control over things. You try to be brave and have a better handle of [the disease].

Asian American CCS deemed controlling one's mood as important in handling a major illness, specifically having a positive attitude, maintaining a sense of peace, and avoiding stress. While some Chinese CCS believed that illness could be controlled through proper diet, physical activity, controlling one's mood, and following doctors' advice, other Asians felt frustrated over developing CCA despite a healthy lifestyle. The more acculturated CCS felt that women need to be involved in their medical treatment by asking questions and educating themselves.

Latina CCS discussed the importance of the following in handling CCA/dysplasia: (1) be informed about the illness, get treatment, and be actively involved in one's care; (2) practice healthy behaviors (better diet and better hygiene after sex); (3) seek family support; and most importantly, (4) accept God's will because one does not have much control over cancer.

The Caucasian CCS likewise believed that one does not have much control over getting cancer. However, they found it helpful to gain a sense of control by gathering more information, practicing healthy behaviors (dieting and exercising), and being involved in their treatment.

Health socialization: Traditions and values affecting cancer experience—Cultural beliefs shaped the women's feelings about illness and health outcomes. Most had theories about causes of the cancer. Asian American and Latina CCS believed that being married, monogamous or older translated into lower risk for CCA. Stress and poor diet, on the other hand, were thought to be causes. While Caucasian, African American, and Asian American CCS were more likely to attribute some responsibility to their partners, Latina CCS were more likely to assign blame to themselves, to view cancer as a form of punishment and a death sentence, and traditional herbs and diet as curative:

> The day after my diagnosis I went to visit my father, I held his hand and asked him for his forgiveness if I had been disrespectful or failed in something. He wondered why I was doing that but I preferred to keep quiet.
>
> Traditions have a lot to do with our behavior today and attitudes towards getting informed about any other disease but particularly about cervical cancer, because in the Latino community a topic related to female organs is a sexual issue to be considered a taboo. It is something not discussed even within the family.

Most of the women of color believed that 'keeping clean' or douching/washing before and after sex prevents CCA. A Latina survivor stated:

> I think cervical cancer can be controlled, if we wash before and after having sex, and if we watch what we eat, maybe we can prevent getting it. Women with cervical cancer should avoid having intercourse which can cause infections.

Additionally, the African Americans were taught to partake in low fat diet, exercise, and regular doctor's visits to keep healthy. The Asian women described general health practices taught by their families: avoid certain foods, eat fruits and vegetables, and promptly treat symptoms.

Medical concerns regarding cervical cancer/dysplasia—Recurrence of the cancer, metastasis, and early death were common fears across ethnicity. Latinas were concerned about leaving their families without caregivers, while Caucasians expressed fears about painful deaths, isolation, and the unknown. Worry about daughters developing cancer was discussed by the Latinas. The African American CCS attributed some of their fears to lack of information received from doctors. Additionally, many were concerned about doctors' lack of sensitivity during pelvic examinations. Besides fear of deterioration of their condition, the CCS indicated that pain and fatigue from the illness were also disruptive. One African American noted that intense pain associated with dysplasia has made her life more difficult.

Femininity and Body image—Most of the African American and Caucasian CCS expressed feeling damaged and worn out after the diagnosis. One African American CCS confided:

> My body is gross. I don't feel clean until I find out what is wrong with me. I bathe a lot and scrub down there.

Asian and Latina CCS were extremely concerned with illness and treatment effects on fertility and appearance (hair loss). Loss of fertility was particularly distressing for women who had not yet had children. One Japanese survivor lamented:

> You grow up thinking you'll have kids. Now you won't. What is my role as a woman, I ask myself? What is different from a man?

While concerns about physical appearances existed across ethnicity, Latinas expressed more negative feelings about their bodies after surgery (abdominal scars, adverse effect on self-image and self-worth as women), and deep concerns about the impact on their relationships:

> Nothing will be the same. My body won't be the same because they removed my ovaries, fallopian tubes, and womb.

In general, CCS felt that younger women are more affected than older women. Additionally, the dysplasia survivors expressed little femininity and body image concerns.

Effects on intimate relationships—Some single African Americans experienced loss of libido in part due to fear that sex would worsen their condition. Those with sexual desires often had difficulty finding partners. Married African Americans reported forcing themselves to have sex with their husbands. One woman's comment exemplified the group sentiment:

> I have no sexual desire. I force myself. He's just on top of me and I wait until he's finished.

Most of the Asian American dysplasia survivors did not feel their relationships were adversely affected. However, some disclosed problems, such as lack of libido and pain. Additionally, fears about injuring or aggravating the affected area adversely affected the frequency and quality of sexual relations. According to a Japanese survivor:

> It is a psychological thing. You're just afraid. It's just such a delicate area. You think about when it would hurt. We're intimate but it is not the same. You are afraid when you visualize what is going on in there. What are you going to disrupt? As a married couple, you want to give, but you're not as free. The love is the same, but the quality of the sexual activity went down.

The Latina CCS discussed how the perception of women with hysterectomies as 'incomplete' and 'lacking sexual desire' resulted in stigma and abandonment by their sexual partners:

> Two months after my diagnosis my husband left me for another woman. It has been a nightmare for me not only because of the diagnosis but also because my ex-husband's woman constantly calls to insult me that I'm not good as a woman anymore, that I can no longer have children and that I will die from cancer.

Some Latina CCS reported positive effects of CCA, including stronger relationships, ability to end bad relationships, and relief from not having to engage in sex:

> After my cancer diagnosis over a year ago, I decided to leave [my partner] before he did it to me. Even before my diagnosis, we were having problems because of his alcoholic habits and I would not want to be a bother or to be insulted as a woman. It also has been a relief not having to worry about pleasing him sexually.

Caucasian CCS experienced many physical symptoms from the illness and treatment that made it difficult for them to enjoy sexual intimacy. Single women found it hard to date after diagnosis and treatment. Sexual problems resulted in relational difficulties among the married women.

Relationship with doctors—African Americans, Caucasians, Latinas, and more acculturated Asians all believed women need to be proactive, educated, and involved in their health care. Most of the monolingual Asian Americans, however, preferred doctors to make the decisions for them. The majority of the women of color did not seek second opinions.

Overall, Asian Americans expressed more satisfaction with support received from doctors and in their relationships with doctors than the African Americans, Latinas, or Caucasians. One Chinese survivor noted, 'The relationships are very good. Doctors are caring for us. We feel comfortable.' Although some African American CCS felt their doctors were congenial, they were dissatisfied with their insufficient explanation of test results:

> My pap was abnormal and the doctor called and simply said it would be addressed during my next visit… when I asked, they said I had pre-cancer cells but [the doctor] didn't explain what that was.

Another African American survivor recalled her experience and frustration in vivid terms:

> Just because they told me there is nothing there, I don't believe it. I want to see what they are doing and taking out of me. When I got the colposcopy, they put that yellow stuff in me. I was wearing pantiliners and noticed snuff looking stuff. I called the doctor because I didn't know if my insides were coming out. I thought I was going to die. They said that it comes from the medicine. They treat us like cattle and didn't tell me beforehand that that will happen.

Another common complaint was doctors' lack of sensitivity during physical examinations. One African American survivor put it eloquently:

> When [doctors] insert instruments …don't just stick it up there. I'm not a prostitute. I'm not wide open. My body is a temple.

Latina CCS also expressed a number of concerns: lack of continuity of care, embarrassment and doctor insensitivity during pelvic exams, insufficient time with doctors, language barriers, and long wait for appointments. Sentiments shared included:

> It took hours for [my doctor] to see me and even then I was only seen for a few minutes because he did not have the time to listen to me. He only reviewed my chart and recommended that I make an appointment to go back and see him. To me that was and still is frustrating.
>
> I don't speak English and the doctors don't speak my language so how can I or anyone who does not have the ability to communicate be assured they are getting the proper care? We have to depend on a translator and still feel like they are not asking what we really want to ask the doctor.
>
> It is uncomfortable and embarrassing to be seen by a stranger especially for this particular exam. We are not raised like that and those are private issues. It interferes with getting care and we wait until it is completely necessary, maybe that contributes to having a higher risk of getting the disease.
>
> The male doctor is too rough. I felt like I was dying.

Immigration status was also a concern for undocumented Latina and Asian women. Fear of being reported to immigration officials inhibited receipt of certain services. Additionally, they felt that removal of language barriers would improve their relationships with providers.

Latinas and Caucasians agreed that one's financial and insurance status affect quality of care. Education and knowledge about CCA also influenced care. These CCS felt that educating women about post-surgery issues (e.g. pain, psychosocial concerns) were lacking and needed. Caucasian CCS related both positive and negative relationships with their doctors:

> We had a good relationship. He was very young, but he was also very comforting. I found the doctors to be wonderful and they remind you to have your check-ups and taking my meds.

> Some doctors like to play God and they won’t say when they did something improperly. The way I found out that a doctor could do a pap smear incorrectly is by reading the pathology report that I got in my medical file. I was surprised at how many times my doctor didn’t get the correct sample when I had already been diagnosed and treated. The smear would come out inconclusive and he’d say, ‘You’re fine, just come back in 2 or 3 months.’ But he wouldn’t say anything else.
>
> When it was obvious that I had cancer, I went to see my gynecologist. I had a pap smear which they said was inconclusive. And it horrified me to realize that I had a huge tumor in my cervix and the pap smear didn’t detect it. I went to two doctors who didn’t give me complete and accurate exams. The cancer was already so advanced. I was in complete pain and unable to walk. I got a female doctor…she did everything right. Two days later I saw an oncologist.

Doctor’s involvement in patient adherence—The African Americans did not experience much doctor support. Often the only recommendation given was for follow-up tests. However, they would like to have received health practice-related recommendations. All the participants reported attending the follow-up appointments. While all the Asian American CCS reported following doctors’ recommendations, they did not feel that their doctors provided any special help. Some Chinese survivors’ reported their doctors recommended increasing water intake and exercise, and applying ointment (for dysplasia). About 30% of Latinas followed doctor’s recommendations (e.g. diet) and abstinence for dysplasia. Many were more willing to comply after seeing other CCA patients who became disabled as a result of non-adherence to treatment. While some reported receiving support from doctors and others reported receiving none, notably none of the Latinas were informed about cancer support groups.

Access to care and quality of care—The African American and Latina CCS believed lack of money or insurance results in poorer quality of treatment. One African American stated:

> I went to a hospital one time and the nurse treated me very rude when she thought I didn’t have health insurance. But when she found out I did, she became more friendly and helpful.

Another African American related how she was passed over in a clinic where most of the staff and patients were Latino. The Latina CCS believed that doctors at low-cost clinics were less competent, less professional, and unable to provide continuity in care. Translators were often unavailable or poorly trained. Similarly, Caucasian CCS felt that in less expensive clinics, where gynecological doctors are also obstetricians, pap tests are less thoroughly conducted and results not carefully reviewed. The Asian American CCS did not perceive any barriers and/or discriminatory treatment in accessing care, even those who were uninsured.

Stress and the psychological effect of cervical cancer—Competing demands (work, household chores, finances, commitment to family and children) placed considerable stress on the women. The African American survivors’ experiences included:

> Kids, taking the kids to school, taking care of things for me and the kids, and not having enough time to sleep. It’s very hard to manage day to day. The cervical dysplasia has affected my life because I am in a lot of pain.
>
> I want to get my medical situation dealt with which has added to my overall stress. I also stress about budgeting.

One Asian self-professed ‘workaholic’ discussed the difficulties in avoiding insufficient sleep and overwork. A few Asian women related strategies for dealing with stress:

> Talking with my friends, then I will feel better. Talking to my husband and friends will help.

The Latina CCS faced many stressors: becoming incapacitated, being dependent on others, and ultimately unable to care for their children. Depression and anxiety resulting in insomnia were not uncommon. Several ‘felt empty’ after the surgery. Many were plagued with intrusive thoughts about the illness. Several participants discussed efforts to keep things from their families to avoid burdening them. Experiences included:

> I have faith and believe in God. I pray and ask Him to give me health and if it is not possible to cure me, to give me more time—enough to take care of my eleven-year-old daughter who needs me.

> I’m very worried. I don’t want to end up in a wheel chair, depending on someone else. I have a handicapped son who totally depends on me and my mother lives with me and if something happens to me, who will care for them? Most of the nights I’m sleepless and often cry alone. I don’t want my family to know how I really feel and keep my feelings to myself but it’s hard to maintain the calm, it is very stressful for me.

The Caucasian CCS discussed the possible role of stress in cancer and/or recurrence. However, some found it hard to live less stressfully. On the other hand, several mentioned positive changes as a result of CCA. One Caucasian explained:

> It made me stronger. My goals and priorities changed, I want to ‘give back’ to society.

A few felt lucky that they survived, and that losing their uterus is a small price to pay.

Neighborhood stress—Many African American, Caucasian and Asian American CCS did not consider their neighborhood a source of stress. However, a number of Latinas and a few of the African American and Asian American CCS voiced dissatisfaction with neighborhood quality and safety. Some Asian survivors were concerned about possible carcinogenic effects of pollution. With few exceptions, most Latina CCS were concerned about neighbors’ perceptions of them after the illness. They feared shame and embarrassment, as well as social isolation.

Employment issues—In general, Latinas were uncomfortable disclosing private matters to coworkers/supervisors, concerned about being unable to perform job duties, and feared losing their jobs and being unable to provide for their families. Most African Americans did not disclose the illness to their supervisors; most did not believe that their employers would be supportive. One African American woman had to stand up for herself in front of her supervisor:

> An insensitive supervisor didn’t want to give me the day off but I knew the law and she gave me the day off.

Similarly, most Asian Americans did not disclose the illness to their employer/supervisor. Of those who did, none reported receiving support. However, several indicated that disclosing the illness to co-workers was helpful. One Chinese survivor mentioned:

> Discussions with coworkers helped a lot because they may know somebody who had the same thing and can tell you what to do, what to expect, and how to deal with it. Among 2 or 3 of us, we talk it out. If their friends share the same illness, they will share what they know. They can give us comfort.

One Caucasian CCS reported that she was forced to retire early. Others reported having to reduce work during surgery and recovery period. Several Asian and Caucasian women felt that co-workers treated them as if they were now more fragile and limited in their abilities. Overall, none of the women reported being discriminated against as a result of their illness. However, a few Latina participants were uncertain how such discrimination would be recognized.

Most important concerns—Many women experienced depression due to worry about the illness, social isolation, and lack of physical activity. Other concerns included fear of passing CCA to daughters and treatment-related side effects (hair loss, pain, fatigue, and urinary incontinence). African Americans were concerned about preventing recurrence, available treatment options, and staying healthier overall as well as financial situation, family responsibilities, and emotional well-being. Some Chinese CCS related concerns about lack of finances, particularly feeling shame in having to ask for assistance:

> I will be more secure if I have more money. Because I'm not working, I have to ask my husband for money…But he makes a big fuss. I feel bad for myself.

The Latina CCS were most concerned about their family's health and emotional well-being, followed by their own health and financial problems.

Summary of focus group findings

Among all women, family support, spirituality, and quality of medical care were very important to recovery and coping; however Caucasian women stressed the importance of the relationship with medical staff, while African American, Asian American, and Latina women emphasized the salience of spirituality, prayer and family. All women agreed that family support was essential to emotional well-being and treatment adherence. Unfortunately for some African American, Latina, and Caucasian women, families did not provide adequate support.

DISCUSSION

Overall, the CCA diagnosis and its treatments left many survivors with moderate to poor HRQOL and psychosocially burdened. The CCA experience was profoundly shaped by medical characteristics (e.g. stage at diagnosis, treatment, pain) and contextual factors (e.g. cultural and socio-ecological aspects). Findings indicate that cultural and family factors promote coping and well-being, but may foster delay in care seeking and self-deprecation, particularly among Latina and Asian CCS. Women of color in particular, relied on faith and God for comfort, strength and healing; many believed that their faith determines the CCA outcome.

There were common systemic concerns regarding quality of care and delay of health care, particularly for women of color and lower-income women. These survivors experienced tremendous difficulties with access and quality of care; navigating the health care 'Goliath'; inadequate insurance; barriers to good physician-patient relationship, such as language and doctors' time constraints; inadequate knowledge about CCA due to insufficient information from medical staff; and feeling a lack of control over their health care management and treatments.

Additionally, some medical (e.g. illness outcome, recurrence) and physical concerns were reported (e.g. persistent pain, numbness in the abdominal area and leg, bowel and urinary problems). In the functional domain, socioecological issues related to CCA and its treatments were prevalent. These included high cost of treatments, worry about job loss, and worry about financial and overall welfare of the family. Psychosocial issues (e.g. isolation, anxiety, depression, friendship relationships and support), spirituality (e.g. faith, punishment); marital and relational challenges (e.g. fidelity, quality and longevity of relationship); fertility, sexuality (e.g. sexual self-evaluation, desire and enjoyment), womanhood (e.g. self-definition, lacking uterus), body image issues (e.g. desirability, attractiveness) were important and persistent concerns. *These survivors expressed a need for more resources specifically afforable follow-up medical care, research, patient advocacy and support groups.*

CCA affects women across all ethnic groups, however ethnic minority and socio-economically disadvantaged women are disproportionately afflicted. Several risk factors for psychological problems among CCS include lack of social and medical support, younger age, Latina ethnicity, and limited socioeconomic resources.

LIMITATIONS

This study is limited because it draws on retrospective data from a convenient sample. Further, the generalizability of the findings is limited due to the small sample sizes. Additionally, due to snowball and flier recruitment methods, there is no record of the response rate and the characteristics of the non-responders.

In conclusion, there is a dearth of research that targets HRQOL, including psychosocial well-being, with CCS. Cultural and socio-ecological factors have not been adequately studied in cancer control research, and may be particularly pertinent to ethnic minority and low-income populations (Ashing-Giwa, 1999 a, b, manuscript under review). Given growing incidence rates in some geographic areas and increasing evidence of negative psychosocial sequelae of CCA and its treatments, it is imperative that further studies are conducted with larger, more diverse samples. Research designs should include qualitative and quantitative methods to access valuable cultural and contextual information regarding the survivorship experience. Oversampling of ethnic minority CCS is essential given higher incidence rates and possibly greater psychological distress.

The findings reflect persistent concerns in the physical and psychosocial domains presented in the literature with Caucasian women. However, the results document even greater physical and psychosocial challenges for lower income and Latina CCS. The burden of socio-ecological stress further exacerbates poor HRQOL outcomes. Moreover, these survivors reported health-care system problems that resulted in negative treatment sequelae, some of which could be avoided. The CCS and the key informants highlighted the need for health professionals to better explain procedures related to diagnosis and treatment of CCA. Enhanced communication will increase understanding, trust and adherence. Information about CCA and HRQOL is urgently needed in Spanish and Asian languages. Media, including the African American media, can be an effective medium to spread awareness and understanding of CCA and its treatments, particularly for younger women. The findings from this exploratory study highlight the pressing need for more research on the HRQOL of diverse populations of CCS. The results can inform future investigations on HRQOL, psychosocial burden and health disparities among CCS. There should be a marked increase in the attention paid to CCA because ‘reducing cancer-related health disparities’ and increasing quality of cancer care are central to the National Cancer Institute’s (NCI) mission (NCI, 2002). In conducting this study, the stories of many remarkable, resilient women with CCA were brought to light.

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APPENDIX

See the Appendix Table in the Figures and Tables section.

Table 1

Key informant interview domains

Impact of cervical cancer
Factors affecting the experience
Role of culture
Socio-ecological factors
Barriers to health care
Barriers to psychosocial care
Healthcare system factors
Patient-physician relationship
Medical adherence to CCA treatment
Actions needed to address concerns

Table 2

Focus group interview domains

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

Table 3

Focus group demographics

	African American *N*=10	**Asian American *N*=10**	**Caucasian *N*=5**	**Latina *N*=26**
Current age (years)				
Mean (range)	33 (22–57)	48 (35–60)	56 (45–73)	47 (36–66)
Marital status				
Single	60%	10%	20%	30%
Married	20%	90%	40%	48%
Divorced	0%	0%	20%	9%
Widowed	20%	0%	20%	13%
Number of children				
Mean (range)	1 (0–3)	1 (0–3)	3 (2–3)	5 (1–10)
Years since Dx				
Mean (range)	<1 (0–1)	2 (1–9)	5 (1–9)	2 (0–10)
Stage				
Dysplasia				
CIN 1	0%	10%	0%	8%
CIN 2	0%	10%	0%	13%
CIN 3	0%	30%	0%	0%
CIN unspecified	100%			
Cancer				
I	0%	0%	20%	4%
II	0%	10%	40%	8%
III	0%	0%	20%	17%
IV	0%	10%	0%	13%
Unknown	0%	30%	0%	38%
Treatment[a]				
Surgery	0%	50%	80%	50%
Radiation	0%	20%	80%	38%
Chemotherapy	0%	0%	0%	54%
Hormone	0%	20%	0%	8%
Biopsy only	60%	0%	0%	0%
Not specified/ Don't know	40%	20%	0%	21%
Obtained second opinion				
Yes	20%	30%	60%	38%
No	80%	70%	40%	62%

[a] Respondents may report more than one treatment.

Appendix Table

MAJOR THEMES FROM CONTENT ANALYSIS OF FOCUS GROUPS WITH AFRICAN AMERICAN, ASIAN, CAUCASIAN, AND LATINA WOMEN

	African American (N=10)	**Asian American (N=10)**	**Caucasian (N=5)**	**Latina (N=26)**
Health Beliefs: Factors Helping Recovery and Coping	• *Self-awareness*: Be aware of changes in body • *Prompt medical attention:* Go to the doctor as soon as you notice a problem	• *Adherence*: Obey doctors' directions re: treatment • Check health every 3 months	• Keep normal life • Doctor support • Obtain 2nd opinion • *Education* about cancer • Contact with others who have had same illness	• Children: Desire to see children grow up • *Lack of support*: difficult recovery, more depressed • *Positive attitude, faith* • *Surgery*, *treatment* most important to survival
Support from family and friends	• *Family support*: very important, but sometimes keep information to self, don't want sympathy • *Partner support*: one had supportive boyfriend; one husband not fully supportive/ understanding • *Friends*: Share with only few trusted people	• *Family support*: important in coping, recovery • *Spouse support*: one felt husband provided most support, this was most important • *Friends' support*: All felt provided a lot of support	• *Spouse*: keep normalcy in life; kept positive attitude • *Family:* helped keep them going; stayed at hospital, accompanied to appts • *Children*: did chores, cook • *Friends*: helped provide information about cancer • *Mother*: emotional support, cooked meals	• *Family*: helps adherence, recovery; don't feel alone; accompany to dr visits • Concern of worrying family: may delay disclosing illness or problems, reject support • *Spouse*: provide will to survive, emotional stability • *Friends*: able to talk about private issues
Person Most Supportive	• *Mothers*: very supportive; one is a nurse, helps explain medical info • *Boyfriend*: offered to go to doctor's appointments • *Other family*: son, sister, aunt, cousin	• *Husband*: All felt were most supportive • *Mothers*: also very supportive • *Children*: Daughter is a doctor; persuades her to go to doctors' appointments		• *Siblings* • *Friends*: provide emotional support • *Immediate family* • *Husband*: most important; financial support • *Children*
Spirituality, Religion and Illness	• *Prayer*: very important to ask God for assistance • *Religion*: guidance in what to do to prevent and heal illnesses	• Able to tell God when one is in pain • Gain confidence from faith	• *Prayer* gives comfort/peace • *Priest's support* • 2 did not rely on faith or prayers	• *Support, catharsis*: through church; comfort in prayers, reduce fear • *God's will*: fate is up to God, accept His decision

	African American (N=10)	Asian American (N=10)	Caucasian (N=5)	Latina (N=26)
Handling a Major Illness	• *Quarantine until you go to doctor* • Go to the doctor	• *Positive attitude* • Keep peace • *Faith*: Thankful to God • *Husbands' support* most important	• Visualization of healing • *Get best doctor* • Be proactive, not reactive: get 2nd opinion, follow-ups; gives a sense of control • *Positive attitude*	• Get treated • Get stronger • Healthier diet • Be involved in health care • Family support • *Gods' will most important*
Control over Your Body and Illness	• Cleanliness, disinfection • Act quickly to changes • Try to stay healthy, but no total control over illnesses	• Control through diet • Obey doctors' instructions • Keep internal peace • Engage in exercise	• Not much control—healthy diet, exercise, obtain annual pap smears • Information gives control	• Getting treatment • Better hygiene before sex • No control over cancer • Sexual habits, diet
Fears about Cervical Cancer/Dysplasia	• *Distrust doctors*: don't Provide information (prevention); harsh use of instruments • *Recurrence, dying*	• Fear of dysplasia turning into cancer	• Dying, painful death • Recurrence • Fear of the unknown • Isolation	• *Dying*: concern with who will care for loved ones • *Metastasis* • Daughters may get CCA
Health Socialization Childhood Learning About Health; Traditions and Values; Family Sayings	• *Diet*: Eat fruits/ vegetables drink a lot of water • *Exercise* • *Regular doctor's visits* • *Cleanliness*	• Illness unrelated to traditions; don't blame yourself • *Diet*: Fruits/ vegetables helps health; avoid pineapple • *Early treatment*: deal with symptoms before severe • *Personal hygiene*: keep clean, wash hands often		• *No discussion on health*: parents unaware, priority on family activities • Uncomfortable with exam, seek care when problem • *Cause of CCA*: Having kids young, close together • *Myths*: married w/ children, abstinent, not at CCA risk • *Diet*: Avoid cold fruits, lemon during menstruation
Relationship Issues: Intimate Relationship Single	• Loss of sexual interest; fear that sex will worsen condition	• All married	• Not involved in a sexual relationship	• Some men see women with hysterectomy as in-complete • Belief that CCS lack sexual desire

	African American (N=10)	Asian American (N=10)	Caucasian (N=5)	Latina (N=26)
	• Still interested in having sex but no available partner			• Vaginal dryness affects intimate relations • Excuse for men to leave
Intimate Relationship Married	• *No sexual desire*: force self to have sex and wait until he's finished	• None felt illness affected relationship • *Negative effect*: No libido • *Psychological effect*: results in decrease in sex	• *Negative effect*: husband left; difficulties with intimacy • Treatment shrinks vagina, sex painful, lack of desire after removal of ovaries, lack of hormones	• *Positive effect*: stronger relationship • Relieved to not have sex • *Negative effect*: Guilt over inability to have sex • Fear pain during sex • Fear sex worsens illness • Concern husband will leave
Feelings About Her Body	• Feel unclean • Worn out and beaten • One noted no change	• None felt dysplasia affected feelings about their bodies so far	• Feel damaged; scar • Losing fertility like losing a child	• More concerned with effect on sexual relationships, emotional feelings
Quality Of Care Participation in Medical Treatments	• Doctors don't provide information or explain things understandably • Important to ask questions and speak up • Insensitive medical staff	• Depends on the severity. If severe, cannot do much • Just listen to the doctor	• Aggressive participation • *Involvement in health care*: ask questions, find out about side effects, be informed	• *Knowledge*: of illness, consequences increase timely care-seeking • Postponed treatment due to denial, problems with kids • Uncomfortable with exam of private parts: avoid pap test • Screening ineffective • Be aware of changes, seek care, annual exams. • Accept diagnosis
Doctor Recommendations	• *Follow-up* was the only recommendation • Many want more health recommendations	• *Diet*: Drink more water • *Exercise* • Provided with ointment		• *Diet*: Eat healthier • No recommendations, but decided to eat healthier • *Exercise*: increase activity
Followed Doctor's Recommendations	• All the women now come to follow-ups • One avoided follow-ups due to insensitive staff, fear of finding out condition	• All say they follow doctors' recommendations		• 1/3 follow recommendation • 1 ignored diagnosis until more advanced; willing to comply after seeing disabled CCA patients

	African American (N=10)	**Asian American (N=10)**	**Caucasian (N=5)**	**Latina (N=26)**
Support By Doctor	• Didn’t feel much support	• All feel doctors provided support to follow recommendations • Drs did not provide any special help	• Some felt doctor was supportive • One was not informed about lymphodema and preventative care	• Some felt doctor did not provide support, esp. those seen by different doctors • A few received support • None knew about support groups prior to focus group
Relationship With Doctor	• Doctors are nice but don’t explain test results • One noted that doctors need to be more gentle with instruments	• All feel relationship with their doctors is good • Doctors show that they care • Feel comfortable with their doctors	• Some have good relationship with doctor • Some felt that their doctors did not give complete exam – tumor not detected early, no follow-up for abnormal	• *Concern over continuity, quality of care*: 1/3 see different doctor each time • Embarrassed to ask questions during exams • *Time concerns*: insufficient time with doctor; long wait • *Language barriers* • With Spanish-speaking Dr: able to ask questions, understand treatment; more optimistic, compliant
Felt Treated Differently; Discrimination	• One noted being passed over in a clinic where staff, clients were Latino	• None felt discriminated against • Doctors provided good care even though uninsured		• None felt treated differently or discriminated against
SES: Factors Affecting Quality of Treatment	• *Low income/ uninsured*: Poorer quality of treatment at clinics	• None felt financial status, educational level or insurance status affected quality of treatment	• *Time concerns*: gyn drs who are also obstetricians do not spend a lot of time performing pap test	• *Doctor competency* • *Lack of continuity of care*: patient insecurity • *Language barriers*: translator inadequate • *Access to care*: long wait creates stress, poor out-comes; lack of childcare, transportation results in treatment postponement • *Finances*: delay in obtaining care if can’t afford
Socio-Ecological Factors: Overall Stress; Effect on Overall Life	• *Caring for children*: lack of time for self • *Fear* of medical condition • *Pain*: dysplasia made life more difficult	• *Reduce stress* by talking to others • Several felt housekeeping stressful, boring and tiring	• *Stress*: possible cause of cancer, may cause recurrence, but stress is hard to reduce	• *Recurrence-related stress* • *Worry over family*: being unable to care for children

	African American (N=10)	**Asian American (N=10)**	**Caucasian (N=5)**	**Latina (N=26)**
	(intense pain); one told to lose weight but no diet has been effective	• Work and life cause stress • Those with dysplasia: no effect on life yet	• *Change in priorities*: in goals, desire to ‘give back’ • Became stronger person • Feel lucky – losing uterus is small price to pay • Treatment side effects – painful to walk, intestinal problems	• *Fear of incapacitation* • Hard to manage without support system • Feel empty after surgery. • *Keeping illness private*: difficult to do with hair loss • *Depression*: hide problems to avoid worrying family • Keep busy with chores to avoid thinking about illness
Neighborhood Stress	• No effect on stress level	• No effect on illness • Violence on TV, neighborhood thefts, but not worried about safety • Neighborhood quality good • Concern about pollution causing cancer	• No concerns	• *Concerned with others’ perceptions*: stressed, depressed, ashamed: don’t want neighbors to know about illness or to gossip • Unsatisfied with safety of neighborhood for children • A few not concerned
Supervisor Co-Worker Support	• One is a homemaker, has little energy for housework • Two did not work • One had difficulty with supervisor not allowing her to go to appointment until told it was the law	• Most did not disclose illness to employers • One told supervisor, coworkers: not much support • Disclosure helpful if going through same experience or for advice on treatments	• Coworkers worry, treat differently – think she will get sick again, not as strong, they ‘mother’ her	• 2 disclosed, received support from employer, job available after recovery • Co-workers gave money • 2 laid off due to illness: time missed for treatment, appts • 2 not working at diagnosis
Doing Same Work	• Doing same work	• All are doing same work	• Had to retire early • Cut down on work during surgery, recovery period	• None currently working due to treatment, difficulty in getting job, or being a caregiver for ill husband
Concerns about Maintaining Job	• No concerns	• No concerns or effects on job due to the dysplasia	• No concerns	• Most have no concerns • One worried about lack of income, financial problems
Employment Discrimination	• No employment discrimination	• No discrimination, they have not had the illness for very long yet		• Don’t know how to identify discrimination • None felt discrimination

	African American (N=10)	Asian American (N=10)	Caucasian (N=5)	Latina (N=26)
Other Issues	• No additional issues	• Concerns about hormone treatment: worry about side-effects		• Concern about CCA heredity
Most Important Concerns	• Prevention; how to keep from coming back • Treatment options • Staying healthy • Family • Mental, physical, emotional health • Economics	• Finances: lack of money, ashamed to ask for help • Inactivity: causes depression if isolated at home • Exercise: to improve life expectancy • Diet: avoid 'poisonous' foods; drink more water; eat healthier; worry about diet being cause of dysplasia • Health		• Children, family health and well-being • Health, side effects of treatment • Financial concerns • Diet • Insurance • Hair loss • Family knowing about the disease • CCA being hereditary
How Felt At Conclusion	• Concerned about coming, fear of being judged; but felt understood and not alone at conclusion.	• All felt fine, peaceful		• Feel good, better after talking, impressed with the questions asked, they have never thought about