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Living My Family's Story:

Identifying the Lived Experience in Healthy Women at Risk for Hereditary Breast Cancer

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Abstract

Background—Based on known or suggested genetic risk factors, a growing number of women now live with knowledge of a potential cancer diagnosis that may never occur. Given this, it is important to understand the meaning of living with high risk for hereditary breast cancer.

Objective—The objective of the study was to explore how women at high risk for hereditary breast cancer (1) form self-identity, (2) apply self-care strategies toward risk, and (3) describe the meaning of care through a high-risk breast program.

Methods—Interpretive hermeneutic phenomenology guided the qualitative research method. Women at high risk for hereditary breast cancer were recruited from a high-risk breast program. Open-ended interview questions focused on experiences living as women managing high risk for breast cancer. Consistent with hermeneutic methodology, the principal investigator led a team to analyze the interview transcripts.

Results—Twenty women participated in in-depth interviews. Analysis revealed that women describe their own identity based on their family story and grieve over actual and potential familial loss. This experience influences self-care strategies, including seeking care from hereditary breast cancer risk experts for early detection and prevention, as well as maintaining a connection for early treatment “when” diagnosis occurs.

Conclusions—Healthy women living with high risk for hereditary breast cancer are living within the context of their family cancer story, which influences how they define themselves and engage in self-care.

Implications for Practice—Findings present important practical, research, and policy information regarding health promotion, psychosocial assessment, and support for women living with this risk.

Keywords

Genetics; Hereditary breast; cancer risk; Nursing; Phenomenology

In the past decade, advancement of genetic science has given rise to an influx of research and information regarding hereditary risk for breast cancer. Analysis of hereditary

information allows clinicians to quantify a given person's breast cancer risk, with some estimates stating up to an 86% lifetime breast cancer risk for those with an identified BRCA1 or BRCA2 gene mutation.¹ Information regarding hereditary disease risk, especially in cancer, has been given increased media attention, raising individual and family awareness of potential risk.²

A consequence of this scientific advancement and increased awareness is the existence of a population of women who have never had a cancer diagnosis now living with knowledge of increased risk based on known or suggested genetic factors. Importantly, these are healthy individuals living with knowledge of a potential vulnerability to cancer that may never occur. Given this, it is important to examine personal experiences and understand with greater depth the meaning of living with high risk for hereditary breast cancer. Therefore, the purpose of this study was to engage in dialogue with women living with knowledge of risk and determine how they identify themselves and care for themselves within this context.

Background

Current Clinical Recommendations

Women identified as having a high risk for hereditary breast cancer based on personal or familial cancer history receive multiple recommendations for early detection and risk reduction strategies. Options range from intensive surveillance to lifestyle changes and medical management through chemopreventive or surgical strategies.¹ Although early detection and risk reduction recommendations are found to be efficacious, surveillance focuses on early detection not prevention of disease, and surgical prophylaxis and chemoprevention do not eliminate risk completely.¹

Psychosocial Considerations

Risk reduction and early detection strategies have both positive and negative psychosocial and physical health implications. Within available literature, it is cited that participating in regular surveillance can cause distress during the screening visit³⁻⁶ and while waiting for results.⁷ Distress is higher when abnormalities are identified within the imaging.⁸ In addition, physical discomfort can be associated with both mammogram and magnetic resonance imaging (MRI).⁹ This discomfort occurs with other risk-reducing strategies as well, including chemoprevention, which causes increased vasomotor symptoms and changes in sexuality.¹⁰⁻¹³ In terms of surgical implications, prophylactic mastectomy can lead to physical pain, body image concerns,¹⁴ and sexuality changes.¹⁴⁻¹⁶ Despite these psychosocial and physical implications, these strategies are perceived by both families and clinicians as important to follow because of higher than average cancer risk.¹⁷⁻¹⁹ Women who undergo prophylactic mastectomy report feeling the strongest sense of control over their breast cancer risk^{16,20,21} and are often satisfied with surgical decisions.^{22,23}

None of the strategies, including prophylactic mastectomy, offer women complete sense of ease regarding cancer risk, and even after surgery, women can be left with feelings of physical loss¹⁴ and ongoing cancer worry. Therefore, evidence shows that although women engage in strategies for risk reduction and early detection aimed at controlling risk, psychosocial burden persists. This burden is even more present in a subset of women who have high levels of baseline distress,^{5,16} poor coping abilities,^{3,4,24,25} are of young age,^{23,26} and have a known personal genetic mutation.^{8,24,25}

Therefore, evidence demonstrates that, in certain groups of women, risk reduction and early detection behaviors can both positively and negatively relate to distress and cancer worry. However, as most of the current evidence is focused on surveillance and prophylactic

mastectomy, more information is required that focuses on in-depth understanding of experiences with all recommendations.

The first author engaged in initial work with high-risk women from an online community, Facing our Risk for Cancer Empowered,²⁶ which helped yield insight into personal experiences of women at high risk for hereditary breast cancer. The preliminary exploratory study revealed that women cared for themselves by considering all potential risk reduction and early detection strategies, were undergoing surveillance at the time interviewed, and eagerly sought experts to support their care. It became clear that in order to facilitate successful adaptation to living with high risk for hereditary cancer, understanding how women identify themselves and care for themselves within this context and why they so actively seek expert resources is important to further understand the needs of high-risk women.

Objective

Based on the synthesis of the literature and initial research, the purpose of this study was to explore how women at high risk for hereditary breast cancer incorporate living with knowledge of this risk into their lives. Aims were to (1) understand how living with knowledge of hereditary risk influences and is incorporated into self-identity; (2) explore practical, self-care strategies women apply to managing this risk; and (3) describe the personal experiences and meaning of receiving care through a high-risk breast program.

Methods

Philosophical Framework

An interpretive hermeneutic phenomenological approach^{27,28} guided this qualitative study. Hermeneutic phenomenology focuses on interpretation of lived experiences and posits that everything within our “life world” is important because we interpret it to be so. Therefore, it is not the object, but what that object means to the individual that is essential.²⁹ Applying this approach to nursing research allows for in-depth understanding of the personal experience and meaning of living with a phenomenon.³⁰ Phenomenology sheds light onto certain aspects of humanity that may be overlooked or taken for granted. This allows for deeper insight into contextual underpinnings that clinicians and scientists seek to understand and aim to improve,³⁰ making the method applicable to inform the research aims of this study.

Setting/Sample

A convenience sample of women at high risk for hereditary breast cancer was recruited from a breast cancer risk reduction and prevention program offered through an academic comprehensive cancer center in the Northeastern United States. Eligibility for this study included having no history of cancer, being older than 21 years, speaking English, able to consent, and at high risk for hereditary breast cancer based on National Comprehensive Cancer Network (2010) guidelines.

Recruitment

Permission and support with study recruitment were provided by the physician director, project coordinator, and nurse practitioner. Institutional review board approval was obtained prior to beginning study recruitment. Women were recruited by the first author through the high-risk program, and interested and eligible participants were provided study information and consented to participate. Twenty-five women volunteered to participate, and 20

consented and were included in the analysis. Recruitment occurred from May 2010 through August 2010.

Data Collection

All women were interviewed either in person (n = 6) or over the telephone (n = 14). Interview length ranged from 20 minutes to 2 hours. An unstructured to semistructured interview guide provided the data collection framework (Table 1). A brief demographic questionnaire was also completed. The first author wrote field notes of context of the interview immediately after each meeting^{27,28} to enrich understanding of the data during analysis. Data saturation, or redundancy in interview data, occurred at the 14th interview; however, in an effort to increase ethnic diversity among the sample, recruitment continued until 20 interviews were complete. All interviews were audiorecorded and transcribed verbatim. Data were verified and deidentified by the first author prior to analysis.

Interpretation Procedures

A research team completed data analysis to provide multiple interpretations of the text and promote methodological rigor, based on a dynamic method of hermeneutic interpretation (Table 2).^{27,28} The research members met weekly, led by the first author, to interpret each interview, deliberate results, and document findings. Common themes were summarized across all interviews and organized within a matrix to help identify data saturation. Once analysis neared completion, participants were sent an overview of the results for verification and feedback, with 4 women responding and acknowledging that the themes reflected their experience.

Results

Overview

Through the interpretive process, 5 themes and 1 constitutive pattern emerged from the narrative text. Data were obtained from 20 participants with ages ranging from 22 to 73 years, 90% white, most having attended some college. Sixteen of the women interviewed had children and were married or partnered. Eleven of the women had undergone genetic testing, with 4 having identified BRCA1 or BRCA2 gene mutations. Only 2 individuals were referred to the high-risk program by their clinician; all others sought the program independently or by guidance of a family member. Eighteen of the women had participated in the high-risk program for over 6 months at the time of recruitment. Participant demographics (Table 3) were reflective of the program as a whole, which included a total of 344 participants at the time of study recruitment.

THEME 1: IDENTIFYING SELF—Identifying the self, or forming self-identity, was described as being influenced by family or any person with whom the woman felt a connection. It was this connection that was described as giving life purpose and the participants' reason for caring for themselves.

Defining Self Through Family and Work Experiences: Each woman began by sharing that the purpose of her life was family. As a woman summarized, "...I have 2 children. I've been married for 16 years. ...That's my life. I love to scrapbook, and I love to be with my kids and my family." This sense of identity driven by family was the foundation in which all other discussion was based. Some women did not have children and therefore had an expanded family definition. The definition included nieces, nephews, or pets. One woman, who did not have children, described identity through her career, geographical location, and educational background.

All women in the sample had close family members with a diagnosis of cancer, and more than half of the women identified themselves as caregivers to those family members. Breast cancer was part of their reality, and for some, familial cancer was experienced throughout their lifetime at multiple points in time. When women went on to share background about their own personal breast cancer risk, the story focused on their familial experience. One woman who had lost a mother to breast cancer shared, “I don’t really have a story ...if I had cancer, then I could come with a story... my story is that of my mother.”

Living for my Family: Women with families discussed how children in their family gave them a sense of purpose that motivated them to care for themselves. Women without children discussed their parents, siblings, or spouses as influencing how they approached their life or their desire to have advanced education, family, and career. It was the connection, or desire for connection, to others that defined their personal identity. This was often the reason cited for attending a specialized breast cancer risk program. As one woman discussed why she cared for herself and sought to manage her breast cancer risk, the importance of family was evident:

I do all this... for my children. We're extremely close, and I'm extremely close to my grandchildren, and I couldn't hack anything happening to them because of my carelessness with my life.

These women wanted to maintain health in order to continue toward their life purpose, often family, and to “be there” for important life events. This sense of purpose was influential in all aspects of how women described the meaning of breast cancer risk and its past, present, and future family implications.

THEME 2: CONSTRUCTING RISK BELIEFS AND DECISIONS FROM THE CONTEXT OF CANCER EXPERIENCE—In order to make meaning of risk within their own personal context, women compared themselves to others with similar experiences. This could be family or other women their age with whom they felt similar. These comparisons influenced how the women made decisions about strategies to manage risk.

Comparing Self to Family: When describing beliefs about their breast cancer risk, women viewed their affected relatives' stories as a baseline definition of the cancer experience and then compared themselves to that baseline to conceptualize cancer and form personal perceptions of cancer vulnerability. Women shared stories such as “my sister was 44 when she was diagnosed, and I was 42; I thought, wow 2 years will go by pretty fast, I don't have much time left.” Any connection individuals had with the affected relative led them to feel more of a risk. Women would feel that “they were headed down the same path” as their family member who had cancer.

This was also true if women felt that they were healthier than their affected relative. For instance, a woman felt exposed to less environmental toxins than loved ones who had developed cancer. Other women felt that they had practiced healthier lifestyle behaviors, such as exercising or eating healthy, than their relative with cancer. Because of these perceptions, women felt less breast cancer risk than their family member.

...My sisters and I discussed why I haven't gotten breast cancer like they did. One of the things we talked about as a possibility is that they are both very overweight, and I lost the weight, I kept it off, I exercise, and I have my little binges, but I basically eat healthy. I've determined now that I'm going to keep that going. Who knows whether that's why or not?

Comparing Self to Others: Women not only compared themselves to their family, but also to any person experiencing cancer, such as a media figure or a neighbor and family friend, with whom they shared similar characteristics such as background or age. Exposure to others with cancer and then the connection of that cancer to themselves raised their awareness of their own risk and acted as a breast cancer cue, causing women to recognize their own mortality.

Women who were not yet at the age of general population breast cancer screening often compared themselves to other women their age and felt that “it wasn't fair” because others their same age did not live with the same breast cancer risk. One young woman, who was 22 years old, recognized that other women her age were not actively dealing with breast cancer risk or worrying about developing breast cancer.

Once I found out that I had the gene for it, and I would have to go twice a year to see a doctor, it started to really hit me, and I'd be in the waiting room and look at everybody and think, what if I don't make it to that age? There would be old people sitting in the waiting room. I was like, it's not fair that I have to go through all of this, and some other people my age really don't worry about it as much.

Applying Comparison to Self-care Decisions: Family experiences informed women's interpretation of what was being recommended by healthcare providers. For example, a woman who smoked cigarettes stated that she was aware that smoking increased her risk for developing cancer and that she was aware of a need to quit. However, then she stated,

...when I think about what has happened in *my* life with *my* family, it is like you pick up a cigarette and that is the wrong move. But then I say, well, my mom didn't smoke [pause], and she died of breast cancer...

Another example was provided by a woman whose healthcare provider recommended tamoxifen. Her mother had taken tamoxifen and then developed uterine cancer. Witnessing the negative outcome that occurred after her mother took tamoxifen made this woman feel that chemoprevention was not an option because she did not want the same experience. Women looked toward the outcomes their loved ones had with prevention and early detection to form the basis for how they moved forward with their own self-care and future possibilities.

THEME 3: ANTICIPATING A CANCER DIAGNOSIS—Women living with a high risk for breast cancer experienced an underlying feeling of emotional sadness associated with actual and potential loss that stemmed from a lifetime of exposure to familial cancer experiences. These feelings influenced how women viewed their own future and cancer potential and their reaction to being cared for within a cancer center.

Grieving Over Familial Loss: For women who had lost a loved one, emotions were demonstrated as a sense of sadness, fear, and regret that persisted years after experiencing the familial cancer diagnosis or loss. One woman remembered her sister's breast cancer experience:

I was very, very close to both sisters, so, for me, I had a hard time believing that something bad could actually invade both my sisters' bodies and kill them. To this day, I don't know if I've totally accepted it. Both of them lost their lives [crying].

Grief shaped a woman's view of her own life and perspective of her own future as described by one woman, “Whatever I think about my own death, it's always of course going to be cancer-related.... It's very present in my mind because there's just so much cancer in the family.”

Participants who were active caregivers to those with breast cancer described having “firsthand information” about the breast cancer experience and vivid memories that permeated their daily life. One 25-year-old woman stated, “I wouldn’t wish what I saw my mother go through on anyone, not even my worst enemy.” As another woman shared through tears:

...It's hard to be a family member when someone has cancer, and when a number of family members have cancer, it's very difficult. Breast cancer is very personal.

Women who currently had a family member with breast cancer experienced anticipatory sadness and fear related to that diagnosis, often feeling responsibility toward their loved one with cancer. This was even more powerful for the 2 women who were mothers and had experienced or were experiencing a breast cancer diagnosis in a daughter. Prayer and distraction, through keeping busy, were described as ways the women who were caregivers lived with sadness and worry over their loved ones' cancer diagnosis. In addition, being able to talk to someone outside the situation, such as a spiritual advisor or counselor, was helpful.

Women who had not experienced familial cancer loss had a different story to tell. For example, one woman who had multiple sisters survive breast cancer felt that she would also survive “when” diagnosed. This woman voiced a need for early detection so that disease could be detected and treated early. Sadness was not associated with loss of a family member but was related to experiences with witnessing cancer and cancer treatment in the family and risk for future affected family members.

“When Not If”: Mixed in with stories of hope for a cancer-free future was a consideration that breast cancer was a future possibility. As one woman states:

There's always this countdown, so every time I go there, either it's this time or it's one less time till they do find something. I know it sounds very negative, but I can't help but feel that way. With the way that they're talking, it's just inevitable.

Women felt fear of leaving behind their family and losing their loved ones if they received a diagnosis of cancer. Fear was focused not only on cancer death but also on reliving the cancer treatment experience and exposing future generations to familial loss.

How women approached their anticipation of cancer often focused more on psychosocial health than physical health. One woman describes how feeling at risk for cancer influenced how she approached life:

...It puts me in the position of vulnerability that I'm not necessarily comfortable with. It's not like a specific vulnerability, but the general sense that things aren't as defined and definite and strong as... guaranteed—that's the word that I'm looking for. It's not guaranteed that you're going to be all healthy and wonderful forever.

This woman wanted to spend time with her daughter and enjoy life while she was able and did not have a cancer diagnosis. A strategy was to “have perspective,” as women reflected feelings that everyday stress was insignificant to them compared with what they had seen their family endure. Women who had not yet started a family or finished college discussed trying to accomplish life goals through achieving an education or learning to live on their own. They focused their lives on trying to build a self-identity that was focused on their life accomplishments and not on a cancer diagnosis.

Being Reminded of the Cancer Experience: Women were confronted with a reminder of past family experiences each time they entered into the cancer center. Often, family members had been cared for at the same hospital, even by the same clinician, with whom they were now interacting to manage their own personal risk. Therefore, emotions were

triggered by memories of loved ones lost or the pain experienced by family members undergoing cancer treatment. As one woman shared, "...every time I went before I was visiting somebody who passed away [pause] and now I was going for myself. That was hard, [pause] just reliving all the times I'd been there before for somebody else." The women described their experiences witnessing others with cancer, as stated by one participant:

As soon as you walk into the cancer center, you see all the people with cancer, and it's very depressing. It's a beautiful facility, but it's just a shock... I think that first time was more life altering because you think this could be me.

Women learned from this difficult experience the need to have a family member available for support during the appointment.

Exposure to people with cancer caused women to "be thankful" that they were not currently living with cancer. As one woman described her feelings:

...Here I am, lucky not to have had anything like that, and these people already know what's coming—maybe the loss of hair, or the way that they look—that they do have cancer. I thank God for blessing me so far.

For one woman, this exposure provided insight that individuals can live through the cancer experience. Prior to witnessing women living through cancer treatment, she had not considered the possibility of life after cancer because of her mother's death from breast cancer.

THEME 4: FACING MY RISK BY "BEING PROACTIVE"—Women sought strategies to control their own personal breast cancer risk. It was important for these women to understand their risk and how to care for themselves within their daily lives. This was identified as unique to simply accessing specialist care; it was focused on what the women could do independently to understand and manage cancer risk.

Seeking Personal Control of Cancer to Care for Self and Family: Women were driven to personally "do something" to proactively face risk, mainly through being knowledgeable about cancer risk. One participant described, "I have read anything I can get my hands on about breast cancer I've read or tried to read and understand it (because it's sometimes very technical) and share it with my siblings." Experiences with information interpretation could be overwhelming because of scientific language or conflicting information between sources. As one woman shared:

I think that knowledge is important. Knowledge will help you to be less anxious if you have that knowledge, if you have the education... I'm thankful for the articles, but it's very confusing sometimes. You read one thing, and you go, 'why?' ...So I would say sometimes it's confusing to read the things, definitely confusing. I almost need an interpretation.

The women in their 20s who were still incorporating cancer risk management into their lives described being encouraged by family members, such as fathers, or sisters to act toward managing their breast cancer risk. These young women were still learning about themselves, how to care for themselves as young adults, and additionally how to face knowledge of increased breast cancer risk. Younger women were "...not yet used to taking care of all of this stuff by myself."

Experiences with health behaviors in the family guided decisions about lifestyle recommendations, such as maintaining adequate weight through diet and exercise. One woman felt that eating organic food would aid in cancer prevention; another felt that limiting red meat intake would help not only in cancer prevention but also in overall health.

Some women described how their family members developed cancer despite healthy lifestyles, leading to uncertainty in the efficacy of lifestyle modification augmented by lack of consistent available information. All women felt that lifestyle influenced cancer risk even when questioning efficacy within their own personal risk and discussed an awareness of the importance of lifestyle in overall health quality or because of other disease risk, such as cardiovascular disease. Health behaviors reported by these women are presented in Table 4.

Outlook on life was an important self-directed strategy to decrease perceived cancer risk. Some women tried to maintain optimism and reduce stress, as it was considered by them as a cause of cancer. Mechanisms for being optimistic often included faith, prayer, seeking support, or finding humor in distressing experiences, such as waiting for surveillance results.

THEME 5: MANAGING RISK THROUGH A HIGH-RISK PROGRAM—Attending a specialized program was a mechanism external to self that allowed women to feel that they were “doing something” to manage cancer risk. By attending the high-risk breast program, women felt that they were receiving the best possible care. This program offered access to specialists who then helped women connect to valuable resources.

Engaging With Experts: Attending a high-risk program provided women with feelings of relief and comfort by providing connection to the expertise they sought. These women wanted to be proactive; attending this program allowed women to feel that this was being actualized.

I trust [cancer center] better because they deal with cancer, so the chances that they're going to be very conservative and watchful and diligent are better for early detection versus going somewhere else where they might not have the awareness. Probably they do, but it just seems in my mind like the cancer center's the best thing for it.

Attending this program also led women to feel that they were doing everything they could to help future generations and other families. These women actively sought opportunities to help others through research participation at the cancer center, cited as the reason for participating in the present study.

Some women felt that accessing the cancer center was beneficial not just for prevention and early detection, but also treatment as well. Women felt it was important to be able to seek treatment quickly “when” diagnosed, therefore being in a cancer center with specialists available to provide care if needed was an appealing part of the program.

It's reassuring to know that there's a place to go already if I have a question about anything. I find that it's nice to have it set up already. That way I don't have to go through the whole process of figuring where to go, who to go [see], how to figure out where it is. Just having been there a number of times is helpful... It's set up. I know who to contact, how to contact, and in that sense, it's part of the support structure.

Taking part in an in-depth multidisciplinary program that focused on both prevention and advancement of science, as well as being evaluated based on cancer risk, could be intrusive at times for certain women, especially those who may have been apprehensive about attending the program or new to undergoing breast care. One young woman shared this experience:

...I said to a couple of my friends, “if ever I had the desire to become a stripper or anything there'd be no need because more people see me naked at that hospital than anywhere else. I swear!” Last time, there were like 10 people who came into my

room, and half of them were guys. I was like, you want to order pizza and have a party?

This had the potential to lead women to feel that they were “being a patient without being a patient,” or being treated as ill when they were healthy.

...I needed to tell everyone, “I don't think I'm having these because of cancer.” At the same time, I think they were being wonderfully diligent about cancer and doing what they have to do. I was like, “Oh, wait. No, I'm not a cancer patient.” I felt kind of bad for using up their time. But again, their attitude was never like, “You're wasting our time.” They were very embracing and caring and compassionate.

Obtaining Genetic Knowledge: Genetic assessment by experts was a way in which some women sought information about their personal risk.

I have to say that the cancer center gave me a wealth of information on my last gene testing appointment with my mother and with my husband; he came too. They really laid it on the line and said, “This is this.”

Not all women had moved forward with genetic testing or counseling at the time of the interview. One woman described worry of genetic discrimination regarding testing results.

It is concerning to know that if they do identify the risk and, let's say I get a new job, is that going to affect my ability to get new health insurance? That's going to be a big deal because the cancer already is a real dinger for people not being able to get insurance coverage.

A genetic predisposition to cancer was not identified in the family of one woman; however, she questioned this finding because of her lifetime of familial cancer experience, leaving a sense of uncertainty:

How far we've come and how little we still... I couldn't believe my cousin would die after my grandmother died 50 years before, and we *still* don't know enough about the thing to control it. What bothers me most is that I've seen this my whole life.

Undergoing Breast Surveillance: In addition to interacting with expert clinicians, surveillance was a component of this program. One woman actively sought breast MRI because “when my sister was diagnosed with breast cancer, she had been getting a mammogram annually. They told her she had probably had breast cancer for 3 years at that point... I needed to be looked at closer....” Women relied on early detection as “prevention” or to prevent them from having to experience cancer as they had witnessed in their family. This vulnerability to cancer made waiting for surveillance results a worrisome time for some women. One woman described, “putting life on hold” while waiting for results.

... You just don't know. If they [surveillance results] come back positive, things are going to change; you're going to have to cancel things.... When I have my MRI, let's say I'm going to have it in 2 weeks, if we want to do something or schedule something 3 or 4 weeks after that, I'm thinking in the back of my mind that maybe we're not going to be able to do that if my results are different....

Although surveillance could be uncomfortable or time consuming, most described gratitude toward the technology. One woman compared herself to her sister who had a cancer diagnosis as she underwent a breast MRI:

I got to this point [during MRI] where I just kept thinking, “just a little bit longer, and just a little bit longer... I can do this, I can do this. If your sister is going through what she's going through [chemotherapy], you can do this...”

Women found that having someone with them for their surveillance appointments as support, such as a husband, friend, or family member, helped calm them and alleviate some fear and offered them an outlet to share their concerns.

Considering Medical Prevention: Each woman described considering medical prevention unique to her specific life situation. For example, a postmenopausal woman who had a known BRCA2 gene mutation felt that she wanted to keep her breasts as long as possible to “keep my body intact” and did not want prophylactic mastectomy because she felt her body image was important. One younger woman also felt similar regarding chemoprevention.

I'm more concerned about my quality of life today.... I can go on chemoprevention and die at age 50. I just feel that I have to be functional at home and at work, and I can try the tamoxifen. I'm just not excited about being thrown into a potential... going into menopause early. It puts you in an unnatural state....

In contrast, a woman who was 34 years old had undergone prophylactic mastectomy, and another 36-year-old woman was currently in process of planning surgery. Both of these young women had gene mutations, and both had young children who were cited as being the reasons for wanting surgery. These women felt that they “had no choice” and that surgery was necessary.

Constitutive Pattern: Living My Family's Story

These women lived their personal cancer risk through the unique story of family experiences. Family experience became incorporated into how women identified and cared for themselves within the context of hereditary breast cancer risk. Women lived their lives within the historical context of their past and present cancer experiences, as well as future possibilities of cancer experiences within their family. As part of living this family story, these women shared sadness associated with remembering cancer in the family, which directed their anticipation of cancer and led them to undertake steps toward prevention and early detection and interpret these experiences within the lens of their family history. One woman summarized the meaning of her family story of cancer risk:

Growing up, it was always in the back of my head knowing my mother had breast cancer. I always thought that eventually I would have to deal with it in some way.... Obviously, when I found out my sister had it I thought that it was escalating the time frame for me.... That was when I thought that we've got to be able to do better than that. If someone is accessing care and doing everything they're supposed to be doing, what else can be done?

Discussion

This phenomenological study focused on the lived experience and meaning of living as a healthy woman with high risk for hereditary breast cancer including experiences with risk reduction and detection strategies.

Self-identity

Women identified themselves and their breast cancer risk by the family experience, which is consistent with other reported hereditary breast and ovarian cancer literature both from North America^{31–34} and internationally in Israeli high-risk women.³⁵ In addition, participants shared that family cancer experience led to a sense of sadness or grief. The

phenomenon of healthy high-risk women being affected by grief or trauma is relatively understudied. In a recent study, 56% of the high-risk sample experienced grief; however, only 18% had depression, suggesting that feelings of grief are a process associated with living through a cancer experience and potentially not an illness such as depression.³³ This was true in previous work in which high-risk women, most with a cancer diagnosis, reported feeling distress and even trauma³⁴ after experiencing cancer in the family, especially if the familial cancer experience was within the past 10 years.³⁵

The present study adds narrative accounts about how women living with high risk feel and the magnitude of the impact of their emotions. The results suggest that women make behavior choices based on emotional considerations, which trigger them to expect a future cancer diagnosis and may influence their decision making. Interestingly, although the women in this current study did not have a history of cancer, our findings are similar to a recent study in which women from the United States with a cancer history applied information gained after genetic counseling in similar ways such as in the manner in which they sought knowledge and made health decisions.³⁹ This similarity of healthy women to women living with cancer also translates into experience reported from women with diverse cultural background. Recent work with women from Pakistan⁴⁰ and Lebanon⁴¹ demonstrates that the cancer experience is filled with a need for support from family, a need for knowledge, and fear and uncertainty associated with death and cancer reoccurrence. Understanding that women from the present study are living with similar experiences as those with a cancer history has important implications for promoting health and a wellness model in healthy women at high risk for breast cancer. In addition, comparing these findings to international reports demonstrates a need for cultural competency and assessment when providing health promotion and support.

Self-care

Our finding that women with high breast cancer risk seek control of risk is supported by current literature.^{17,18} This study adds an understanding of practical strategies women use to care for themselves. These strategies permeate all resulting themes of our analysis and are summarized in Table 5. Despite this need for control, women in the present study often undertook unhealthy lifestyle choices. More than half of the women interviewed were overweight, and half did not exercise regularly, although a few were attempting to adopt healthy behaviors. Evaluation of differences in this sample based on demographic information revealed that postmenopausal women had a greater incidence of being overweight or obese, smoking, and not exercising. Body mass index, limited activity, and smoking are known factors associated with breast cancer risk in the general population⁴²; therefore, this is an important implication for health promotion. This study demonstrates that subjective feelings toward future cancer risk may play a role in motivating women to engage in both healthy and unhealthy behaviors. Young women in this study were adapting to living with risk, and this can be associated by other unique age-related factors, such as concerns of relationships and dating.⁴³ Factors other than breast health may be more salient based on time of life and need to be taken into account when making recommendations and helping women interpret and apply information.

Theories such as the Health Belief Model⁴⁴ or Social Cognitive Theory⁴⁵ may give further insight into this process. Perceptions of threat, barriers, benefits,⁴⁴ and personal efficacy⁴⁵ could mediate these women's behavior change. Although women may feel increased threat from cancer, some may feel that there is little benefit to behavior change due to susceptibility to cancer or that they are unable to improve their health behavior because of lack of understanding of strategies. The Theory of Genetic Vulnerability³² further suggests that high-risk individuals may base their subjective risk perception on a comparison of themselves to their family more than objective numerical data. This is supported by Werner-

Lin,³⁴ who reported that in women at high risk for hereditary breast and ovarian cancer there was a “family trump card” that indicated that family history and experience were more meaningful and salient than provider information or data. This study further informs current theory to describe the importance of the family experience in both perceptions of risk and decision making, as well as health behaviors.

It is known that hereditary cancer risk information is complex and difficult to interpret^{44–46} and that often personal experience helps individuals construct risk beliefs.⁴⁷ Through this study and previous work,²⁶ it is evident that women at high risk for breast cancer seeking health promotion, risk reduction, and early detection information find this information difficult to interpret yet sought regardless of objective risk data.⁴⁸ Accurate interpretation is significant in terms of risk perception, as literacy can determine how an individual perceives her health status as well as understands her cancer risk.⁴⁹ When considering these findings from a cultural perspective, recognizing the importance of family on decision making, sharing of information, and spirituality influences are important to consider when caring for women from diverse backgrounds.^{35,40,41} Women in the present study sought personal control of risk. However, based on cultural background, “personal control” and reaction to knowledge of risk or disease status could be dynamic and are related to country of origin and the cultural or social context.⁴⁰

Context of High-Risk Program

Results demonstrate that women are grateful for attending the high-risk program and find reassurance in having expert connection, which is consistent with previous literature.^{17,19,26} However, the influence of being a healthy woman cared for within the context of a cancer center has not been previously explored in-depth. It is now apparent that women seek not only reassurance from a center for women at high risk, but also a connection to experts for early treatment “when” a diagnosis occurs. Participant stories reflected emotions triggered by receiving care within a cancer center. As women who take part in these programs may encounter a cancer center every 6 months for surveillance based on current recommendations,¹ this trigger of grief is important for clinicians to understand and explore.

Surveillance led to distress leading up to the appointment and while waiting for results, indicating the potential for maladaptive coping. The individual's ability to cope can influence how women behave and manage their perceived cancer susceptibility and subsequent distress.⁵⁰ This research adds to that understanding by recognizing that high-risk women of all ages anticipate a cancer diagnosis, undergo surveillance, and then put their lives on hold to cope with threat perceptions as they wait for results.

Future Implications

Practice

As healthcare enters into an era of developing science that focuses on applying genetic information to clinical care, it is imperative that clinicians do not discount the importance of holistic care and understand the subjective experience, which stems from the personal, social, and cultural context. There is much opportunity for advancement in the area of health promotion for women at high risk. This study reveals that there is a captive audience of healthy women eagerly seeking answers to questions of uncertainty, as well as knowledge to care for themselves, not only within the context of hereditary risk, but also as women seeking to be healthy. As clinicians, it is our duty to maximize the potential of these women to seek optimal mental and physical health and help them to actualize their full potential of wellness.

Clinic visits should provide women the opportunity to share stories of personal perceptions of the familial experience, as well as cultural and spiritual beliefs or values that may guide health-related decision making. This in-depth understanding can guide the development of future clinical services tailored to meet the unique needs of these high-risk women. Accessing resources available within a community, such as support and our counseling services, would allow women opportunity to share stories outside the clinic visit. As support was found to be important in this US sample as well as international samples reported in the literature, offering this support is an important practice implication.

Research

This study sample was 90% white. Therefore, further exploration of ethnic and cultural variations within this phenomenon would be important to provide culturally sensitive care. It was evident that there are subtle variations in personal meaning based on the lived experience and that experience influenced behavior. Understanding how these experiences and the meaning of the experience changes over the course of a woman's life influence decision making and the impact of the patient-provider relationship on this process would be important for future research to guide tailored intervention development.

In addition, through understanding that these women seek information, research should aim at identifying the mechanisms that facilitate successful interpretation and application of knowledge to potentially improve risk interpretation and subsequent decision making and health behavior.

Policy

Within other areas of healthcare, specifically oncology, it is standard practice to assess and intervene to address psychological distress. Care for individuals with high risk for hereditary breast cancer needs to also reflect this standard and become policy to assess and address these emotions. Central to practice, research, and policy implications is the need for expanded clinician education and awareness. As science advances and genetics becomes a part of standard healthcare, clinicians need to be equipped with knowledge to accurately care for, educate, and support individuals living with disease risk.

Limitations

The personal experience presented in this study was shared only by women who volunteered to participate and were partaking in a high-risk program in an academic cancer center. These women may be more motivated to seek care and have different experiences than other women living with high risk or receiving care in different types of centers and community settings. This study was also limited in ethnic variation, although attempts were made to recruit ethnically diverse women. As each person's story is grounded in the personal, social, historical, and cultural experience,²⁸ differences may be found between ethnicities and should be respected within clinical practice and future research. In addition, this study focused on women who are at high risk for breast cancer but have never had cancer, and therefore, it should be understood that variations may occur with women who have previously had a cancer diagnosis.

Conclusions

Healthy women living with high risk for hereditary breast cancer are living within the context of their family cancer story, which influences how they define themselves and engage in self-care. Seeking an expert through a specialized program is one way that women aim to control their risk. Future clinical practice, research, and policy should continue to understand the experience of living with hereditary breast cancer risk with an aim of

improving the current standard of care and promoting wellness and optimal personal health in persons living with high risk for hereditary breast cancer.

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Table 1

Interview Framework

Interview Question	Probing Question
Tell me a about yourself.	<ul style="list-style-type: none"> • I would like to understand background about you, please describe in detail a little about yourself.
Describe your personal risk for breast cancer.	<ul style="list-style-type: none"> • How does this make you feel? • How have your feelings changed over time? • Can you tell me what it is like to live at high risk for breast cancer?
Describe how you care for yourself because of this risk.	<ul style="list-style-type: none"> • Describe how you learned these strategies. • How does doing these things make you feel? • How is your life different now that you are doing these things?
Describe your experiences with attending the high-risk program.	<ul style="list-style-type: none"> • What brought you to attend the program? • How does attending this program make you feel? • How is this care different or the same as from other care that you have received?
Describe a memorable experience that you have with managing your breast cancer risk.	
Is there anything I haven't asked you or you would like to share?	

Table 2

Process of Hermeneutic Interpretation

Stage ^a	Process
1	Examine each original text (interview) to gain overall understanding.
2	Identify common themes from text to support interpretation of meaning.
3	Meet collectively as a research team to compare interpretations for similarities and differences, returning to text for clarification and further interpretation.
4	Reread all original text to link themes and determine exemplar quotations.
5	Develop constitutive pattern demonstrating interrelationship of themes across text.
6	Validate findings by sharing results with participants and comparing with literature.
7	Produce final manuscript with practical implications to be disseminated and validated by reader.

^aAlthough listed in a stepwise manner for ease of understanding, this process is dynamic, and often steps are addressed nonlinearly.^{27,28}

Table 3

Description of Sample

Demographic Data		n
Age, y	30	2
	31–49	7
	50–64	9
	65	2
Race	White	18
	African American	1
	Native American	1
Highest level of education	High school graduate	1
	Some college	5
	College graduate	8
	Graduate school	6
Income ^a	\$10,000–\$29,999	2
	\$30,000–\$49,999	2
	\$50,000–\$69,999	3
	\$70,000–\$99,999	5
	>100,000	7
Marital status	Married/partnered	16
	Single	4
Has children	Yes	16
	No	4
Genetic status	BRCA1	1
	BRCA2	3
	No gene mutation identified in family	7
	No genetic testing	9
Familial cancer–related death	Yes	13
	No	7
Currently experiencing familial cancer	Yes	3
	No	17
Referral to high-risk program ^b	Self	11
	Family member	8
	Clinician	2

^aOne participant did not disclose income level.

^bOne woman was referred by both her mother and clinician; that is why total n = 21, not 20.

Table 4Health Behaviors of Sample^a

Health Behavior		n (Total n = 20)
Body mass index, kg/m ²	Underweight: <18.5	0
	Normal weight: 18.5–24.9	9
	Overweight: 25–29.9	6
	Obese: 30	5
Current smoking status	Yes	4
	No	16
Exercise	Yes	7
	No	10
	Attempting	3
Chemoprevention	Yes	2
	No	18
Prophylactic mastectomy	Yes	1
	No	19

^aEight of the 11 women overweight or obese were postmenopausal; BMI criteria based on guidelines determined by the National Institute of Health51 (<http://www.nhlbisupport.com/bmi/>); the woman who had prophylactic mastectomy had a known genetic mutation; exercise was coded based on interview transcripts. If a woman discussed exercising, she was coded as “yes”; if she mentioned exercise being important but was not currently exercising, she was coded as “no”; and if she did not mention exercise at all, she was coded as “no.”

Table 5

Practical Advice for Women

Practical Advice	
Informational interpretation	<ul style="list-style-type: none"> • Bring information to experts to assist with interpretation. • Ask questions about health behaviors to understand importance.
Caring for self while undergoing recommendations	<ul style="list-style-type: none"> • Bring someone with you to appointment for support. • Utilize distractive techniques, such as exercise or being with family, to overcome fear of results. • Find humor in experience to overcome fear. • Prayer may be helpful. • Share emotions with others who support you.
Living with sadness and loss	<ul style="list-style-type: none"> • Understand that feeling sadness over the loss of a loved one is a normal process. • Share your emotions with others and your provider if you are comfortable. • Recognize the importance of your personal story. • Seek support from someone outside the situation to talk with about your feelings. • Prayer may be helpful.
Caring for yourself	<ul style="list-style-type: none"> • Recognize what is important to your personal health and wellness. • Seek guidance from experts and ask questions when determining what behaviors to change. • Seek help from experts when changing behavior, such as smoking cessation.