

Cancer Risk Management Decision Making for BRCA+ Women

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Abstract

Women with pathogenic *BRCA* genetic mutations face high risks for cancer development. Estimates vary among mutation carriers, with lifetime risks ranging from 41% to 90% for breast cancer and 8% to 62% for ovarian cancer. Cancer risk management options for *BRCA* mutation positive (*BRCA+*) women have life-altering implications. This qualitative, phenomenological study explored the experience of cancer risk management decision making for women who are unaffected carriers of a *BRCA* mutation (previvors). Fifteen previvors recruited from Facing Our Risk of Cancer Empowered (FORCE), an online informational and support group, were interviewed. Findings consisted of four major themes: the early previvor experience, intense emotional upheaval; the decisional journey, navigating a personal plan for survival; lack of knowledge and experience among health care providers; and support is essential. Findings highlight the different decisional perspectives of previvors based on age and individual factors and the need for increased competence among health care providers.

Keywords

BRCA, genetics/genomics, oncology, qualitative, phenomenology

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Approximately 1 in 400 Americans carries a pathogenic *BRCA1* or *BRCA2* mutation. *BRCA* mutations cause a hereditary syndrome, characterized by specific patterns of cancer development within a family, and the majority of hereditary breast and ovarian cancer (HBOC) is associated with *BRCA* mutations (National Comprehensive Cancer Network [NCCN], 2013; Welch & King, 2001). Compared with the 13% risk for breast cancer and less than 2% risk for ovarian cancer in the general population, *BRCA* mutation positive (*BRCA+*) women's risks are dramatically higher. The probability of developing cancer varies among carriers based on individual and familial factors (Antoniou et al., 2003), with lifetime estimates ranging from 41% to 90% for breast cancer and 8% to 62% for ovarian cancer (NCCN, 2013). Estimated cumulative risk by age 70 for women with *BRCA1* mutations is 55% to 65% for breast cancer and 39% for ovarian cancer. Estimated cumulative risk for those with *BRCA2* mutations is 45% to 47% for breast cancer and 11% to 17% for ovarian cancer (Antoniou et al., 2003; National Cancer Institute [NCI], 2013). Current cancer risk management recommendations for previvors (unaffected *BRCA* mutation carriers) include options for prophylactic mastectomy, prophylactic oophorectomy, intensive surveillance, and chemoprevention (NCCN, 2013).

Each option for cancer risk management has potentially negative outcomes that must be considered. The decision-making process is complex, with life-altering implications that differ with each choice and change over time. Prophylactic surgeries afford the greatest cancer risk reduction benefit. Bilateral prophylactic mastectomy reduces the risk of developing breast cancer by more than 90%. Bilateral salpingo-oophorectomy not only reduces the risk of developing ovarian cancer by 80% to 90% but also reduces the risk of breast cancer by 50% (NCCN, 2013; Rebbeck, Kauff, & Domchek, 2009; Schwartz et al., 2003). However, in addition to surgical risks, bilateral prophylactic mastectomy has effects on body image and femininity, and precludes breast feeding; and prophylactic oophorectomy results in menopause and loss of fertility (Armstrong, Schwartz, Randall, Rubin, & Weber, 2004; Finch et al., 2011; NCI, 2013).

Chemoprevention is a second option for cancer risk reduction. Oral contraceptives reduce the risk of developing ovarian cancer in *BRCA+* women by up to 70% (Iodice et al., 2010; NCCN, 2013; Rice, 2010; Whittemore et al., 2004). Few studies have been done to evaluate the use of tamoxifen or raloxifene in previvors. In a randomized clinical trial, tamoxifen was shown to decrease breast cancer incidence in *BRCA2* previvors by 62%, but there were no significant findings in the *BRCA1* group (King et al., 2001). Few previvors report having used tamoxifen or having discussed it with their providers (Metcalf et al., 2005).

A third option for cancer risk management is intensive screening. Although risk is not reduced, there is a survival benefit to early detection of both breast and ovarian cancer. For BRCA+ women, current recommendations for breast cancer screening are mammography and magnetic resonance imaging (MRI) annually, performed on Day 7 to 15 of the menstrual cycle for premenopausal women, beginning at age 25 or based on the earliest age onset of disease in the family; clinical breast exams semi-annually starting at 25; and monthly breast self-exams beginning at age 18 (NCCN, 2013). Due to the lethality of ovarian cancer and the low predictive value of screening measures, prophylactic oophorectomy remains the primary recommendation for previvors between the ages of 35 and 40 when childbearing is complete (Balmana, Diez, Rubio, & Castiglione, 2010; Kurian, Sigal, & Plevritis, 2010; NCCN, 2013). For those who choose not to have this surgery, transvaginal ultrasound and CA-125 antigen blood tests should be considered every 6 months starting at age 30 or 5 to 10 years earlier than the earliest age onset of ovarian cancer in the family (NCCN, 2013).

The challenge of decision making for BRCA+ women lies in the complex process of weighing risks and benefits of cancer risk management choices over a lifetime (Balmana et al., 2010; NCCN, 2013; NCI, 2013). Health care professionals' assessment of risk perception, fear, anxiety, and apprehension are important issues in counseling and managing HBOC families (Berliner & Fay, 2007; Lynch, Snyder, Lynch, Riley, & Rubinstein, 2003). For BRCA+ women, genetic counseling and support in the decisional process (Chen et al., 2002) with consideration of individual needs and concerns are paramount (Schwartz, Peshkin, Tercyzk, Taylor, & Valdimarsdottir, 2005). Experiences of cancer within the family, particularly the loss of a mother, influence cancer risk management decision making (Hamilton, Williams, Bowers, & Calzone, 2009). Open communication with friends, family, and significant others reduces feelings of stigmatization and isolation and decreases psychological distress (den Heijer et al., 2012). Young previvors rely heavily on parents for support and although formal support reduces distress, services are often unavailable or underutilized (Werner-Lin, 2008b). For 18- to 24-year old previvors, readiness, autonomy, and confidence in making cancer risk management decisions are evolutionary processes. In this process, parents are a strong means of support (Werner-Lin, Hoskins, Doyle, & Green, 2012).

BRCA+ women view themselves as being genetically damaged and are concerned about passing on a mutation to biological children. This concern is tempered by the hope for future, positive developments in genetics and cancer risk management, and in most cases does not deter them from deciding to have children (Hamilton, 2012; Werner-Lin, Rubin, et al., 2012). Among childless BRCA+ women, knowledge of a deleterious mutation overshadows

dating and establishing intimate relationships. They feel a sense of urgency to find a suitable partner and have children before having prophylactic surgery or being diagnosed with cancer (Hamilton & Hurley, 2010; Werner-Lin, 2008a). For BRCA+ women with children, the desire to survive for the sake of children leads to the decision for prophylactic surgery (Hamilton, 2012). Other factors that lead to prophylactic surgery are fear of cancer, anxiety, and high perception of cancer risk. Concerns about body image, surgically induced infertility and menopause, and fear of surgery lead to decisions against or to delay prophylactic surgery (Hallowell, Jacobs, Richards, Mackay, & Gore, 2001; Schwartz et al., 2003). For BRCA+ women, an experience of breast cancer in a close family member is a predictor for prophylactic mastectomy; likewise, a family experience of ovarian cancer is a predictor for prophylactic oophorectomy (Metcalfe et al., 2008). *BRCA* mutation carriers who undergo prophylactic mastectomy and/or prophylactic oophorectomy report a greater sense of control over their susceptibility to breast and ovarian cancer and a reduction in fear after surgery as compared with those who choose surveillance (van Oostrom et al., 2003).

Over time, previvors maintain awareness of their cancer risk but adapt and change thoughts and behaviors. Engaging in healthy lifestyle behaviors, accepting prevention measures, and adapting to changes in relationships are transitions that occur (Hamilton, Williams, Skirton, & Bowers, 2009).

In this study, BRCA+ cancer risk management decision making is conceptualized as an intellectual and affective process of weighing the pros and cons of cancer risk management options with consideration of personal factors. Phenomenology, a qualitative approach to inquiry used in the study, provides rich and valuable data that contribute to a better understanding of the lived experience of cancer risk management decision making for previvors. Few phenomenological studies have been done in previvors.

Purpose

The study's purpose was to explore the experience of cancer risk management decision making for women who are unaffected carriers of a *BRCA* mutation (previvors).

Method

Design

The study incorporated a qualitative, phenomenological design outlined by Moustakas (1994). Through phenomenological inquiry, the researcher sought

understanding of the lived experience of decision making for women who are BRCA+ previvors.

Sample

Purposive sampling was used to obtain participants for the study. Fifteen participants were recruited from Facing our Risk of Cancer Empowered (FORCE), an online informational and support group. After 15 interviews, the researcher noted data saturation, which determined the final sample size. A recruitment flyer with information about the study was posted on the website and made available in a public area during the FORCE annual conference. Women aged 18 years or older, who were self-reported, unaffected carriers of a *BRCA1* or *BRCA2* genetic mutation, were eligible to participate in the study.

Data Collection/Analysis

Participants who completed voluntary informed consent chose to be interviewed either by phone or in person. Nine were interviewed in person; six by telephone. Interviews were audiotaped, lasting 25 min to 1 hr using a semi-structured interview guide. Participants received a US\$25.00 stipend as compensation for their time.

The researcher began the analysis by identifying all significant statements relevant to the phenomenon of interest. Statements that were repetitive or irrelevant to the chosen phenomenon were deleted. Significant statements with similar meanings were then clustered into themes. Interviews were conducted until data saturation of themes was achieved. This is the point at which the researcher no longer found new information that added to the understanding of themes. From textural descriptions of what the participants experienced and structural descriptions of how it was experienced, the nature and meaning of the lived experience was revealed. Finally, the researcher integrated the structural-textural descriptions into a unified statement; a composite description of the essence and meaning of the experience as a whole. NVivo 9® software was used to organize and classify data.

Epoche and bracketing are processes in which the researcher attempts to record and set aside preconceived ideas to avoid bias in approaching the research topic (Moustakas, 1994). These processes, along with careful maintenance of an audit trail of data, and consultation with an expert qualitative researcher for review of data and validation of themes were methods used to establish trustworthiness in the study. The Institutional Review Board (IRB) of the University of Massachusetts Lowell and the Executive Director of FORCE approved the study.

Table 1. Sample Characteristics (N = 15).

Characteristic	n (%)
Race/Ethnicity	
Caucasian	11 (73%)
Caucasian/Jewish	3 (20%)
Hispanic	1 (7%)
Marital status	
Single	5 (33)
Married	9 (60%)
Divorced	1 (7%)
Have children	6 (40%)
Initial counseling by	
Physician	6 (40%)
Genetic counselor	6 (40%)
None	3 (20%)
BRCA1	6 (40%)
BRCA	9 (60%)

Results

The final sample included 15 women from all 4 regions of the United States and Canada. The majority of the participants were Caucasian, well-educated, and had high household incomes. All were working or college students, and all had health insurance. All participants reported having a primary health care provider and 11 (73%) reported having an oncology specialist. The sample included women ranging in age from 21 to 63 and was evenly distributed in terms of premenopausal and peri/post-menopausal status. All subgroups differing in cancer risk management decision-making choices related to being BRCA+ were represented. Sample characteristics are further summarized in Table 1.

The Early Previvor Experience: Intense Emotional Upheaval

Four significant themes emerged from the data (see Table 2). The first theme was the early previvor experience: intense emotional upheaval. For previvors in the study, the emotional experience at diagnosis of a *BRCA* mutation was profoundly traumatic and overwhelming. They expressed an acute awareness of vulnerability not felt previously, despite feeling prepared for a positive diagnosis. The early previvor experience was characterized by shock, debilitating fear, loneliness, depression, uncertainty, and a sense of urgency to make protective decisions for themselves and their families. Previvors had

Table 2. Significant Themes.

Significant themes/subthemes	Example
1. The early previvor experience: intense emotional upheaval.	1. "It just was emotionally so much heavier than I expected." "It's like having a little bit of cancer."
2. The decisional journey: Navigating a personal plan for survival. <i>Subtheme</i>	2. "The journey is different for every individual."
a. Decisional factors: age, fertility and breast feeding, relationships with significant others, body image changes, caring for dependent children, memories of cancer among family members, and ongoing risk balance analysis	a. "... we all have to respect everybody's path and where they are in life—and how old they are—and where they are in their partnership, or marriage, or child rearing or not—or whatever . . ."
3. The lack of knowledge and experience among health care providers.	3. "I need a guiding light . . . someone who has experience and knowledge in this area and supports me."
4. Support for previvors is essential.	4. "Don't go it alone" "I need a sisterhood."

difficulty coping with the news, and receiving results by phone or mail was a universally negative experience. Amanda (all names used are fictitious) shared,

. . . Even though I wanted that information, the emotional consequences of knowing have been more difficult to deal with than I anticipated . . . they actually notified me over the phone when the results came in, and that was kind of awful. I was just kind of in shock . . . It just was emotionally so much heavier than I expected.

Heidi related her experience of receiving a positive result to that of a cancer diagnosis:

You almost, in some ways, feel like you have been diagnosed with cancer, even though you haven't. You feel closer to having been diagnosed with cancer than you would have the day before . . . it feels like it's a little bit of cancer even though it isn't.

Although all participants were under the care of a health care provider when mutation testing was done, three participants reported receiving no initial counseling around the time of testing. Of those who received counseling,

several described it as being insensitive and impersonal. At the time of the interviews, Myriad© laboratories held the patent on *BRCA* mutations and was thus the only laboratory authorized to do *BRCA* mutation testing in the United States (Myriad, 2011). Myriad requires that testing be submitted through a health care provider. Heidi described receiving her results by mail from her provider:

I don't know if you've seen the package they send you when you get the testing done. I mean they have this huge headline that says (with emphasis) positive for deleterious gene mutation. It's huge! So it's like a neon sign and unless you've been properly prepared for it—you just kind of look at this stuff and you go—like oh my God! And as you read through it, it's pretty upsetting.

Feelings of fear of cancer and concern for the future were characteristic of the previvor's experience at diagnosis. Heidi described a fearful urgency to take action on receiving positive test results saying, "I felt like a time bomb."

The Decisional Journey: Navigating a Personal Plan for Survival

The second major theme was the decisional journey: navigating a personal plan for survival. Participants described a realization that they needed to make important cancer risk management decisions to ensure survival. They also recognized that the choices for cancer risk management would affect other significant life issues. For previvors, cancer risk management decision making was complex, changed with age, and had effects across the lifespan. Decisions differed based on each woman's unique characteristics, preferences, and situations. Previvors repeatedly described the decision-making process as a journey; a lifelong risk balance analysis, with each cancer risk management decision having different pros and cons that changed over time. Weighing these pros and cons to make choices based on individual factors and preferences characterized the decisional journey.

Several issues emerged as important factors in the decisional journey. These issues constituted a subtheme, decisional factors. Decisional factors were age, fertility and breast feeding, relationships with significant others, body image changes, caring for dependent children, memories of cancer among family members, and ongoing risk balance analysis.

BRCA+ women recognized that although they shared having a genetic predisposition for cancer, each woman was unique, with individual needs, desires, and plans for her life. Rory said,

One thing I'm realizing is that everybody's on their own path, and that we all have to respect everybody's path and where they are in life—and how old they are—and where they are in their partnership, or marriage, or child rearing or not—or whatever—cause everybody's, you know, everybody's got their own gig.

She summarized the risk management options from her perspective:

I realized that it's really kind of about this big decision that I'm gonna have to make . . . you can be watchful-waiting, so you have tests done every six months and MRIs and mammograms and blood tests and stuff, until you actually get cancer and then you treat it early. Or I would have to make a decision to remove the body parts that are gonna be the troublesome ones, and I kind of knew in the back of my mind—I told friends and family—and in my heart of hearts I know what I need to do. I'm a mother. I have young children. I saw what happened to my mom. I want to be around for my children. I don't want to get cancer.

As the age and stage of life of the previvor changes, her risk changes, as well as her views of significant relationships, marriage, childbearing, and childrearing. Thus, the cancer risk management decisional journey involves choices that evolve and change over time for each individual. Jane, who is BRCA+ and has a daughter who is BRCA+, described the difference in the journey for women of different ages:

My daughter, having found out at age twenty-five, and me having found out at age fifty-three is completely different. I was at lunch with two sisters last year and one of 'em was married and one of 'em was single and the single said, "I don't know what I'm gonna do"—cause she was still trying to meet guys—so she said, "I don't want to have anything major done to my body." But the other sister who was married said, "I'm gonna have my kids, two or three in a row, and then get all this stuff taken out."

Prophylactic surgeries have a profound effect on body image, intimate relationships, and fertility (van Oostrom et al., 2003). Because prophylactic oophorectomy results in infertility, ovarian cancer surveillance is the only option for younger, premenopausal women who intend to have children. Prophylactic mastectomy results in the inability to breast-feed; therefore, it is not an option for the childbearing woman who wants to breast-feed. Andie spoke adamantly about her choice to preserve her fertility: "I was like—there is no freakin way that this is gonna take my chance of ever having my own children."

Younger, premenopausal previvors felt pressured to plan for significant life events such as dating, marriage, childbearing, and breast-feeding to

create a decisional timeline that allowed for eventual prophylactic surgery. This was a source of stress, as Julie, age 26, reflected,

I think psychologically for a young woman it kind of feels like it puts somewhat of like a time-line on your life and your decisions, and I feel like I'm sort of pressured to have children earlier than maybe I would have originally, just because I feel like I need to have prophylactic surgeries, you know, down the line . . . it can just feel limiting as far as your life path.

Older previvors felt the pressure to act, being closer to the age at which their cancer risk dramatically increased. Jenny commented,

When I decided to take the test, I knew that if it came back positive that I would look into having prophylactic surgery. I was already in my late forties by that point and I knew that I was pushing it if I had this, in terms of time, you know, that I was really in kind of the danger zone of cancer diagnosis.

Cancer experiences are often traumatic and pervasive in the families of previvors. Participants described multiple cancer diagnoses among family members. Audrey said,

I've just been around cancer so long. My mom—I was five the first time she got it. My mom has had breast cancer twice, and it runs really heavily through her whole side of her family . . . and then just within the last year all of the younger generation girls decided to get tested and we're all coming back positive.

Painful memories of family cancer experiences accentuated the anxiety and fear of cancer. Andie shared painful memories of her mother's cancer:

I'll say that I was about eleven, twelve the first time and it didn't make any sense to me; I mean I saw my mom go from having hair to no hair. That's about really all that I recognized. She really hid a lot of her pain . . . the second time I was a little older, about sixteen-ish and, ah, and it tore me apart because my mum got really sick and this time I got to see some of that pain, some of that anguish and I actually got to see my mum, oh my gosh . . . look like a skeleton, which was really scary.

The Lack of Knowledge and Experience Among Health Care Providers

The third significant theme was the lack of knowledge and experience among health care providers. Previvors recognize the vital role health care providers play in their lives, particularly in the cancer risk management

decision-making process and plan. However, they were concerned about the scarcity of competent health care providers able to give guidance for comprehensive, preventive care. This was of particular concern for those who lived and sought care in rural areas. Rory shared her story:

I'm in a rural area, and people here don't know anything about it . . . then a friend pointed out that there's a new gynecologist in town and she has an ad in the paper and on her ad was a little by-line that said—experienced in heredity ovarian and breast cancer. So I called her up and said, . . . what do you know? What's your experience—and I'm like—I need you as my guiding light. I need someone who has experience and knowledge in this area and supports me.

The state of the knowledge is developing rapidly, and clearly prescriptive or definitive guidelines for all aspects of cancer risk management of BRCA+ women do not exist. Women in the study sought answers to their individual risk management questions, which their health care providers could not always provide for them. Kathy said,

I said things to her like—how much worse would my chances be if I had a mastectomy when I was like 55 instead of 45? And she was like, “well we don't really know” . . . or I would say, well so how much risk reduction do I have if I had the oophorectomy versus Tamoxifen? And she was like, “We don't really know.”

With a lack of competent guidance, previvors felt that the pursuit of appropriate cancer risk management decision making fell largely to themselves, as Julie described,

Having a place to go where you feel like someone is knowledgeable about all the options is really helpful, and I felt like my nurse practitioner that I see—I actually seem to be educating her a bit—in the options and the whole process, and that can give you a little bit of a sense of—not mistrust, but just feeling, you know, that you aren't necessarily being taken care of—that you are kind of guiding the ship.

Previvors sought clarity and accuracy from providers. They experienced frustration and confusion when information or recommendations conflicted. Bethany shared the following:

I see a lot more doctors than most people my age . . . something that's been frustrating for me is just hearing conflicting things, you know, one doctor saying you should have mammograms every six months, one doctor saying at your age you should never have mammograms, and being able to have more clear information.

Previvors valued a holistic approach to care from providers with comprehensive knowledge and understanding of decisional issues and interventions. They also expressed concern about providers seeing them through the narrow focus of their specialty area, neglecting a comprehensive view and approach to care. Amanda communicated her views:

I find it difficult when I go to providers—that if I see a gynecologic oncologist, they’re really focused on, you know, whatever they can do to make sure you don’t get ovarian cancer. But then if you ask about well, you know . . . what about the cardiovascular risk, like, oh well, that’s nothing compared to your risk of cancer . . . I sort of felt like no provider that I was seeing was seeing me as a whole person.

Participants identified not only a lack of knowledge but also a lack of resources, such as pamphlets, decisional tools, or plans of care. Jean shared,

I mean you don’t want to wait a month for an appointment with the doctor and then you go into the doctor—and then they don’t have any experience with it . . . they need the education . . . because none of the doctors I went to had any pamphlets on it or anything. No information at all in their offices about it.

Support for Previvors Is Essential

The fourth major theme was that support for previvors is essential. Previvors described feeling alone when diagnosed with a *BRCA* mutation and experienced an immediate and ongoing need for support. Few reported receiving adequate referrals for support resources from health care providers. Cheryl stressed, “Don’t go it alone.”

The strongest means of support came from other women who were *BRCA+*. Sally reflected, “I think it’s important to have that feeling of, you know, that you’re not alone, and just that there is someone else out there that understands exactly what you’re going through.” Rory exclaimed, “I need a sisterhood . . . I need someone to talk to.”

Participants recognized that although many support groups exist for cancer survivors, there are few for previvors. They emphasized the importance of health care providers making referrals. Jenny recommended,

. . . so I think medical providers who work with women have to have some recognition of that . . . you do need other people to talk to that are dealing with this kind of diagnosis—and that it is different than having cancer—and that when they leave the office there isn’t gonna be this giant support structure in place . . . it’s a very difficult thing to go through alone.

Several previvors recommended using FORCE for online informational and emotional support. Jenny stated,

There was no one local to me, but on-line and through the FORCE message boards—that was a great source of support, and I think connecting women with that is great . . . any organization that provides support for people who are previvors—or who have this diagnosis without a cancer diagnosis—because there are lots of support groups for people who have cancer, but there aren't really for people who don't.

As a young previvor, Amy described support through Bright Pink, an online educational and support organization for young women with high risk for breast and ovarian cancer:

I've learned a lot and I've met a lot of young girls and, um, I was a part of Bright Pink . . . I've talked to a lot of girls that didn't have the same experience that I did, um, my doctor provided me with all the resources really, Bright Pink and FORCE and everything—and a lot of other girls that are close to my age, their doctors did nothing to help them.

Using Moustakas's (1994) method, the researcher developed a composite description of the experience of cancer risk management decision making for previvors.

For previvors in the study, cancer risk management decision making was experienced as a lifelong intellectual and emotional journey. The journey began with diagnosis of a deleterious *BRCA* mutation. Shock, fear, and a sense of urgency for protection from the threat of cancer through cancer risk management decision making ensued at diagnosis. Traumatic memories of cancer among family members increased fear related to cancer and the seriousness with which previvors approached cancer risk management decisions. Each decision involved weighing the pros and cons of risk management options with consideration of multiple decisional factors unique to each woman and potentially changing over time. Knowledge and support were critical to this process. Having knowledgeable health care professionals who were sensitive to individual needs and respectful of autonomy was valued.

Discussion

The results of this phenomenological study provide rich data for better understanding cancer risk management decision making for previvors. It is one of the first studies to provide a holistic, lifelong view of the lived experience. Findings substantiate evidence that *BRCA* mutation carriers experience

emotional distress on receiving a positive mutation result and that ongoing emotional support is needed (Halbert et al., 2011). The results augment the importance of previvor peer support identified in previous studies (Kenen, Shapiro, Friedman, & Coyne, 2007) and emphasize the emotional and experiential knowledge valuable to previvors at diagnosis and throughout the decisional journey.

Findings substantiate that fear associated with family experiences of cancer, particularly the loss of a mother to cancer (Hamilton, Williams, Bowers, & Calzone, 2009; Werner-Lin, 2008a), and concerns about fertility and body image (Phillips et al., 2006; Samuel & Ollila, 2005-2006) are factors affecting cancer risk management decisions. They also corroborate the young previvor experience of urgency to establish intimate relationships and complete childbearing before having prophylactic surgery (Werner-Lin, 2008a). Further research is needed to identify best practices for assisting previvors in early adulthood.

Findings support previous research documenting the lack of knowledge and guidance from health care providers for previvors facing cancer risk management decisions, including the lack of educational and decisional support resources provided (Metcalf et al., 2007) and the deficiency in referrals to support organizations (Loescher et al., 2009). The challenge to meet the need for expert care is attenuated by the explosion of genetic information over the past two decades, making it difficult for health care providers to keep up with advancing knowledge in genetics and genomics related to the care of BRCA+ women. Although health care professionals, including nurses, have an increased awareness that genetics and genomics competencies are important for practice (Hamilton, 2009), the competence of most nurses in these areas is poor (Skirton, O'Connor, & Humphreys, 2012). Snyder, Lynch, and Lynch (2009) suggest that the advanced practice oncology nurse specializing in genetics and genomics is appropriate to meet this need. Although few formal support organizations exist and the need for education and support in rural areas is sparse, referral to online informational and support groups such as FORCE and Bright Pink, help bridge this gap. Other opportunities lie in the use of telehealth in connecting knowledgeable specialists with rural care centers, where individuals may not have access to specialized care. Educational resources and comprehensive decisional support tools for this population are needed. Findings from this study make a valuable contribution to the development of such measures.

Study findings also warrant concerns related to health policy. As a result of the supreme court ruling against patents on *BRCA1* and *BRCA2* genes (*Association for Molecular Pathology v. Myriad Genetics, Inc.*, 2013), increased availability and decreased cost allow greater access to *BRCA* testing. Direct-to-consumer genetic testing for *BRCA* mutations is currently

available in the United States. Without the guidance of a qualified professional, those undergoing this type of testing may be vulnerable to inaccurate testing and invalid or misunderstood results. Although there is conflicting literature as to whether telephone disclosure of genetic testing results is equal to in-person disclosure in terms of the effect on anxiety and general well-being (Croster & Dickerson, 2010; Jenkins et al., 2007), findings from this study support in-person disclosure of positive results.

Findings from qualitative research are not meant to be generalizable but provide better understanding of phenomena under study. With this in mind, several limitations of the study are noted. Participants' self-report of a *BRCA1* or *BRCA2* mutation was not confirmed by the researcher. Sampling was limited by recruitment from a single source, self-selection of participants, and the inclusion of only English speaking participants. The final sample lacked racial and socioeconomic diversity; therefore, the study could not include a broad range of perspectives.

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