



# SOJNR

SOUTHERN ONLINE JOURNAL OF NURSING RESEARCH

**Volume 8 – Number 3**

[www.snrs.org](http://www.snrs.org)

**Perceptions of Cancer Risk, Risk Management and Family Issues:  
Views of Women At Risk for Hereditary Breast Cancer**

Running Title: Perceptions of Hereditary Breast Cancer Risk

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## ABSTRACT

**Objective:** To examine views of early-onset breast cancer survivors at risk for hereditary breast cancer who had not undergone cancer genetic counseling/testing concerning issues related to familial breast cancer.

**Methods:** A qualitative study that included 22 women recruited from a state registry, diagnosed with breast cancer < age 50 years. At-risk status was determined by responses to a questionnaire. In-depth audiotaped interviews addressed participant's beliefs and attitudes regarding the influence of their

personal/family history on breast cancer causation, management, family cancer risk, and family communication.

**Results:** Interviews were transcribed, and content-analyzed. An emergent category system generated multiple categories including: causation; expectations of breast cancer (self); expectations of breast cancer (relatives); cancer detection/prevention; and family communication.

**Conclusions:** This work provides insight into how early-onset breast cancer survivors engage with issues related to familial breast cancer and informs development of educational and genetic counseling strategies for at-risk women.

**Keywords:** family issues, hereditary breast cancer, qualitative research, risk perception, communication

## ***INTRODUCTION***

In the past decade, there has been remarkable growth in the understanding of the molecular basis of hereditary breast cancer. This knowledge has resulted in the availability of DNA testing for several breast cancer-related disorders. For individuals with a personal or family history suspicious for these syndromes, genetic counseling and testing can help to direct future medical interventions and provide valuable information to family members.<sup>1,2</sup> Cancer genetics services have developed to provide risk assessment, counseling, DNA testing, and a discussion of screening and therapeutic options to those at-risk.<sup>3</sup>

Because the ability to assess and test for inherited breast cancer predisposition is relatively new, knowledge is still developing regarding the best ways to inform and educate individuals at potential risk. In particular, information is limited regarding awareness of the impact of personal and family history on breast cancer causation and management among women who have not sought formal cancer genetic risk assessment. Furthermore, additional research is needed concerning how members of at-risk families who have not undergone cancer genetic counseling and testing communicate regarding their family history of cancer. These issues are particularly important for breast cancer-affected women, because information regarding risk for and the management of hereditary breast cancer facilitates genetically informed medical decision-making. Likewise, these issues are important for relatives because of potential shared genetic risk.<sup>1,2</sup>

The goal of this work was to examine the thoughts, beliefs, and attitudes of early-onset breast cancer survivors, at risk for hereditary breast cancer, concerning the impact of their personal and family history on their own disease etiology and future cancer risk as well as their past, present, and future treatment decisions. In addition, this study explored the views of these women regarding the impact of

their personal and family history on their perceptions of cancer risk among relatives and family communication in this regard.

## **MATERIALS AND METHODS**

### ***Design***

This work involved the initial phase of a larger five-year, mixed-methods study, designed to explore the thoughts, beliefs, and attitudes of a diverse population of early-onset breast cancer survivors, from throughout the state of Virginia, regarding hereditary breast cancer. In the component of the study reported here, we used a qualitative approach to examine the views of a subset of these women. The data obtained as a result of this work were used to inform a larger survey-based study of the target population.

The Institutional Review Board at the University of Virginia Health System approved all components of this work. Informed consent was obtained from all participants prior to study.

### ***Study sample***

The study sample was drawn from a cohort of all early-onset (< age 50 years) breast cancer cases among women reported to the Virginia Cancer Registry between 1994 and 1997. These women completed a detailed family history questionnaire that was assessed by a medical oncologist to determine risk for hereditary breast cancer. The questionnaire included items addressing personal and family history, as well as basic demographic information. The criteria used to determine whether a woman was at risk for hereditary breast cancer (Table 1) were based on the published data available at the time of study. A total of 132 women met these criteria and were deemed to be at risk for hereditary breast cancer.

All 132 women were eligible for inclusion in the qualitative portion of the study. We sought to include the most diverse group of women possible for the interviews. Thus, potential participants were identified based on demographic factors to include place of residence (urban/rural), education level, race, ethnicity as well as experiences with cancer (personal and family). A total of 25 women were selected for study.

### ***Interviews***

The women chosen to participate in this study were contacted by telephone and asked to schedule a convenient interview time. All interviews were done by a medical anthropologist and were held at a location convenient to the participant. Often, this was the home of the woman. The interviews were structured to take one to two hours to complete. An interview guide\* was developed to provide

structure to the interviews, without directing the flow or outcome of responses. Sample questions are included in Table 2. All questions were open-ended and asked in a way that enabled the woman to elaborate on topics that were seen as most important to her. Primary topics addressed in each of the interviews included: cancer treatment experiences; disease causation; risk perception; prevention strategies; and family issues. All interviews were audiotaped and transcribed.

### ***Analysis***

The transcripts of three interviews were reviewed independently by two investigators to identify new themes and to develop initial coding for several predetermined categories. This coding scheme was used to develop the initial code book consisting of the title and the definition of each code. Subsequent transcripts were reviewed independently by the investigators to refine codes as necessary. The code book was maintained through this iterative process of transcript review and coding (including sub codes). All transcript data were entered and managed using NUD\*IST software. The two investigators responsible for the analysis maintained separate written notes regarding their coding and analysis impressions throughout the study.

\*Complete interview guide available upon request.

## ***RESULTS***

### ***Description of participants***

A total of 22 women completed the one-on-one interviews in the time allotted for this component of the study. Eighteen were Caucasian, three were African American and one was Native American. The educational level of these women varied; seven had graduated from college or graduate school, thirteen had graduated from high school, and 2 had less than a high school education. The average age of participants was 47 years.

All of the women interviewed were presumed to be at risk for hereditary breast cancer based on their responses to the family history questionnaire. None of these women had undergone cancer genetic counseling or testing at the time of interview.

### ***Categories***

Overall, women's stories went far beyond a straightforward description of their own experiences with breast cancer. Of the many themes present in the interviews, five were most prominent. These were related to women's views regarding the impact of personal and family history on their thoughts related to their own disease etiology and risk management, cancer risk among family

members, and communication about disease risk among relatives. Specifically, these categories, defined in Table 3, included: 1) causation, 2) expectations of breast cancer in self, 3) expectations of breast cancer in family members, 4) risk reduction and disease prevention, and 5) family communication. Three of these categories (causation, risk reduction and disease prevention, family communication) were identified as important topic areas prior to the interviews.

**Causation.** Participants were asked about their thoughts and beliefs regarding the cause(s) of their own breast cancer, including the possible influence of personal and family history.

All participants had given considerable thought to the etiology of their disease. In response to questions regarding breast cancer causation, most participants attempted to integrate their own personal and family history, information that they had been provided by health care provider(s), materials from professional and lay literature, as well as the perspectives of relatives and friends into their discussions. Notably, there was considerable variation in women's explanations of the causes of their breast cancer, and each explanation was unique.

Most participants believed that there had been multiple and overlapping causes for their disease. Few could attribute their cancer to just one factor, including family history.

“Just because my mother had it, I think that it's hereditary. In my mind it's hereditary. Or with my sister having it, it's hereditary. But I don't believe the environment helps the situation.”

In contrast to these multifactorial explanations, some women identified inheritance as a strong contributor to their cancer etiology.

“I always knew that it would probably happen. So it would almost have to do with genetics.”

Although many participants were able to list several of the risk factors commonly associated with breast cancer including diet, lack of exercise, and family history, not all could list many of the more common risk factors. Other participants discussed causes not known to be associated with breast cancer, such as:

“I would think that if you abused your breasts, had these men that squeezed them a lot...But, you know, I never had that. So I don't know how they can really associate all of this together.”

Some women had developed very complex frameworks that addressed the causes of their disease. In the end, several women demonstrated confusion and frustration as they questioned why they had developed breast cancer, including the possible influence of genetic factors on their disease occurrence.

“I guess the way I look at it, if I do [have breast cancer], why doesn't my sister? And the only thing that's different is, I had a hysterectomy, I took hormone therapy...I didn't have children, she didn't have children. So, if it was to do with family history, I don't understand why she wouldn't have gotten it too.”

“I think that a lot of it has to do with your own birth control pills...how many children you've had, or when you've had children...or at least they say it has a lot to do with it. And then I talk to other people and their life is entirely different from anybody in my family, and they've ended up with cancer, breast cancer. So, sometimes I just think there's not any rhyme or reason to who gets breast cancer.”

***Expectations of breast cancer in self.*** Those interviewed were asked to discuss whether they had expected to develop a malignancy prior to their breast cancer diagnosis.

Among participants, the discussion about the influence of family history on their own diagnosis of breast cancer was inconsistent. Of note, despite having hereditary risk factors for breast cancer, many participants had not expected to develop this disease.

“I don't think that I ever did [think that I was going to develop breast cancer], I really didn't think that I would. So I think that's why it was such a shock. Sitting on the table in the examining room. Dedah, dedah da, it was like somebody throwing a bucket of cold water on me and trying to rein in my emotions while he was telling me.”

“Well, the first time I felt it, I actually trembled. My hand trembled and my, and I was saying, 'no, this is not this'. Even though my mom died of it, you know, I still said 'this is not this.'”

Others believed that, based on a number of risk factors including family history, they were at high risk to develop cancer. Interestingly, several women were surprised to have developed cancer of the breast as, based on their family histories, they anticipated developing a different type of cancer.

“Probably [I did believe that I would develop cancer], but not breast cancer. Probably some sort of stomach cancer, like my dad. But never in a million years was I thinking breast cancer. So cancer, yes, because so many people in my family have had cancer. I knew that it was probably one of the things most likely to take me.”

“...One of my grandparents had skin cancer a couple of times, a stomach cancer, I think. But none of my aunts or anyone like that so far, but all four of my grandparents, so I figured, my goodness, I've got a good chance here. It's coming from all angles for me you know.”

Having experienced cancer in loved ones, often at a very young age, some participants were quite pessimistic in terms of their risk for disease.

“Well, my mother died of cancer. She didn’t have breast cancer, she had colon cancer and died at age 32. She spent most of her last year in quite a bit of pain at home and I guess that has quite an impression on a child...So I was pretty fatalistic about it. I guess I always assumed that I would not live to be old...If I made it to 30, that was good. If I made it to 40, that was good.”

“Like I say, I had more or less expected it, so I wasn’t really that surprised.”

“Yes, I did [expect to develop cancer], and that was my greatest fear. I always thought I would rather die of anything but that, you know a car wreck or anything.”

Moving beyond their original breast cancer diagnoses, participants discussed their expectations regarding their future risk for recurrent disease or a second primary cancer. Among many participants, there appeared to be limited recognition that their previous history of breast cancer, in association with their family history of cancer, put them at increased risk to develop a second primary cancer. They appeared to be far more focused on disease recurrence.

“I don’t really think that I am [at risk for a disease recurrence]. Because I do feel like it was the extra estrogen in my body that brought this on. And I’m on tamoxifen, which is a blocker for the estrogen going to the breast. And I don’t have a uterus, so there’s not chance of getting uterine cancer. I exercise a lot. I try to eat properly.”

“I really don’t know. It could [recur] in ten years. I keep saying, give me ten more years. I have ten years to get my kids ready, sent off to college. Then I don’t care what happens after that.”

“It’s always a concern in the back of your mind, but I don’t let it consume me. I’m doing everything that I can do so there’s no use worrying about it. I’m trying to eat better, I’m trying to exercise more than I used to, so there’s nothing I can do about it if it does happen. I probably worry about that the most when it’s time for a check up or when I’m doing my own self-examination on the other side...but really I don’t worry about that a lot. At times, I think the, I worry the most about it when I hear a story about a, you know, I either read about it in a magazine or...someone says ‘my aunt had breast cancer ten years ago and it’s back.’”

***Expectations of breast cancer in family members.*** Participants were questioned whether they felt that others in their family, including their children, were more likely to develop breast cancer. These women were also asked to address whether family members felt that they were at increased risk to develop cancer.

“My older sister is, is a professional person. She’s very well educated and very accomplished and she’s in the church choir and all these different things. Well, she just reacted [to participant’s diagnosis] in a very extreme way. She said that she was looking into prophylactic mastectomies and things that I thought were absolutely ridiculous. And I told her that was a little bit extreme. So I think she just calmed down. But I thought that was very extreme of her.”

“She [sister] said that she has absolutely no worries that she’ll ever have cancer. She’s she has a spiritual growth and whatever that she’s, and a physical situation she is absolutely not concerned whatsoever. And [she] seems to be very level-headed about it and calm and serene. And I told her that I was very glad to hear that. And that was the end of that discussion.”

“I was worried at first that it created a risk factor for my niece who’s young. What I’ve read suggests that it’s really just a spill-over effect to my more immediate family.”

Women with children talked about the reasons that they expected their children to develop breast cancer and the relationship of their own diagnosis with their children’s future risk.

“...And my daughters, I read that they have an eighty percent chance of getting cancer. ...One of them says ‘I think I have a ninety-five percent chance of getting it Mom.’ I said, ‘No no, just eighty.’”

“Oh absolutely, my daughter [is more likely to get cancer]. Dr. H...says she thinks I carry the breast cancer gene and I’ve warned my daughter. ...I say, we’re a cancer family and you better get your damn check-ups.”

At times it seemed as if women with children were hopeful, fearful, or suspending of their expectations so that they did not have to worry about their children’s risk.

“I think my daughter is more aware and knowledgeable about everything that is going on now so I think she stands a better chance of not getting it. I mean she’s already cut out red meats. She cares about the things she puts in her body and she exercises a lot. So, I think she’s got the advantage of really taking good care of herself.”

“She looks a whole lot like my husband but I can see her changing and she’s starting to look kind of like, she’s in between. She’s built like me, she is, but I hope she won’t take after my side. I really hope she won’t.”

“Who is to say that my daughter is going to have breast cancer? She may be one of those that doesn’t develop it...I have three sisters. Two of us have breast cancer, two don’t. Will the other two develop it later on?”

“I worry for her [daughter] now, to a point. And yet, there’s nothing we can do at this point in time. Just hope and pray that you know, we can get some cures and understand breast cancer, before she gets it, if she does.”

“I tell her [daughter] all of the time, you have got to pay attention. I have never told her when you have breast cancer when your thirty, it’s fatal. You know, it’s very tough to make it out of 30 to 40. It keeps spreading on, you know. But I have told her that she has to pay attention to it. And she says, ‘Well, you know mom, you were 48, my aunt was 55, 56, so I’ll be...’ That’s not necessarily true and I do explain to her that, that she has got to do it early. I don’t know when and I do hope that all these drugs and whatever else they’re doing now, she’s only 25, maybe it will hold off for her for twenty years. Maybe there will be a cure. Maybe there will be some kind of medication that she can take to prevent it, in a hereditary situation or to diminish her odds, you know.”

***Risk reduction/disease prevention.*** Participants addressed their thoughts regarding both primary and secondary cancer risk reduction and prevention strategies. Although many of the participants understood common risk reduction strategies, some had developed their own ways of applying them.

“But I believe it’s, I think red flagging every person that’s high risk. I should have had a big red star on my folder and every time anything started slipping or sliding, they should have said, ‘Hey, wait a minute. We’d better check.’”

“...Now my sister never had children. Well actually, she had an abortion. So that’s, there’s a link but I’ve never said that to her. We haven’t talked about that for twenty-five years. But my daughters, I started nursing at thirty and that’s the line. If you nurse after thirty it doesn’t help, because cancer works. If you do it before thirty, you don’t seem to get it, breast cancer. And that’s a lot of nursing.”

“I live my life, my prevention is living happy. That’s my code for prevention. I am not going to measure the damn food. I’m not going to say if I want something that, now I don’t go out and look for it. But if I want a cheeseburger, I’m going to eat a cheeseburger. I do not fly into the face of fate and say I will eat all fat, but my life is one of I say the best medicine I have is being happy. To enjoy what I do. And I don’t particularly care about talking about cancer.”

“Because medically, I don’t know, if you have cancer, do you ever get rid of it before you’re diagnosed? I don’t know anything about that. Is it going to affect something in your body? Can you get rid of it? Can you get rid of it before it affects something? And if you can, is the environment making it grow? It comes to mind, it’s a weird thought. You know, can you get rid of cancer by eating green vegetables? And if you can, would the environment work against that?”

Participants also discussed risk reduction strategies among family members, particularly among daughters.

“So I don’t know what my daughters will do, but I told them that they can probably go on the tamoxifen. That’s what the nurses told me. And they, you know, in their twenties, they’ll probably go on some kind of treatment to prevent it.”

“In the refrigerator I’ll have washed grapes in bowls so that will look more enticing, you know. I certainly let my kids have cookies and things like that. I mean, I cannot say I’m one of those health freak moms who will not allow the kids to have...I’m not sure that works for one thing. I’ve known kids like that and then as soon as they got out of mom’s sight, they has [sic] all that fat stuff. But I try to let it be their choice. I just try to have it all out and available and the healthier stuff easier to grab.”

“The only thing that has changed is if there is a possibility of prevention other than doctor’s appointments and eating right and all the things that we’re going to do and are doing. But, oh if they found a pill that might prevent this in the future, sure, then I’d have my children tested, give them the pill. Like you know, but not just for the information, not just to know and worry.”

Some women had a more pessimistic view of breast cancer early detection and prevention strategies.

“Well, my experience was that they [mammograms] failed me. Even when it was identified, even when they knew or thought a problem existed, it was only through surgery and it was only through the dimpling of the breast that the surgery came about. The three mammograms had failed to address it.”

“I do a breast self exam on an irregular basis. I actually don’t trust my ability to find anything. I obviously blew it before.”

“Until we have figured it out, until we have figured out the genetics, the only thing that we have is a pitiful type of situation in which we say, ‘Oh exercise and diet’ and that’s all crap basically. But that’s fine, it makes people feel better. Now, there is one very real intervention, and that is catching that woman at the stage that you can take it out through surgery or excise it through radiation and then she has a fighting chance.”

**Family communication.** Many women addressed how cancer was discussed in their families. Several of the women interviewed reported that communication within their families had been limited or difficult.

“And she [mother] and I have a very loving relationship. At the same time, she’s a very private person and I would have to ask her a question point blank to get a specific answer. And to tell you how this works, she had a mastectomy in 1968 and I was in college then. I was not a child, I was a young teenager. She told me she had cysts removed. I did not know until close to the second mastectomy that

she's had the first one. And my first reaction was pure anger. I was so angry at her, that she didn't trust me, that she couldn't confide in me."

"Well, when it was first discovered, I mean it's one of the hardest things to deal with, aside from thinking, I was probably going to die...you know it was telling my family, telling my children and telling my sisters."

"Well, you know of course that's part of the questions that they ask you, was family history, and I was pretty unaware at that point of family history. You know once I let my grandmother and my mother's sister know, my sister told them that I had it, because I hadn't planned on telling them either. And actually, I didn't tell them until after the surgery. You know they told me bits and pieces of things that I didn't know about family history. There again, I had no idea what kind of cancer my mom had. I mean, I was old enough to know that it was something, but the word cancer was never spoken. It's well like your mother is sick and then she is in the hospital and then she is back and then, and it was always, she is going to be home and that's where it was."

"She [mother] was diagnosed in I think '94 because they didn't tell us and I was very upset about that too. They didn't tell anybody. We just heard it from the street."

"And then the one other aunt that's still surviving has had, she had nine children. We just had a family reunion. Two of her girls, she had four or five girls, one died of breast cancer. Two have had breast cancer and are going through treatment right now. Another has a brain tumor, and one other child has, it's tumors, but they're not cancerous. So there are five children in that one family...females, my cousins...all females. It's real interesting that we found this out at a family reunion."

A summary of the major findings from the qualitative interviews is presented in Table 4.

## ***DISCUSSION***

A breast cancer patient's orientation toward her disease state and family may influence her ability to recognize and deal with her own risk for hereditary cancer predisposition. This study characterized the views of early-onset breast cancer survivors who had not undergone formal cancer genetic risk assessment or counseling regarding the impact of their personal and family history on their disease etiology, cancer risk management, risk to relatives, and family communication. Knowledge of these views is essential to the future development of effective strategies designed to increase awareness of hereditary cancer susceptibility among those at risk.

Much of the previous work exploring the views of individuals with or at risk for hereditary breast cancer has involved women from tertiary medical institutions. The participants in these studies generally were from families documented to be at high risk or confirmed to have inherited mutations in either BRCA1 and BRCA2.<sup>4-8</sup> Other survey-based research has examined knowledge and attitudes about genetic testing among those from less highly selected populations, including individuals with a breast cancer-positive family history<sup>9-12</sup> presenting for routine care<sup>13-15</sup> or from the general population.<sup>16,17</sup> In contrast, the women who participated in the study presented here were recruited from a statewide population of early-onset breast cancer survivors with additional characteristics (personal or family history) suggesting risk for hereditary breast cancer. The results of the one-on-one interviews presented are unique in that they reflect the individual voices of at-risk women who had not been exposed to formal cancer genetic risk assessment, counseling, or testing.

All participants had given considerable thought to the cause or causes of their breast cancer. Many of the women had developed very complex models to explain why they had developed this disease. This is consistent with findings from two earlier qualitative studies. One of these studies, utilizing focus groups of women, some of whom had had breast cancer, found that patients had idiosyncratic, superstitious, or fatalistic beliefs about cancer causation. The authors noted that these beliefs were sometimes driven by fear, personal experience, or individual stories of other people, rather than by generally accepted medical information.<sup>18</sup> The other study found that, among cancer patients in a clinic waiting room, perceptions about cancer causation were heterogenous and complex, and drew upon “idiosyncratic experiences, knowledge, interests, and inclinations.”<sup>19</sup>

In this study, family history of cancer was merely one thread in the framework of causation that each woman had fashioned to account for her disease. Notably, despite the potential risk for hereditary disease, it appeared that some of the women had not integrated family history into their breast cancer causation models. This finding contrasts several studies that have examined knowledge among women at various risk levels about breast cancer etiology. These studies demonstrated a high level of awareness of family history as a breast cancer-associated risk factor.<sup>20-23</sup> The difference in results between these earlier studies and our work may be explained by the methods used to ascertain knowledge, as previous studies directly questioned participants about family history as a risk factor for breast cancer. However, the difference in results could also signify that, although women may abstractly recognize family history as a breast cancer-associated risk factor, they may have difficulty incorporating this knowledge into their own cancer experience. This raises concern for if breast cancer-affected individuals are unable to fully integrate family history into their perception of their own disease etiology, then they may have difficulty recognizing the need for cancer genetics services.

Despite the availability of breast cancer risk screening and prevention strategies for at-risk women,<sup>24-30</sup> among our study participants, there appeared to be a limited understanding of these therapeutic options. While most of the women discussed their concerns regarding disease recurrence, very few addressed their risk for a second primary tumor or the risk-reduction interventions available to them. Although several women directed attention to intensive surveillance for early detection or tamoxifen as a chemopreventive agent, none of the women reported considering risk-reducing surgery. Indeed, one woman described her sister's interest in a prophylactic bilateral mastectomy as "absolutely ridiculous" noting that she felt that her sister was reacting "in a very extreme way" to her breast cancer diagnosis.

Understanding was variable among participants regarding the impact of personal and family history on cancer risk for relatives. However, women wondered about risk to relatives, and concern about daughters was especially prominent. This concern parallels findings from research on families with or at high risk for BRCA1/2 mutations, in which an important motivation to undergo genetic testing was to help define risk to children.<sup>5-7 9-11 31-35</sup> Concern for daughters was also reflected in the participants' focus on breast cancer risk reduction and early detection in daughters. However, participants did not discuss cancer risks for sons or other male family members. This suggests that these women may not have recognized the impact of their personal and family history on cancer risk in male relatives.

When the issue of family communication was addressed with several of the women, it appeared that discussion of the occurrence of cancer within the family was restricted and difficult. Furthermore, despite the potential inherited cancer risk within these families, it appeared that discussion was limited about the possible risk to relatives, as well as the screening and treatment interventions available to family members. Knowledge about how families discuss potential or proven inherited cancer risk is continuing to develop.<sup>32,36-39 40-47</sup> Several studies on attitudes about communication regarding breast cancer risk to children<sup>36</sup> or BRCA1/2 test results to relatives<sup>37,38</sup> have found high rates of endorsements of discussion with family members. However, in this earlier work, potential barriers to communication were identified, including difficult family relationships, the unpleasant character of the news to be delivered and the disturbance it would cause.<sup>37</sup> Some researchers studying actual behavior in women undergoing hereditary breast and ovarian cancer counseling<sup>32</sup> or individuals disclosing BRCA1/2 test results,<sup>39-44</sup> while finding an overall high rate of communication, have identified difficulties in family communication. Participants in these studies cited multiple reasons for not informing others in the family, including not wanting to upset or alarm relatives, not being close to certain family members, or assuming that someone else had communicated with the relative. One study on disclosure of BRCA1/2 test results found that carriers were more likely than non-carriers to experience "difficulty and distress" in communication of results to relatives.<sup>43</sup> Another report on a psychoeducation group for women with BRCA1/2

mutations identified difficulty among participants with disclosure of DNA test results.<sup>45</sup>

In the work presented here, participants identified some of the same barriers to family communication as has been noted previously. This suggests that these communication difficulties are present from an early point in the process of a woman's perceiving herself to be at inherited risk for breast cancer. For some families, lack of communication about cancer within the family could be a barrier to the recognition of potential genetic risk.

There are several limitations to this study. First, through our collaboration with the statewide cancer registry, we sought to recruit a demographically diverse population. Nevertheless, racial diversity was somewhat limited in our study population. Participants differed in terms of education level and geographic locality throughout the state. Second, the qualitative nature of this study limits our ability to generalize the findings presented. Third, this work was the initial phase of a larger five-year project. The interviews were conducted in late 1998 through early 1999, at a time when knowledge among those with breast cancer about the impact of personal and family history on hereditary disease risk may have been more limited.

Future studies should extend the results of this work to a broader and more diverse population using both qualitative and quantitative methods. There is a need to explore how to effectively reach and educate women at potential risk for hereditary breast cancer, both cancer-affected and cancer-unaffected. Furthermore, there is a call for improved understanding of which information resources (primary care providers, specialty physicians, brochures, lay literature, or the Internet) would be most useful and accessible for patients. These studies should explore the psychosocial, cultural, ethnic and religious influences on a woman's/family's information and support needs related to risk status. There should be further exploration of how risk for hereditary breast cancer impacts health behavior. Finally, there is a need to better understand the barriers to family communication about potential inherited cancer predisposition and to address means to remove these barriers. Additional work in this area will allow for the development of effective educational and counseling tools for breast cancer survivors regarding risk for and management of hereditary breast cancer, and the family issues that these engender.

## **CONCLUSIONS**

Continued growth in scientific knowledge about inherited cancer predisposition will drive expansion of cancer genetic counseling and testing services for at-risk individuals. An essential component of provision of cancer genetics information involves evaluating awareness of the impact of personal and family history on cancer risk and risk management for self and family among potential users of these services. The factors affecting an individual's recognition of these issues

are likely complex. There is a need for informational materials for breast cancer-affected women concerning the risk for and the management of hereditary breast cancer for themselves and their relatives.

### **ACKNOWLEDGEMENTS**

We wish to thank the staff of the “Every Woman’s Life” program as well as staff of the individual hospitals who dedicated their time to this project. We are also indebted to the remarkable women who revealed their stories to us.

This study was supported by grant R29HG011554 from the National Human Genome Research Institute.

### **Table 1. Risk Criteria**

- One or more first-degree relatives with pre-menopausal breast cancer
- Two or more first-degree relatives with post-menopausal breast cancer
- One or more first-degree relatives with ovarian cancer
- Personal or family history of breast cancer diagnosed before age 40 years
- Other risk criteria on a case-by-case basis

### **Table 2. Interview Guide Topics and Sample Questions**

Topic: Relevant Medical History

When were you first ever diagnosed with cancer?

Do you think you are likely to develop another cancer?

Topic: Family

Do others in the family have cancer?

Has your doctor discussed the cancers in your family as they relate to your own health?

Topic: Causation

In general, what causes cancer?

Of these, are there any you feel caused your breast cancer?

Topic: Sources of information about breast cancer and risk reduction

Where do you get information about prevention?

Do you feel that a woman can do things to lower her risk to develop breast cancer?

**Table 3. Emergent Categories**

<b>Category</b>	<b>Definition</b>
<b>Causation</b>	Any factor or process that is seen as a cause for the participant's breast cancer
<b>Expectation of breast cancer in self</b>	Any factor or process that led the participant to believe, prior to her breast cancer development, that she would or would not develop breast cancer
<b>Expectation of breast cancer in family members</b>	Any factor or process that led the participant to believe that family members (including children) would or would not develop breast cancer
<b>Risk reduction and prevention strategies</b>	Any discussion of strategies used or ideas about reducing risk or preventing breast cancer for self or other family members
<b>Family communication</b>	Any discussion of communication regarding the occurrence of cancer within the family

**Table 4. Summary of Major Findings**

1. All women had given considerable thought to the causes of their own breast cancer.
2. Breast cancer was perceived to be the result of the complex interplay of a number of risk factors.
3. Information concerning the cause(s) of breast cancer came from a number of sources.
4. Family history was not always identified as a significant risk factor for breast cancer.
5. Many did not fully integrate their personal and family history into their understanding of cancer risk for relatives.
6. Understanding was limited about the risk reduction strategies available to this at-risk group of women and their family members.
7. Family communication was limited regarding cancer and familial implications in some cases.

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