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Knowledge, Attitudes, and Beliefs of Arab-American Women Regarding Inherited Cancer Risk

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Abstract

The increasing incidence of breast cancer in the Arab world, coupled with a relatively early age of onset, raises concern for the presence of hereditary risk factors in this population. However, due to potential structural and cultural barriers, Arab Americans make up the smallest percentage of individuals tested for Hereditary Breast and Ovarian Cancer Syndrome in the United States. The objectives of this qualitative pilot focus group of 13 Arab-American women were to explore attitudes, knowledge and beliefs regarding hereditary breast cancer in the Arab-American community in metropolitan Detroit, identify barriers that would prevent women from seeking hereditary cancer screening/testing and determine who women would talk to about inherited cancer. Results indicated that cultural beliefs and personal experiences with cancer influenced the women's perspectives on hereditary cancer risk. A high level of secrecy about cancer within Arab-American families was present, which may prevent accurate risk assessment and referral for genetic services. Other identified barriers that may influence hereditary risk assessment included stigma, fears and misconceptions of cancer. While these barriers were present, participants also expressed a strong need for education and tailored cancer risk information for their community.

Keywords

Arab-American; Hereditary breast cancer; Cancer risk; Cancer screening; Genetic counseling

Introduction and Background

Breast cancer incidence is increasing in women throughout the Arab world (El Saghir et al. 2007). In 2012, there are expected to be an estimated 229,060 new cases of breast cancer in the US, with approximately 5 % of these cancers attributed to inherited mutations (American Cancer Society 2012). However, Arab-American women are an understudied group with a lack of population-based reported data on breast cancer incidence and mortality rates among Arab women in the United States (Darwish-Yassine and Wing 2005). This may be attributed to individuals of Middle Eastern descent being categorized as white without a separate ethnic category in population-based registries or that some women may not seek treatment in the US and instead choose to return to their home country. In Metropolitan Detroit, home to a large concentration of Arab Americans, researchers created an Arab/Chaldean surname list and matched it to the names in the Metropolitan Detroit SEER registry (Schwartz et al. 2004). In their study of self-reported cancer cases in 3,531 Arab-American women, breast cancer was the most commonly reported cancer. Information also indicates that Arab-American women are more likely than white women to develop breast cancer at less than 50 years of age (Do et al. 2000), and have a younger average age of diagnosis than White and African-American women (Alford et al. 2009), although these comparisons are complicated by the fact that elderly Arab-American women are less likely to obtain mammograms than their younger counterparts, and thus may be underrepresented in these studies (Darwish-Yassine and Wing 2005).

Studies of breast cancer trends in Israel have also shown that the incidence of breast cancer in the Arab population is often underreported (Cohen and Azaiza 2005; Nissan et al. 2004), that 49 % of Arab-Israeli women diagnosed with breast cancer were less than 50 years (El Saghir et al. 2005), and had more advanced disease at diagnosis and a lower 5-year and disease-free survival than Jewish-Israeli women (El Saghir et al. 2005; Nissan et al. 2004; Tarabeia et al. 2007). While having an affected first-degree relative is generally considered a risk factor for breast cancer, research has reported that the relative risk of breast cancer was higher among Arab-Israeli women if they had an affected first-degree relative than for American women (Aghassi-Ippen et al. 2002; Slattery and Kerber 1993). These findings suggest that family history of breast cancer has an important impact on the risk of breast cancer among Arab women, and also suggest that it is important to consider the possibility of hereditary disease such as Hereditary Breast and Ovarian Cancer Syndrome (HBOCS) among Arab women with a strong family history of breast and ovarian cancer (Ford et al. 1994; Ford et al. 1998).

Given the relatively early age at diagnosis and later stages at presentation, the Arab-American population is a group that is in need of breast cancer risk assessment and screening for hereditary breast cancer by health care providers. However, despite these identified risks, Arab Americans make up the smallest percentage of individuals tested for HBOCS in the United States (1.1 % of all individuals tested from 1996 to 2006) (Frank et al. 2002; Hall et al. 2009). The low use of genetic testing in the Arab American population is likely due to structural and cultural barriers that reduce access to preventative healthcare. Relevant structural barriers to breast cancer screening include a lower level of income, lack of health insurance, language barriers, and lack of reliable transportation (Meleis and Hattar-Pollara 1995). Cultural barriers to screening include the fear and stigma associated with cancer, fatalistic religious beliefs, misconceptions about genetic inheritance, fears of being stereotyped by healthcare providers, and concerns about modesty, which may prevent women from discussing sensitive topics such as breast health or undergoing examination by male physicians (Al-Gazali 2005; Azaiza and Cohen 2008; Banning et al. 2009; Baron-Epel et al. 2004; Meleis and Hattar-Pollara 1995; Saleem et al. 1998; Shah et al. 2008; Underwood et al. 1999).

Obtaining an accurate family history is another barrier to effective HBOCS screening since minority immigrants such as Arab Americans are more likely to report inaccurate family histories, leading healthcare providers to underestimate their hereditary cancer risk and not refer them for genetic counseling (Orom et al. 2008). In the Arab population, family members may keep a diagnosis of cancer secret from the affected person (Younge et al. 1997), further compounding the difficulty in obtaining an accurate family history.

In summary, there is a need for increased breast cancer risk assessment and appropriate genetic counseling in the Arab-American population. Research on genetic counseling in this population has focused predominantly on patients receiving preconception, prenatal, or pediatric genetic services; however, to date, no research that we are aware of has been conducted on genetic risk assessment and counseling for HBOCS. The purpose of the present qualitative pilot study was to explore attitudes, knowledge and beliefs regarding hereditary breast cancer in the Arab-American community in metropolitan Detroit and barriers that would prevent women from seeking information about inherited cancer risk. A secondary purpose was to discover which individuals, either family or other individuals in their support network, women would talk to about inherited cancer.

Methods

This pilot study was part of a larger community-based educational project to increase the knowledge and awareness of hereditary breast cancer risk in the low income Arab-American community in southeastern Michigan. Additionally, the larger project's purpose was to reduce the barriers of access through providing breast cancer risk assessment and cancer genetic counseling services for at-risk individuals. The qualitative focus group was the first stage in identifying the attitudes, knowledge and beliefs of this population to develop culturally-appropriate hereditary cancer risk materials and interventions that addressed risk, inclusion of family members and available surveillance options.

Sample

The focus group participants were recruited from an existing southeastern Michigan breast cancer outreach project at an Arab-American community center using a convenience sampling method. Women were recruited by a trusted outreach worker at the center. Potential participants were told the purpose of the group was to gather information about knowledge, beliefs, and attitudes of genetic breast cancer risk in the Arab-American community to use in developing educational materials about breast cancer risk. Arab-American women were recruited who met the following criteria: (1) 18 years or older, (2) a personal or family history of cancer, (3) ability to speak English, and (4) ability to provide written informed consent to participate in the focus group. No restrictions were placed with family members attending the focus group. Eighteen women were invited to participate in the focus group.

Measures

Sociodemographic Factors—Information was obtained through a researcher-developed questionnaire administered at the time of the focus group and included information on age, country of origin, time in the United States, religion, marital status, education, employment, income, health insurance status, family history of cancer and personal history of cancer.

Beliefs, Knowledge and Attitudes—A semi-structured interview guide with open-ended questions was utilized to conduct the focus group (Table 1). Open-ended questions explored the women's personal experiences with cancer, beliefs about cancer, knowledge about hereditary cancer, how and with whom they speak to about cancer and who they

would like to include in discussions about hereditary cancer (i.e. family, friends). During the focus group, participants were asked initially about their experience of cancer in their family and what the words “genetics” and “inherited cancer risk” meant to them. A genetic counselor then provided general information describing hereditary breast and ovarian cancer prior to participants’ being asked specific questions pertaining to hereditary breast cancer and what it meant to them and their family.

Procedure

Investigational review board (IRB) approval was obtained from Wayne State University Human Investigation Committee prior to the initiation of the focus group. Preceding the focus group, each participant was asked to complete written informed consent and a demographic and cancer medical history questionnaire. The two-hour focus group was tape-recorded and was co-led by a member of the Arab-American community who had experience in focus group methodology and the Principal Investigator, a cancer nurse researcher. Each participant received \$25 for her time.

Data Analysis

Descriptive statistics were used to report the demographics and cancer history of the sample. All focus group tapes were transcribed and entered into *QSR NVivo* qualitative software (QSR NVivo 2002). Focus group transcripts were analyzed to identify themes pertaining to beliefs, knowledge, and attitudes regarding hereditary breast cancer using content analysis and following guidelines of data coding, reduction, display, and conclusion drawing (Miles and Huberman 1994). Procedures for establishing trustworthiness of the data were done according to established qualitative analytic criteria (Lincoln and Guba 1985; Miles and Huberman 1994). Two investigators coded the data independently and compared results to ensure reliability in coding and analysis throughout the entire analysis phase.

Results

Sample Characteristics

The focus group consisted of a select group of 13 women originating from Lebanon ($n=11$), Syria ($n=1$) and Iraq ($n=1$), 12 of whom described themselves as Muslim and one as “other.” Age ranges were between 19 and 58 years (median 42 years). The participants included a mix of Arab Americans and new immigrants from Arab countries with the amount of time residing in the United States between 5 months and 27 years (median 17 years). All were personally impacted by cancer, including three with a personal history of breast cancer, and 11 with a family history of either breast or ovarian cancer. Affected relatives within the family histories included mothers, grandmothers, and aunts with breast or ovarian cancer and cousins with breast cancer. The entire group was fairly well educated with either a high school diploma alone ($n=4$), college degree ($n=7$), or post-college degree ($n=2$). Eleven women were employed outside the home with nine having some form of health insurance and an annual household income ($N=9$) below \$50,000. Marital status varied in the group which was comprised of married ($n=7$), divorced ($n=2$), single ($n=2$) and unspecified ($n=2$). At the time of the focus group, three women indicated they had prior experience with genetic services for cancer.

Themes

The results of the focus group analysis revealed four major thematic categories: cultural knowledge, feelings and beliefs about cancer, communication patterns, influence of the family, and experience with the healthcare system and community. These categories and sub-themes are summarized in Table 2.

Cultural Knowledge, Feelings and Beliefs about Cancer—The first major thematic area included six subthemes.

Cancer as a Shame and Stigma: Several women expressed the belief that a cancer diagnosis can reflect negatively on the family of an affected individual, particularly females. In many cases, this concern led individuals to keep their cancer diagnosis a secret or avoid seeking medical attention when symptoms of cancer were suspected. One woman described how her mother deferred treatment because she was afraid of how her cancer diagnosis would affect her daughters:

My mom was diagnosed with cancer. She was a single mother. She raised me and my sister. She was bleeding. Silently she didn't tell anybody why I am bleeding, or go to the doctor to check. It was like a shame to go to the doctor. She kept quiet over 1 year. Her abdomen was swelling. I still remember, during the night, she used to pray to God to help her relieve her pain. During the day she tried her best to act normal, nothing was happening. First to protect us and second because cancer is like a stigma, like a shame somebody getting it. Oh, maybe she's gonna spread it to her daughters.

Beliefs Regarding Causes of Cancer: Women held different beliefs about the causes of cancer, with some attributing the disease to diet, stress, and other environmental factors. A few of the participants believed that heredity was also a contributing factor, including one woman who had undergone genetic testing for HBOCS. However, there were women who rejected the idea that genes could contribute to cancer risk in light of a negative family history of cancer:

It's not only inherited, because there are some cases or many cases that she was dead and they don't have cases in their family. I feel like the food they are taking, the pressure we are having is that what make cancer...I do not have anybody in my family had breast cancer, and I had it. I was 40 when I got it. So, it's not about inheritance.

Myths and Misconceptions: Participants voiced concern about the lack of cancer knowledge and awareness in the FVArab community. Myths and misconceptions about the disease were also discussed, and included beliefs that cancer is contagious, undergoing an operation can cause the cancer to spread, and cancer is a death sentence. In addition, lack of cancer awareness caused several of the participants to react with shock and fear when they, or a member of their family, developed the disease. One woman described her experience as a teenager when she learned that her mother had been diagnosed with cancer:

When I knew it was cancer I was shocked. Why cancer? What is happening? Why is it happening to her, because that disease can happen to anybody but not to us. There is no knowledge about it. There is no education about it. No self awareness. Nothing to check ourselves or any preventive knowledge about it.

Cancer as a Test from God: Some of the participants identified that in the Arab-American community, cancer is perceived as being sent from God. According to one woman, it [cancer] *"is considered sometimes something different or a test from God. Like God is testing your faith."*

Fear of Cancer Treatment: For many of the women, the treatment of cancer was considered even more frightening than the disease itself. One cancer survivor shared, *"You know that cancer is not scary. The treatment of the cancer is scary. You are [a] fighter, and*

then within one shot of chemo you are down, you can't stand up, you can't do anything. This is what is really scary. "

Accepting and Being Strong in Surviving Cancer: Many of the participants mentioned the importance of emotional fortitude, believing that one's emotions will affect the outcome of the disease. Those individuals who are strong and accept the cancer, rather than denying its existence, were perceived as being better equipped to fight the disease, and more likely to survive it.

Communication Patterns About Cancer—Predominant in the discussion of communication patterns was the concept of keeping cancer a secret, either to avoid the shame and stigma associated with the disease, or to protect family members from experiencing emotional distress due to the diagnosis.

Cancer as the Most Kept Secret: The most prevalent sub-theme was the secrecy present among this population to hide cancer from family and the external community. A majority of the participants recounted how family members' cancer diagnoses had been hidden from them. Several of the cancer survivors admitted to hiding their diagnosis from their own families, especially their children. One participant described how she hid her illness:

I had cancer 2 years ago. I didn't expect to have cancer. It was a new experience to me. But I didn't let any of my family know...I didn't tell any of my children that I have cancer...So, I went by myself to the hospital. I told my kids that I have [a] friend in Canada, I want to visit him. Then, when I had to make the chemo for four sessions and took some radiation. I cut my hair too short. I wasn't wearing the hijab at that time. I put [on] a wig before that. I wanted to know how to deal with my children. So, I cut my hair in ugly way and that I said I want to wear a wig [for a] long time until I get the better look. They accepted me. I took the chemo by myself...It was a very bad experience because I lost my hair; nobody at home knew what I was going through. Everybody said that I look pale, I look different in a certain way, but nobody knew what I was doing.

Keeping Cancer a Secret from the Patient: Women described instances where a diagnosis was kept hidden from the patients themselves, particularly in their native countries. In these cases, hiding the truth appeared to be motivated by the family's desire to protect the patient from emotional distress, rather than concern for the shame or stigma associated with the diagnosis. One woman mentioned how her cousin was never made aware of her own diagnosis, *"My cousin, the one with ovarian cancer, she died without knowing she had cancer. It is hush hush. The family members [know] but the patients would not know. "* Another participant described how a friend's children kept his cancer diagnosis a secret from him:

In my country home, Lebanon, sometimes they don't even tell even to the patient that they have cancer. I have a neighbor who had cancer. He was an old man. His kids knew that he had cancer, and they were treating him and everything. How he found out? Once he went to the pharmacy to get the prescription himself. Then he told the pharmacist, 'Can you tell me who is taking this medicine?' The pharmacist told him that it was obvious. It's for cancer patients. So, that's how he found out that he had cancer. Emotionally he was so depressed, which didn't help him at all. He died after a short period of time. I know so many stories like that. They died without knowing.

Influence of the Family—A third thematic category was the influence of the family, which included two sub-themes.

Worry for Children: The majority of the participants stated that their greatest concern was how their personal or family history of cancer would affect their children. Cancer survivors in the group expressed concern that their daughters could one day develop cancer. Another worry for the cancer survivors was how their diagnosis would affect their children's emotional wellbeing. One woman felt that the best way to protect her daughter's emotions was to defer telling her until she was old enough to learn about her mother's cancer:

Everybody knows that I have cancer and I passed through it until the only one that doesn't know that I have cancer is my daughter. She is 14 years old. I am afraid to tell her that I had cancer because she will not believe that I am gonna survive. I am waiting two more or three more years to tell her about it.

Receiving Support from Family: Many of the women emphasized the importance of having support from family members, especially husbands, after a cancer diagnosis. One participant described how supportive her family had been when her cousin was going through cancer treatment:

Now, she is doing chemotherapy. Her hair fell [out]. Because she was so afraid my aunt cut her [own] hair short so that to support her and tell her that, 'We are like you. We are all in this situation together.'

Experience with the Healthcare System and Community—The fourth thematic category included three sub-themes.

Barriers to Screening: Women mentioned structural barriers when obtaining cancer screening and genetic testing, which included cost of testing, lack of health insurance, illiteracy, scheduling difficulties, and difficulty navigating the American healthcare system. Concerns relating to the importance of female modesty were also identified as a cultural barrier, which could prevent women in their community from seeking cancer screening and treatment, “ *With single girls in our countries, too. If they have female problems they can't be checked by doctors because they are virgins. Right? So deal with that, doctor. How you are gonna figure out if she has ovarian cancer or not...?*”

Interactions with Healthcare Providers: Some participants mentioned instances where they received support from primary care physicians or hospital support groups. However, other attempts to provide the women with support were unsuccessful. One woman relayed an experience when a hospital chaplain was sent to visit her prior to her cancer surgery, causing her significant distress because it raised fears that she would not survive the procedure.

Education as Empowerment: When asked what the participants thought could be done to help the community in raising awareness about cancer and inherited cancer risk, many of the woman in the focus group emphasized that more education would empower their community to fight cancer. The participants listed several methods they believed would be useful in spreading awareness about cancer, including support groups, presentations to the community, written materials, videos, and television commercials. Several women also mentioned the importance of getting friends and family members involved in the discussion.

Discussion

The results of this pilot qualitative study revealed several important findings for the Arab-American population in regards to genetic risk assessment and counseling for possible hereditary breast-ovarian cancer. It is evident that several cultural barriers exist for this population which may affect whether they actively seek genetic counseling or testing. These findings support the importance of designing outreach and intervention programs in the community to facilitate appropriate cancer risk surveillance and cancer genetic counseling that are tailored to this population and their cultural beliefs and attitudes.

One of the key findings of this study was the high level of secrecy in communication about cancer within families. Although previous research has indicated that secrecy in communicating about cancer is present in this population (Azaiza and Cohen 2008; Banning et al. 2009), this pilot study extends this finding and highlights the strongly held beliefs and secrecy that may affect the Arab-American population in keeping critical breast cancer risk information from immediate family members, extended family, and the community. Women in our focus group indicated that some individuals in their community may be frightened by the possibility that other people outside of their family may learn that there is cancer in the family. A major concern that was voiced is that knowledge of cancer in the family could result in their daughters being unmarriedable, which could further contribute to secrecy about cancer in the community, findings also supported in previous research (Azaiza and Cohen 2008; Banning et al. 2009; Baron-Epel et al. 2004).

With the level of secrecy apparent in this population in not disclosing a cancer diagnosis, the ability to obtain an accurate family cancer history is affected and has ramifications for primary care providers in assessing an individual's family history. An inaccurate family history could prevent physicians from identifying and referring high-risk patients for genetic counseling, and may also prevent the patient from receiving accurate cancer risk assessment, since this assessment often relies on the patient's reported family history. There may be a need for genetic counselors to develop communication tools which would facilitate discussion of cancer diagnoses within Arab-American families, leading to greater open communication among relatives, and subsequently overcoming the barrier of not having an accurate family history to determine hereditary cancer risk. Such culturally sensitive tools could also be helpful in the distribution of risk information among family members if a genetic risk factor, such as a deleterious *BRCA1* or *BRCA2* mutation, is identified.

Another finding in this study with significant implications for genetic counseling was the fact that these women were concerned with how their children would be affected by cancer, and dealt with this concern in different ways. Several of the women went to great lengths to keep their own cancer diagnoses secret from their children in order to protect them. No research to date has been conducted on how Arab women communicate about their cancer diagnoses with their children. However, other studies conducted on HBOCS families have demonstrated that, as with our study participants, parents are often torn between the fear of causing their children emotional harm and the desire to inform them of their hereditary cancer risk; the focus is often on daughters, with sons being excluded because they are perceived to be less at risk (Forrest et al. 2003; Kenen et al. 2004; Mellon et al. 2006). Genetic counselors need to be cognizant of the possibility that an Arab-American patient who has been identified with a mutation may not share the finding with her children. The genetic counselor should explore whether this is an issue for the client and offer several options as to how communication with children can occur and at what age it should occur.

Other implications for genetic counseling and testing emerged when the participants in this study shared their beliefs regarding cancer and its causes. While they cited diet, stress, and

God's will as contributing factors to the development of cancer, most did not mention hereditary causes. In addition, the women in our study said that there are many myths influenced by folklore in the community regarding cancer, including beliefs that it is contagious and that operating on a tumor can cause it to spread. The general lack of knowledge and awareness about the genetic contribution to diseases may lead them to reject the idea that inherited factors are related to cancer risk, further reducing their likelihood of pursuing hereditary risk assessment.

Additionally, in this focus group, misconceptions and the stigma of cancer seem to have resulted in a prevalent fear of cancer in the Arab-American community, where cancer is often perceived to be a death sentence. This fear of cancer has been found as a recurring theme in research on Arab women's perceptions of breast cancer, and has been cited as one of the most significant barriers Arab women face with following through with cancer screening (Banning et al. 2009; Baron-Epel et al. 2004; Bener et al. 2001). The fear and degree of stigma associated with cancer in this population may extend to concerns women may have regarding cancer genetic counseling or testing and is a significant obstacle that healthcare providers and outreach programs need to address if they are to successfully increase the number of Arab individuals who obtain hereditary cancer risk assessment.

A secondary purpose of this pilot study was to determine who women would talk with regarding cancer and inherited risk. There was a positive response from the women who participated in the focus group to include multiple family members in discussion of cancer risk.

Women in our study were primarily focused on communicating with and educating their daughters about hereditary breast cancer and cancer prevention. Few women mentioned having such discussions with their sons, although their sons would also be at increased risk for certain cancers if they were found to have a *BRCA1* or *BRCA2* mutation. Women in our study were also open about the importance of communicating with their husbands about cancer and inherited risk. Previous research on Arab women with breast cancer have found that support from the husband is particularly valued (Azaiza and Cohen 2008), a finding also supported in this study where husbands were identified as a main source of support and were involved in various aspects of medical decision making, including genetic testing for one participant. Genetic counselors may want to utilize the husband as a resource in family communication, especially for reaching out to at-risk sons.

Many of the women in the focus group expressed concern over the lack of cancer knowledge and awareness in the Arab-American community. The participants suggested multiple methods for educating the community, including focus groups, brochures, videos, bilingual materials, and television advertisements. These findings suggest the need for targeted cancer education to increase the awareness of available genetic counseling/testing for the Arab-American community. Genetic counselors can and should be instrumental in providing such educational tools. In the educational portion of our program, we developed a tailored bilingual brochure which incorporated the social and cultural barriers that Arab-Americans face when discussing cancer. First, to address the secrecy, fears and misconceptions of cancer, the brochure emphasized that cancer can be a treatable disease when detected early, and incorporating genetic counseling and testing for families with strong family histories can help in the prevention of cancer for themselves and their family members. Second, it provided information about the importance of family history, how to talk with family members about cancer, and why an accurate family history is important for genetic counseling. Lastly, it briefly discussed genetic testing and options for high-risk families. Similar visual aids and learning tools tailored to the patient's culture have been successfully implemented with African-American women receiving cancer genetic counseling (Baty et

al. 2003; Charles et al. 2006), and such methods may help improve Arab women's understanding as well.

Limitations and Future Research Implications

There are several limitations to consider from this pilot qualitative study and implications for future research. Limitations include the small sample size, the convenience sampling method and self-selection into the study. Another limitation was that some of the women attended with their family member which may have affected their responses, and the size of the group ($N=13$) may additionally have inhibited some participation and heightened concerns about confidentiality. Another limitation is that this pilot study of only one focus group included English-speaking Arab-American women with most of the women from one country (Lebanon). Further research is needed with more focus groups to examine a broader population of Arab Americans and their attitudes and beliefs regarding inherited cancer risk information and to include more family members, inclusive of husbands. As more women in this population receive genetic counseling and subsequently genetic testing, it will be important to ascertain how women and their families cope with and communicate these test results to the rest of their families, especially husbands and children. Developing tailored educational programs in the community for the Arab-American population will be critical to assist individuals in discussing their family's specific inherited cancer risk and addressing concerns and beliefs held within their families.

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Table 1**Focus Group Interview Guide**

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1. Tell us a little about your family's experience with breast or ovarian cancer.
 2. What does having cancer in your family mean to you? What are your family's beliefs about breast cancer?
 3. Do you think about cancer in the future for your family? Do you know what should be done if somebody in your family experiences cancer in the future?
 4. What concerns or worries do you have about cancer?
 5. What do you think causes cancer?
 6. What does the word "genetics" mean to you?
 7. What do you think inherited cancer risk means?
 8. Does inherited cancer risk mean something to you and your family?
 9. What do you think your chances (or family members) are to get breast cancer?
 10. What do you do for your health now? (breast self- examination, going to doctor, mammogram). What do you do as preventive measures to lower your cancer risk?
 11. Who would you talk to about breast cancer or about inherited cancer risk?
 12. Would there be anything that would keep you from finding out about genetic or inherited cancer risk?
 13. How would you prefer to learn about inherited cancer risk (i.e., video, written material, one-on-one discussion, group lecture)?
 14. If you were able to speak with someone about a possible inherited cancer risk, who else would you want to join you during the discussion?
 15. This covers the list of specific questions that we have. Is there anything further that you would like to share with us or that would be helpful for us to know?
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Table 2

Major thematic categories and sub-themes

I. Cultural Knowledge, Feelings, and Beliefs about Cancer
Cancer as a shame and stigma
Beliefs regarding causes of cancer
Myths and misconceptions
Cancer as a test from God
Fear of cancer treatment
Accepting and being strong in surviving cancer
II. Communication Patterns about Cancer
Cancer as “the most kept secret”
Keeping cancer a secret from the patient
III. Influence of the Family
Worry for children
Receiving support from family
IV. Experience with the Healthcare System and Community
Barriers to screening
Interactions with healthcare providers
Education as empowerment