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Engaging in Medical Vigilance: Understanding the Personal Meaning of Breast Surveillance

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Purpose/Objectives: To explore how women with a hereditary risk of breast cancer experience living with and managing that risk through surveillance.

Research Approach: Hermeneutic phenomenology guided the qualitative research design.

Setting: The Facing Our Risk of Cancer Empowered online organization.

Participants: 9 women undergoing breast surveillance for hereditary breast cancer risk recruited through purposive sampling.

Methodologic Approach: Data were collected through semistructured interviews lasting about an hour. A team approach guided data analysis of transcribed interview text based on a modified Diekelman, Allen, and Tanner method.

Main Research Variables: Lived experience and personal meaning of hereditary breast cancer risk and surveillance.

Findings: Hereditary risk of breast cancer involves a change in one's view of life and necessitates engaging in medical vigilance, often making these women feel ill when they are otherwise healthy. Most have personal family experiences of cancer and value surveillance, although they live with the "what if" of a cancer diagnosis when waiting for surveillance results. All women discussed a need for accurate information, support, and guidance from healthcare providers.

Conclusions: Women became their own experts at living with and managing hereditary breast cancer risk. Experiences and interactions within the healthcare system influenced the meaning of breast surveillance.

Interpretation: Nurses should be aware of the high level of knowledge among women living with hereditary risk and respect their knowledge by providing accurate and informed care. That can occur only through proper education of nurses and all healthcare professionals working with women at risk for hereditary breast cancer so that they understand current standards of care and how hereditary breast cancer risk is defined and managed.

Mutations in the *BRCA1* or *BRCA2* genes account for 80% of hereditary breast cancers. Women with those mutations have a 36%–85% lifetime chance of developing breast cancer (National Comprehensive Cancer Network [NCCN], 2011). High-risk women hold a substantially elevated lifetime cancer risk burden compared to the average 12% risk of breast cancer in American women (National Cancer Institute, 2010).

Criteria suggesting hereditary breast cancer risk include a personal or close familial history of early-onset breast cancer (i.e., prior to age 50), ovarian cancer, or male breast cancer, or being of Eastern European descent (NCCN, 2011). Women are identified as high risk through evaluation of personal and familial risk factors and may undergo genetic counseling or testing based on that evaluation. Women identified as high risk for hereditary breast cancer through either evaluation mechanism are encouraged to practice surveillance through breast awareness or breast self-examinations, mammography, breast magnetic resonance imaging (MRI), and clinical breast examinations, as well as to consider chemoprevention or prophylactic surgery if indicated (NCCN, 2011). Breast surveillance begins at a younger age than general population breast screening, often at 25 years or based on clinical recommendations and the age at onset of cancer occurring within the family (NCCN, 2011).

Women with knowledge of a potential hereditary breast cancer risk often seek opportunities to enhance their health and control their cancer risk (Hamilton, Williams, Skirton, & Bowers, 2009). Therefore, women may choose to follow surveillance recommendations, thus interacting with the healthcare system about every six months for evaluation

(NCCN, 2011). Interactions may occur more frequently than the recommendations suggest, as additional follow-up is common because of the specificity of mammography and MRI (Warner, 2008; Warner et al., 2008). Additional follow-up may lead to distress in these women, mainly short-term anxiety (Gilbert et al., 1998; Watson, Henderson, Brett, Bankhead, & Austoker, 2005). The nature of the distress surrounding these appointments is important information for oncology practitioners, as the amount that a high-risk woman's life is dedicated to breast health is more than an average-risk woman and has the potential to make a greater impact. Therefore, the authors of the current study sought to explore the personal meaning of living with and managing hereditary breast cancer risk through surveillance.

Literature Review

Women undergoing hereditary breast cancer surveillance may be faced with uncertainties and fear related to developing breast cancer, as surveillance equates early detection of cancer, not cancer risk reduction (NCCN, 2011; Snyder, Lynch, & Lynch, 2009). Although surveillance does not decrease cancer risk, it may lead to more favorable outcomes by enhancing the ability to detect and treat cancer at an earlier stage (Kriege et al., 2004; Lehman et al., 2007). Knowledge of a high risk for hereditary breast cancer, which is known to increase cancer-related fear and distress (Dagan & Gil, 2005; Lynch, Snyder, & Lynch, 2009), coupled with a focus on early detection of cancer, has the potential to cause psychosocial concerns in this group of women.

The risk of psychological harm is validated further by evidence that hereditary breast cancer surveillance causes short-term psychological distress (Brain et al., 2008; O'Neill et al., 2009; Tyndel et al., 2007), particularly when abnormal results are found (Essink-Bot, Rijnsburger, van Dooren, de Koning, & Seynaeve, 2006; Henderson et al., 2008; Rijnsburger et al., 2004; van Dooren et al., 2005; Warner et al., 2008). Premenopausal high-risk women with no personal cancer history, high frequency of familial cancer, and a known genetic mutation have the potential for the greatest increase in psychological distress associated with surveillance (Henderson et al., 2008; van Dooren et al., 2005).

Potential exists for psychological distress associated with undergoing surveillance for hereditary breast cancer. However, an in-depth understanding of the experience regarding these surveillance appointments remains unclear. Much of the literature focuses on survey design methodology measuring women at a cross-sectional time point or prospective pre-established time points. Although that evidence is necessary when building an understanding of psychological outcomes associated with surveillance, it may not capture the subtle and variable experiences important when clinically caring for these women. An in-depth understanding should be explored to gain insight into the personal experiences present to enhance current literature and develop knowledge about the meaning of undergoing surveillance because of high cancer risk.

The purpose of this study was to understand what the surveillance experiences were of women living with hereditary risk of breast cancer. The primary aims were to (a) recognize the common meanings and shared practices of managing hereditary breast cancer risk, (b) understand the practical knowledge women apply to living with risk, and (c) appreciate the value of available resources (e.g., online resources, healthcare providers).

Research Approach

Heideggerian hermeneutic phenomenology guided the qualitative research design (Heidegger, 1962). Hermeneutic phenomenology is grounded in the personal, social, and historical context in which each individual is living (Plager, 1994). When interpreting data obtained from hermeneutic studies, the context is not removed and, therefore, results yield the personal meaning associated with a phenomenon (Annells, 1996). Personal meaning reflects the way in which people are situated within their world and how they engage and live in this situation within the context of what is most important to them (Diekelmann, Allen, & Tanner, 1989). Healthcare providers, particularly nurses, should be aware of meaning, as it guides an individual's actions. Therefore, to be able to provide anticipatory guidance and support—a main goal of nursing care—the personal meaning of experience is vital (Sandelowski, 2004).

Setting and Sample

Sampling was purposive to recruit women undergoing breast surveillance for hereditary breast cancer. Women were asked to volunteer for the study and were included if they spoke English, consented to participate, were at high risk for hereditary breast cancer based on the NCCN (2011) criteria, and were undergoing breast surveillance.

Recruitment was done within the Facing Our Risk of Cancer Empowered (FORCE) community. FORCE is a national online forum for individuals with hereditary cancer or hereditary cancer risk, mainly breast and ovarian cancer (www.facingourrisk.org). FORCE offers information and support for members living with cancer risk. Recruitment occurred at the FORCE annual conference and through the FORCE Web site with the help of the FORCE director. Most participants were informed of the study through the FORCE Web site and one learned of the study at the FORCE conference. All participants who volunteered were eligible and, therefore, were included in the study.

Research Procedures

Approval was obtained from the University at Buffalo institutional review board prior to data collection and all participants completed informed consent prior to being interviewed. An interview guide provided a data collection framework (Cohen, Kahn, & Steeves, 2000) (see Figure 1). Interviews were tape recorded, with seven taking place over the telephone and two in person. Interviews lasted 45 minutes to two hours. Relevant demographic data were collected at the completion of each interview. Field notes were written immediately following each interview to capture the context of the interaction. Data were collected from May 2009 to August 2009. All interviews were transcribed, deidentified, and verified as accurate compared to the original tape-recorded interview by the principal investigator.

Interpretation

Consistent with hermeneutic methodology (Armour, Rivaux, & Bell, 2009; Diekelman et al., 1989), the data were independently and jointly interpreted by the principal investigator (first author) and a nurse scientist (second author) with expertise in phenomenologic methodology.

Data interpretation was guided by Diekelmann et al.'s (1989) and Armour et al.'s (2009) methodology. Based on that approach, both researchers reviewed and coded transcripts independently, writing narrative summaries. They then collectively identified and discussed themes present until a consensus occurred and then extracted example quotations from the narrative text to support emerging themes. Any discrepancies occurring between the researchers were resolved by returning to the interview text for additional interpretation. The analysis process continued through the act of writing and by developing a constitutive pattern that captured the essence of the surveillance experience. A matrix was created based on participants' responses to confirm that data saturation of each theme had occurred. Data collection stopped when no new information was yielded from the interviews. Descriptive data analysis of demographic information was performed in SPSS®, version 17.0.

Results

Sample

Participants included nine Caucasian American women (see Table 1). All of the women reported having had breast MRI and mammography during the past year. Participants were dispersed geographically throughout the United States, living in the Northeast (n = 4), Southeast (n = 2), Midwest (n = 1), and Northwest (n = 2).

1. How did you find out about your breast cancer risk?
2. How does this influence your life in general?
3. How do you manage your risk for breast cancer?
4. Describe in detail your last breast screening experience.
5. Describe your interactions with your healthcare provider regarding breast screening.

Figure 1. Study Interview Guide

Emerging Themes

Six themes and one constitutive pattern emerged from the interpretation of the interview text.

Being aware of familial risk: The women's narratives all began with stories of their past experiences with cancer, both breast and ovarian. For most women, their family history made them aware of increased breast cancer risk and led them to form expectations about a future cancer diagnosis. For example, women expected diagnosis at a similar age and type of familial cancer prevalent—particularly in the mother. Women had undergone genetic testing and, therefore, their own subsequent genetic test results often confirmed an already known risk, as shared by one woman.

> My mother, grandmother, great-grandmother, and my great-grandmother's three sisters all had breast cancer and passed away from breast cancer. So, it has always been in my life. And from a young age, probably teenage, I just kind of assumed that was my destiny.

One woman explained her orientation to risk after she witnessed her mother go through ovarian cancer, but had not understood its relevance to her own risk for breast cancer.

> For the longest time for me, I was disconnected from the risk of breast cancer because my mom had ovarian and I watched her die from it. For me, ovarian was going to be my big risk. So, the mammograms were almost more routine for me. I would have been extremely surprised to see something come back. It was just not really what I was anticipating; I know logically on paper, you know, if you look at the statistics, it doesn't make sense, but that was just kind of my gut feeling—oh, that is not my cancer, this is my cancer.

Changing life view by increasing awareness: Although the women had expected their cancer risk, it was confirmed with genetic tests or when they approached the age of a family member who had cancer. They sought more information about their risk from the FORCE Web site, which included options for prophylactic surgery, medications, and surveillance. That initially was overwhelming for some women, so they chose surveillance to manage the risk "for now" as they continued to consider their options and potential risk-reducing behaviors.

The frequent medical attention of having surveillance appointments, often from oncologists, was cancer-focused, and some women began to view themselves as ill instead of healthy. One woman talked about her experience of incorporating breast surveillance into her life.

> I don't like how medicalized my life has become. It feels like every six months I've got to do something and in the meantime I'm supposed to be worrying about it, you know? Checking, trying to be vigilant, and all of that . . . whenever I go in, it feels like calling [emergency phone number] when you don't have an emergency. That is kind of the feeling for me.

Women shared that the meaning of their lives had shifted focus to cancer prevention and early detection as they learned to manage their hereditary risk. Prior to beginning surveillance, the women had felt at risk, but cancer prevention had not been as big a part of their daily life.

Creating a routine to maintain vigilance: Women initially found surveillance intrusive until they formed a surveillance routine over time. The most difficult part of surveillance often was scheduling and "fitting it all in" along with other life responsibilities (e.g., work, school, family). One woman, who had known of her *BRCA2* mutation status for three years, found a way to "make it work" by scheduling the MRI early in the morning before work. However, sacrifices were made to make that happen. For instance, she could not premedicate with sedative agents to make the procedure more comfortable, because then she would not be alert for work. Other women who had begun surveillance within the past year found it more difficult, as they had not yet established a routine and still were undergoing all of the initial follow-ups and appointments, along with the initial stress of learning their cancer risk.

Over time, women developed a surveillance routine. One woman, who had been following a surveillance plan for 20 years, found that surveillance did not impact her everyday life. She equated surveillance with "visiting the dentist" and considered it "just part of life."

> I really don't have anxiety when I go [for surveillance appointments]. It is kind of strange to me because I know a lot of high-risk women who have to take a sedative before they go for mammography . . . I don't really understand why I don't get nervous. It seems like I should and I don't really feel like I do . . . you know [I] have been doing this for, like, 20 years; it is a routine. You do it like the way you go get your teeth cleaned; it is just part of who you are.

Living with medical vigilance: Overall, women were appreciative of surveillance as a way to evaluate their current cancer status, particularly after learning of their genetic risk; however, they described a subtle sense of fear that pervaded these visits. They described the absolute need to be vigilant of impending diagnosis because they now felt viewed as a future patient with cancer, as the statistics portended. Those reminders often confronted the women during the screening visit as they waited for a potential diagnosis and they were relieved when all was declared clear. As one woman explained,

> Well, I'm here with this heavy-duty medicine that is really expensive. And I doubt I have breast cancer. But I shouldn't doubt it because someday they may be calling me back saying, "Oh, yeah, we did find something." I mean, that is as likely as not if my chance is 50%.

Another woman related that "the meaning of screening had changed" for her after identifying her hereditary risk. She had undergone mammography screening prior to having hereditary risk knowledge, but now as she went for surveillance, it represented her risk and a more serious chance for cancer to be detected. She felt as if the

Table 1. Sample Characteristics

Characteristic	$\bar{X}$	Range
Age (years)	42.3	27–63

Characteristic	n
Age (years)	
20–29	1
30–39	2
40–49	5
50–59	–
60–69	1
Race	
Caucasian	9
Marital status	
Married	5
Partnered	2
Divorced	1
No response	1
Income ($)	
10,000–29,999	1
30,000–49,999	1
More than 50,000	6
No response	1
Education	
Some college	1
College graduate	3
Graduate school	5
Clinical characteristics[a]	
Personal history of cancer	2
BRCA1 mutation	3
BRCA2 mutation	4
Unknown variant	1
Strong family history	1
Family history of breast cancer only	2
Family history of ovarian cancer only	1
Family history of breast and ovarian cancer	5
No family history	1

N = 9

[a] Participants could offer multiple responses.

procedure was no longer just screening, but a means to confirm her fears that she now would have cancer.

These women talked about "not expecting to find anything," but worrying "what if." Each time they were screened, they "hoped that [they] had made the right decision" and "were somber, thinking, 'This is it, they could find cancer.'" The feelings of risk were influenced by the family member's age at diagnosis, as shared by one woman. "I didn't think they would find anything," she said. "I just felt, I'm younger than my aunts when their onset occurred."

The women described adding MRI to their surveillance regimens. Initially, MRI caused some anxiety, as it was a new part of their routine. Women felt that MRI was more likely to detect cancer if present; however, once they had a clean bill of health, the MRI gave them some "peace of mind" because it gave them "a different way of looking at things." One woman shared her story with MRI.

> I was definitely more nervous with the MRI. Number one, because it was my first experience with having an MRI in general. I was more nervous about the results. I had been having mammography and they were fine and this is going to look at things new, so this might be it.

Living through abnormal surveillance results: Most of the women's stories included descriptions of abnormal results. This was a "shock," an "eye opener," and caused women to think "Oh no!" and that they had breast cancer. The stories described how time stood still during the testing as they carefully observed the reactions of the healthcare providers, trying to interpret the reality with thoughts running through their minds. Often, the healthcare providers' reactions confirmed their concern. Women felt that radiologists and technicians who understood hereditary risk viewed them as someone who would be diagnosed with cancer.

Some women would talk themselves through the situation. With this self-talk, they calmed themselves and reassured themselves that they would be okay. That helped them to control the anxiety they felt about developing cancer.

> The technician doing the ultrasound just kept going back and forth over this area and looking on the screen saying, "I do see something here. I'm going to mark this." She asked me, "You have a family history of this, don't you?" I said yes. She said, "I'm going to go and talk to the doctor; wait here, I'll be back." I sat there in the room for about 10 minutes and you are just kind of like "Oh no! Not this, come on." Then I would reassure myself. "No, it's nothing, you're going to be fine." The doctor went back and forth over the area and could see where the technician was talking about, [and] she said, "I do see something here but I don't really see distinct borders on it. I'm going to refer you to get an MRI next week." So then my heart sunk a little bit and they asked me if I was worried or if I was okay and I said, "No, I'll be fine." There isn't really much you can do about it.

Additional diagnostic evaluation, particularly biopsies, created strain on women because it required more time out of their schedule and perhaps meant finding the cancer they feared.

> It was like, "Oh my God, how can I possibly be 27 and have cancer." What a fluke that it would be that I just happened to start and get this test and start this screening and then they find something, so it was kind of relief being in there but really scary holding your breath until you find out if it is benign or not.

> I finally got in and the doctor did the ultrasound and he says, "Well, I don't see anything and that is common; half the time we don't see anything." Then, of course, "What I have to do next is have you come back for a MRI-guided needle biopsy." I was so frustrated. I said, "Well, if you know half the time that it's not going to work, why couldn't you schedule both of those things so I'm not coming back here?" I'm already worried that this is something.

One woman dealt with the stressor through humor by laughing about her experience and making fun of its negativity as she told her story.

> I waited there three hours for my ultrasound. And I was so frustrated. It felt like a prison, there were all of these women and they were all sitting around in their pink gowns. They had carnations in the room and cookies for you and water, and whatnot. But by the end of the time I felt like this is like a prison you can never leave! (laughing) It was a horrible experience!

Becoming an expert: All women had a story about the inexperience and lack of knowledge of their primary healthcare providers, gynecologists, or radiologists regarding care for high-risk women or those with a *BRCA1* or *BRCA2* mutation. One woman talked about a need to educate her primary care provider about how to care for a woman with hereditary breast cancer risk.

> My first appointment was kind of a nightmare. The doctor didn't really know much about the *BRCA* gene mutations. He was more of an oncologist. So, me not having cancer, he couldn't understand why I was there. I tried to explain to him that all of this made me at increased risk for cancer and I just want to see someone to start screening. He was just very alarming and not very knowledgeable.

Another woman was not satisfied with her breast MRI experience and did not trust her radiologist and subsequently an entire hospital system because of a lack of perceived high-quality care.

> So I went for the MRI . . . It was like getting tested by the Three Stooges . . . I felt like they were very far behind in what they were doing. They had 30-year-old paperwork sitting out that nobody had bothered to update. They knew nothing about *BRCA1* or *BRCA2*, when they asked about my family history, they asked about my mother's side of the family, [but] did not ask about my father's side of the family. So, the lack of information and interest in the patient was pretty shocking.

All women stated that they would like more information and support from the providers involved in their care. That was particularly true for women who lived in rural areas who did not have access to specialists.

> Your average physician is not necessarily the specialist, but it just kind of drives the point home that a lot of people don't really know what this stuff is and it's kind of frustrating for me to have to go in for these screenings and have to explain why I think I need them to people who probably think that I'm a hypochondriac.

Women who had access to centers that specialized in hereditary breast cancer felt that their needs were better met through being offered information and support by specialists. They stated that they "felt lucky" about having access to specialty centers.

Those not receiving care from specialists recognized that their primary providers were not experts in caring for women at hereditary risk for cancer, which led them to seek additional resources, such as FORCE or the Internet.

> If I didn't have FORCE, there are so many ways things could have gone wrong. . . . I'm glad to have the collective wisdom of people who have been through this. I wouldn't even know about all these options for one, and I think I would have made some mistakes like with the hysterectomy if I hadn't had people to run interference a little bit.

Although the FORCE community and online resources were beneficial, some women needed more individualized support to meet their unique needs. One woman related her need for more local support from women in similar situations who understand her needs.

> For me, FORCE is fine, but the nearest social group is in the [different city] area and that's a trek to go to, so I don't. So I just wish that there were more groups. There is a breast cancer group here, I've gone to some of their sessions—not their sessions for women who have breast cancer, but about reconstruction and all those other things that might be relevant to me. But in that group you don't feel like you fit either because these are women who have had breast cancer or who have breast cancer. So that's a different ball game then, as they say, as being a pre-vivor.

Women shared that at times the amount of information provided by FORCE could be overwhelming. When that occurred, the women described the need to often "walk away" from the information provided on the Web site or at the conference to avoid feeling overwhelmed. FORCE helped guide the thinking process, but ultimately women had the responsibility of interpreting and applying the information to meet their own needs.

Constitutive Pattern

Becoming an expert on hereditary breast cancer by learning to maintain medical vigilance: Each of the six themes was connected with a pattern reflecting a need for women to become informed about hereditary risk and be their own vigilant care advocates. Women reported that some of the care providers in the current health system were not proficient about hereditary risk to provide appropriate guidance. That led them to seek resources at FORCE and become their own expert, which taught them practical solutions to approaching their hereditary breast cancer risk.

Because of the increased risk of breast cancer, women expected themselves to know more about how to prevent and detect cancer. They had made themselves experts in hereditary breast cancer, which also changed their life view to an increase in medical vigilance as they incorporated health information into their lives, changing the focus from health to illness. One woman with a *BRCA2* mutation best summarized that phenomenon and how it changed her life.

> I went from somebody who has always been extremely healthy and rarely ever gone to a doctor to somebody who has been to a whole bunch of different doctors, and gotten a bunch of different tests. So I guess my life in some ways has changed dramatically because of health. I am . . . not concerned too much about anything like cancer but now I'm doing everything I can to prevent it.

Discussion

Through an interpretive approach of listening to women's surveillance experiences, the current study brought to light the influence of the contextual background of women's lives at high risk for breast cancer on making meaning and gaining practical knowledge in managing their risk, as well as the value of available resources. A geographically dispersed group of women was accessed

using a modernized interview style, incorporating telephone interviews and online recruitment into a qualitative research design. Participants welcomed the idea of telephone interviews. The telephone environment allowed women to speak freely and also meet with the researcher at a time that was most convenient, which decreased patient burden and accelerated recruitment. The findings will be summarized according to study aims.

Study Aims

Recognize the shared meanings of living with breast cancer risk: Women collectively reported that their perceptions of risk and living with risk were influenced by family experience. That is reflective of current literature that supports women identifying their risk within the familial context (Hamilton & Bowers, 2007; Hamilton, Williams, Bowers, & Calzone, 2008; Norris, Spelic, Snyder, & Tinley, 2009). For all women, screening offers a chance to detect cancer; however, for those living with high risk, the meaning of surveillance is different because of the familial context. In the view of high-risk women, their past cancer experience caused themselves and providers to react to surveillance results as if they would someday have cancer, rather than just the risk, which influenced their personal feelings toward risk. That is significant because accurate risk perception may influence breast screening behaviors (Katapodi, Lee, Facione, & Dodd, 2004). The current study adds an understanding that meaning of cancer risk is situational, based on the encounters a women has had with cancer in the past and also the contextual framework in which she lives her daily life. The study also demonstrates that a woman continues to weigh her options toward chemoprevention and surgery even when undergoing surveillance.

Knowing their risk made the women in the current study transition from feeling healthy to feeling ill as they began surveillance. Similarly, asymptomatic Israeli *BRCA1* and *BRCA2* carriers lived in a condition of neither feeling ill nor well as they faced invasive surveillance procedures in the absence of a disease (Dagan & Gold blatt, 2009). The current study adds to that knowledge by recognizing similar experiences reported in women from U.S. and Middle Eastern cultural backgrounds.

Women's experiences with breast MRI are not well represented in the literature. The current study explored experiences with all aspects of breast screening, including mammography and MRI. Although the women did not describe acute distress during the screening procedures, having radiologists and radiology staff informed about hereditary risk may improve the quality of the experience.

Understand practical knowledge women apply when managing risk through surveillance: Figure 2 summarizes the things that improved women's experiences with breast surveillance. The figure is a summary of practical solutions that were incorporated into all six themes. The main way that women cared for themselves practically was to become an expert in hereditary risk and maintain medical vigilance, which guided how they subsequently chose to manage their risk.

Educational Resources
- Facing Our Risk of Cancer Empowered community and Web site (www.facingourrisk.org)
- High-risk breast specialists and centers

Developing a Routine
- Set routine around other life priorities (e.g., schedule before work).
- Consistently see the same provider for surveillance.
- Self-talk to maintain optimism and get through negative situations
- Find humor in negative situations.

Improving Comfort
- Listen to music during magnetic resonance imaging.
- Prop head on pillow during magnetic resonance imaging.

Advice for Providers
- Make referrals to high-risk breast specialists, as necessary.
- Become educated in hereditary breast cancer if involved in the care of those with hereditary risk.

Figure 2. Practical Information to Improve Women's Experience With Breast Surveillance

Appreciate the value of available resources: The women in the current study became their own most valuable resource. Although they have FORCE and health professionals, they learned that they alone needed to make their health decisions based on their own perceptions and needs.

Women recognized that their general healthcare providers lacked information pertaining to the care needed to manage their hereditary risk. The lack of hereditary breast risk experts available led women to learn how to manage risk in the absence of a clinical expert. The women shared that the current healthcare community was focused on the medical vigilance of surveillance, which is disease-centered, often making the women feel that they were ill in the absence of actual illness. Those women involved in a high-risk breast center or specialized breast care center reported better surveillance experiences. Evidence from the literature supports the finding that women seek specialist care to facilitate the surveillance process (Appleton, Fry, Rees, Rush, & Cull, 2000; Parsons, Beale, Bennett, Jones, & Lycett, 2000) and primary care providers need to recognize that when caring for this population of women.

Limitations

All women were recruited from the FORCE organization, which is a group of highly motivated and well-educated women who report sufficient knowledge about hereditary risk. That may differ from women who do not actively seek online support. Also, all women in the

study were Caucasian American, which poses limitations to understanding this experience within a different cultural context. In addition, two women had experienced a personal cancer diagnosis. Although differences did not emerge in this analysis, that adds a new dimension to the context of the participants and should be explored further in future research. In addition, the focus of this study was on the breast surveillance experience; however, as many of these women had a family history of both breast and ovarian cancers, exploring experiences with both types of cancer surveillance is warranted in future research.

Implications for Nursing Practice

Advancing research should explore how women live with surveillance and form their self-identity within the context of hereditary risk to better understand how to provide perceived high-quality care and maximize a woman's potential to control hereditary breast cancer risk. Part of how surveillance is incorporated into a woman's life is shaped by the patient-provider interaction. Exploring the meaning of why women seek specialist care, and what part of this interaction is most meaningful, will help shape that understanding. Increasing the understanding of how healthcare providers influence surveillance behaviors and experiences will play a crucial role in developing care. Future research also should seek to understand what women mean by undergoing surveillance "for now" and what influences their decision making.

Results demonstrate that healthcare providers are lacking the necessary tools to help care for high-risk women, which causes women to become their own experts. Nurses should be aware of the high level of knowledge women living with hereditary risk have, and respect their knowledge by providing accurate and informed care. That can occur only through proper education of nurses and all health professionals working with women who have hereditary breast cancer risk about current standards of care and how hereditary breast cancer risk is defined and managed. Results also suggest that general providers should use available resources, such as specialty centers focusing on hereditary risk, so that women have the potential to maximize the care they receive and improve their perceived quality of care.

In addition, the current study suggests that nurses can provide more appropriate support to high-risk women. Women living within a context of hereditary risk experience surveillance based on their past cancer experiences and future cancer possibilities. These women may view surveillance differently than average-risk women, and their care should be tailored to meet their unique needs.

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