

Previvors' Perceptions of Hereditary Breast and Ovarian Cancer Health-related Information

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ABSTRACT

The purpose of this study is to identify female previvors' perceptions of hereditary breast and ovarian cancer (HBOC) health-related information. Previvors are individuals who tested positive for a harmful *BRCA* genetic mutation, which increases their lifetime risk for HBOC, but who have never been diagnosed with cancer. As a part of a larger research project where 25 qualitative interviews were conducted, this manuscript reports on the analysis of ten interviews which are most relevant to the research focus. Using the constant comparative method, themes were created and developed from the interview data. Results indicate previvors view information as a source of power. These women reported feeling personally responsible for seeking and sharing information, while also relying on medical professionals to provide credible sources of information. Furthermore, previvors emphasized a desire for medical professionals to be more informed about *BRCA* in order to assist them in making personal health decisions. This study presents the perceptions regarding HBOC information as reported by this population of previvors. The findings indicate that information is not provided in an organized way relative to their specific needs. Therefore, the authors recommend an educational intervention tool for previvors and their medical professionals.

KEYWORDS

BRCA; Communication; Qualitative; Hereditary Cancer; Health Experiences; Previvors; Medicine; Patient Perspectives; Health Information

INTRODUCTION

What if I told you that there is up to an 87% chance you will develop cancer in your lifetime, and each of your children had a 50% chance to inherit this risk? These are statistics previvors face. A previvor is an individual who is highly predisposed to hereditary breast and ovarian cancer (HBOC) due to a genetic mutation in the *BRCA1* or *BRCA2* (*BRCA*) gene, but who has not had a personal diagnosis of cancer.¹ While genetic test results provide information regarding an individual's lifetime risk for developing HBOC, such results are not always sufficient or helpful in making health decisions to prevent HBOC.² This mutation occurs in both men and women, however, the current study examines women's health experiences.

Within the context of HBOC, receiving information—or lacking information—regarding a genetic predisposition to such serious health conditions can produce negative effects such as emotional distress, anxiety, and uncertainty.³ At the same time, information can also provide patients with a sense of empowerment and comfort.⁴ To understand these nuances, this study investigates previvors' perceptions regarding HBOC health-related information. To understand previvors' perceptions, first, we provide an overview of previous literature examining HBOC, and then we describe the current study's research approach and methods. Ultimately, the results are analyzed and discussed to convey the perceptions of the interviewed previvors.

Receiving genetic test results

Women can undergo genetic testing to determine if they have a high lifetime risk for developing HBOC. Testing positive for a *BRCA* genetic mutation means that one of the individual's parents has the mutation, and the individual's siblings and biological children have a 50% chance of carrying the same mutation.¹ The knowledge of being at high risk for developing HBOC can drastically change a previvor's emotional well-being, as she not only worries about her own lifetime risk, but also her family's possible genetic risk.¹ Moreover, while testing positive for the *BRCA* genetic mutation reveals information about one's risk for HBOC, genetic testing results do not determine *when* and *where* a previvor will develop cancer, nor do such test results guarantee a woman will develop cancer.¹

Because of this uncertain future, previvors often experience negative emotions.³ A qualitative study conducted with thirteen Canadian women who tested positive for *BRCA* and received a breast cancer diagnosis experienced four negative emotions—

anger, frustration, grief, and regret.⁵ More specifically, these women reported the lack of information regarding their genetic testing, rigorous screening, and preventative options produced sadness and regret.⁵ It is important to note that Canada has universal insurance coverage, which is not the case in the US. It is possible that this can change the experiences of previvors, as insurance coverage changes access to care. However, the women in the study still reported lack of information and negative emotions, regardless of their access to health insurance. Results confirm that genetic testing results create a need for further information regarding HBOC, in order to make decisions. Providing patients with organized information in ways that will aid in managing such negative emotions is essential for previvors' emotional well-being.

To reduce such negative emotions and cultivate positive ones, patients can seek health information. Although each patient is sure to have unique information-seeking needs, behaviors, and experiences, analyzing the needs of a specific population—previvors—will allow for a better understanding of how information may assist in producing better health outcomes for HBOC patients. Information regarding HBOC risk can be overwhelming; however, it is necessary for previvors to be aware of their personal risk and their options in order to manage their health and make decisions. Information can be provided in an appropriate and personalized way to increase its effectiveness and helpfulness. For instance, while previvors may take comfort in having an abundance of information resources, they may find unorganized or unreliable sources as overwhelming and unhelpful.⁴ An analysis of previvors' perceptions will provide a basis for creating effective information resources to manage the anxiety and uncertainty associated with testing positive for *BRCA*.

Making health decisions

After receiving genetic test results, previvors are confronted with making health-related decisions. First, previvors must decide who to disclose their genetic test results to and in what way. In a recent qualitative study conducted in Canada, the authors found women feel great concern for future generations and family members who may be at high risk, as well.⁵ More specifically, some women who test positive for *BRCA* report feeling guilty for handing down their 'bad genes' to their children, and worry about the risk their children may have inherited.¹ While some women perceive their positive test results as a dead end, others see it as an opportunity to take preventative action.¹

Second, previvors can decide to monitor their bodies through cancer screening appointments to detect cancer early or undergo preventative surgeries to prevent the diagnosis of cancer.⁴ Yet, the decision-making process is far from simple, and can sometimes consume patients' lives for extended periods of time.¹ Thus, seeing specialists who can provide information and work with a patient to make the best decision in terms of their personal needs is essential. Armed with information, patients may feel empowered and motivated to fight the odds.¹

However, even after decisions are made, previvors' anxiety and uncertainty may still persist.⁴ For instance, electing to undergo increased surveillance means constant cancer screenings. Four common screening methods are as follows: breast self-exam, clinical breast exam, mammogram, and magnetic resonance imaging (MRI).⁴ This opens up an entirely new window of uncertainty and fear as increased surveillance may lead to more false-positive screening results.⁶ False-positive results are defined as identifying normal breast tissue as suspicious and incentivizing unnecessary biopsies.⁴ Receiving false-positive results may increase thoughts regarding a cancer diagnosis and create distress, anxiety, and worry.⁷ False-positive results also tend to provoke a greater perceived risk among women.⁷ Being reminded of their cancer risk right before each cancer screening is likely to have an impact on a patient's well-being. In fact, some patients mention missing their mammograms to gather more information regarding *BRCA* and their options.¹ Important here is that while increased surveillance is an appropriate option for *BRCA*-positive women it does not prevent HBOC.

Previvors interested in prevention options for HBOC may consider chemoprevention and preventative surgery. Chemoprevention is defined as using medicine/drugs to prevent cancer from developing.⁸ Yet, there are several ways chemoprevention may also create additional negative emotions and uncertainty. First, although chemoprevention reduces the likelihood of HBOC, it does *not* ensure that cancer will not develop.⁴ Second, even though chemoprevention is noninvasive, it has potential side effects such as menopause-like symptoms, increase of blood clots, and increase risk for uterine cancer.⁴ Third, many healthcare providers question whether or not this form of prevention treatment is effective (i.e., Tamoxifen and Raloxifene seem to reduce risk by only 50%).⁴ In short, it is important for providers to offer previvors clear information about chemoprevention, so they can weigh their options.

The third health option for previvors is preventative surgery. Preventative surgery is the most effective risk reduction option for HBOC.⁴ One example is a prophylactic bilateral mastectomy (PBM), which involves surgically removing one's natural breast tissue to reduce breast cancer risk.¹ A PBM has been found to decrease breast cancer risk by about 90%.⁴ A second option is a prophylactic bilateral salpingo-oophorectomy (BSO)—removing one's ovaries and fallopian tubes in order to prevent ovarian cancer—which reduces one's risk for ovarian cancer by 80% and risk for breast cancer by 50%.^{4,9} It is important to note that

while these procedures do not guarantee that cancer will not develop, they do reduce a previvor’s risk to below that of a women with no mutation.¹ As such, previvors need to understand their risk and not perceive it to be greater than it actually is.⁴

With the previous literature in mind, this study asked the following research question: What are previvors’ perceptions regarding HBOC-related health information?

METHODS AND PROCEDURES

Recruitment and participants

After receiving IRB approval from the University of South Florida (IRB#: Pro00022422), participants were recruited through Twitter and Facebook using an IRB-approved flyer. Eligible participants were: 1) age 18-years or older, 2) female, 3) *BRC4*-positive, and 4) interested in research on HBOC issues.

Demographics	Total Number <i>N</i>		Selected Transcripts <i>n</i>	
Age Range				
20–30	5	(20%)	2	(20%)
31–40	10	(40%)	4	(40%)
41–50	3	(12%)	1	(10%)
51–60	6	(24%)	3	(30%)
61 and older	1	(4%)	0	(0%)
Race				
Asian	0	(0%)	0	(0%)
White	24	(96%)	10	(100%)
Other	1	(4%)	0	(0%)
Ethnicity				
Hispanic	2	(8%)	1	(10%)
Non-Hispanic	23	(92%)	9	(90%)
Ashkenazi Jewish Heritage				
Yes	8	(32%)	4	(40%)
No	17	(68%)	6	(60%)
Marital Status				
Married	17	(68%)	7	(70%)
Single	3	(12%)	1	(10%)
Other	5	(20%)	2	(20%)
Type of Mutation				
<i>BRC41</i>	14	(56%)	5	(50%)
<i>BRC42</i>	11	(44%)	5	(50%)
Type of Health Decisions				
Increased Surveillance	6	(24%)	4	(40%)
Chemoprevention	0	(0%)	0	(0%)
Preventative Surgeries	19	(76%)	6	(60%)
Health Insurance Coverage				
Workplace	19	(76%)	7	(70%)
Purchased	4	(16%)	2	(20%)
Government	2	(8%)	1	(10%)

Table 1. Participant Demographics. (*N* = 25) (*n* = 10). Note: The demographics for Ashkenazi Jewish Heritage were collected, because there is a significantly high frequency of *BRC4* mutations among this specific ethnic group, with 1 in 40 testing positive, when compared to the general population, where 1 in 350 will test positive.⁴

The final sample included 25 positive female *BRCA* carriers. Twenty-four (96%) of these women identified as white, and one (4%) as other. Two of these women identified as Hispanic (8%), and twenty-three as non-Hispanic (92%). Five of these women were age 20–30 (20%), ten were 31–40 (40%), three were 41–50 (12%), six were 51–60 (24%), and one was 61+ (4%). Seventeen of these women were married (68%), three were single (12%), and five identified as other (20%). Fourteen of these women carried a *BRCA1* gene mutation (56%), and eleven carried a *BRCA2* gene mutation (44%).

The ten selected transcripts represent two women age 20–30 (20%), four age 31–40 (40%), one age 41–50 (10%), and three age 51–60 (30%). All ten women identified as White (100%). Nine of the women identified as non-Hispanic (90%) and one as Hispanic (10%). Seven of these women were married (70%), one was single (10%), and two identified as other (20%). Five women carried a *BRCA1* gene mutation (50%) and five women carried a *BRCA2* gene mutation (50%). See **Table 1** for participant demographics.

Data collection

After receiving informed consent from participants, the second and fourth author—trained in qualitative interviewing techniques—conducted phone interviews with participants. The interviews were recorded and transcribed by a professional transcription service. The transcribed interviews were then audio checked by research team members including the first author. Interviews lasted between 30–90 minutes. Example interview questions include: “Immediately after testing positive for the *BRCA* genetic mutation, did you feel like you needed additional information?” “Did you seek information for particular reasons?” “Do you feel like you have all of the information that you need to manage your health?” “Since testing positive for *BRCA*, have you encountered any challenges related to managing your health that you wish you could have known about ahead of time?”

Data analysis

Framed by the constant comparison approach and the selective approach to qualitative analysis, this particular manuscript analyzes 10 of the original 25 interviews, which were collected as part of a larger research study, based on the relevance to the research question.^{10,11} To begin, the first author played the interview recordings and took initial notes, followed by reading the interview transcripts on paper and taking additional notes. These activities were part of the data immersion phase.¹² Coding was conducted by the first author, with guidance from the second author. The transcripts were then read a second time, and a coding scheme was developed using the perspectives that emerged. This stage of coding is known as the primary cycle coding.¹² A list of potential codes and short descriptions were noted during the primary cycle coding. During secondary cycle coding the codes were organized and second-level codes were created.¹² Five transcripts were used to develop a codebook, and revisions were made to the codebook using the last five interview transcripts. The themes in the codebook were identified based on three criteria—recurrence, repetition, and forcefulness.¹³ The interview transcripts were coded using direct quotations from the transcripts to represent the themes and subthemes of the codebook.

RESULTS

Analysis of previvors’ perceptions of HBOC health information revealed four main themes: 1) information as power, 2) responsibility for seeking and sharing information, 3) trust and comfort in information sources, and 4) stage of life. Themes one and four are directly related to a previvor’s state of mind and life, while themes two and three are related to the sources of information. Below, we present the four themes with exemplar quotes to support the identified themes.

Information as power

The first theme to emerge from the data provides an overall framework for how previvors view information. Broadly, previvors perceive information as a source of power, which encompasses two subthemes of control and empowerment. Control and empowerment are described below, with exemplar quotes included.

Control

The first subtheme of information as power is control. Previvors explained that information enables them to know more about their situation, which creates a sense of control over their health and fate. Control was important to previvors, because receiving positive *BRCA* genetic test results made them feel out of control. In other words, information was viewed as a tool in the decision-making process to gain control. For example, Savannah emphasized: “I feel like there’s something hiding under the bed and I can’t see it but I can sense that it is there. And there is nothing I can do about it, and all I want to be able to do is turn on the light. If I can turn on the light to see it’s there then we can deal with it. And this was a piece of data” (p. 4).

Empowerment

The second subtheme is empowerment. Previvors described that simply having information about *BRCA* and HBOC alleviated their feelings of powerlessness, making them feel empowered. While previvors did not always act on the information they sought and found, the very idea of having the information made the previvors feel able to cope with their *BRCA* status. For instance, Iris

explained it this way: “it puts out this sense of empowerment. You can do something about it; whatever you choose to do, whether it's surgery or surveillance. You're getting ahead of something and then information is power, knowledge is -- it's good to know about this and it's good to know if you're at risk and can make decisions based on that” (p. 7).

Responsibility for seeking and sharing information

The second theme to emerge from the data notes that previvors view all parties involved in the communication of HBOC information as responsible for both seeking and sharing this information. Previvors explained that seeking and sharing HBOC information was a collective effort, and no one person can be held accountable for all their information needs. More specifically, the following subthemes emerged based on the key individuals previvors believe should be involved in seeking and sharing HBOC health information: previvor with self, previvor with medical professionals, previvor with previvor, and previvor with family/friends. These subthemes are further described below, with exemplar quotes included.

Previvor with self

First, previvors believe it is their personal responsibility to seek and share HBOC health information. Previvors noted that there is a lot of information available on HBOC, and they just had to seek out the information by doing research, asking questions, and sorting through the information. This mentality was best described by Chloe: “I'm an information seeker I guess. So I think it's out there that you got to look for it” (p. 11).

Previvor with medical professionals

Secondly, previvors believe medical professionals play an important role in seeking and sharing HBOC health information. The need for medical professionals to communicate HBOC information to previvors was evident in previvors' complaints about medical professionals' lack of *BRCA* knowledge as well as their appreciation for medical professionals who sought and shared HBOC information during their consultations. Many previvors reported their medical professionals had no knowledge or limited knowledge about *BRCA*. Some previvors even described situations where they had to explain to their medical professionals what being *BRCA*-positive meant. Previvors also emphasized that medical professionals should not only share knowledge about HBOC, but help them seek information to make informed decisions. As Iris articulated: “I think that's the most important thing, just to have access to professionals that have the data and can share that with you in a way that makes sense to you” (p. 10). Jasmine also stated: “the most important way for a person to get their information is through their doctors and their genetic counselor” (p. 20).

Previvor with previvor

Third, previvors believe it is important to seek and share HBOC information with other previvors. Many previvors talked about wanting to share the information they acquired, through their information seeking journey, in order to help other previvors. They interpreted sharing information with others as a way to raise awareness, offer support, or discuss their own personal stories. This was true for both the women who received support from others, and women who struggled to find useful information sources. To share information, previvors volunteered for HBOC organizations, interviewed with news outlets, and blogged about their experiences. In short, an implied responsibility for being a part of the previvor community was seeking and sharing information with other previvors. Mia's comment articulates this viewpoint: “the type of information which is more like how can I help? What can I do? I'm now looking for less of how can somebody else help me? If that makes any sense. That's sort of the place I'm at right now” (p. 15). Chloe shares: “I have been on local TV and I have been in the newspaper with an article because my genetic counselor is very intentional about getting the word out about prevention. So I think that more people talk about mammograms, the more in that kind of prevention, the more people hear about the previvor and that this is even an option, is huge” (p. 4).

Previvor with family/friends

Finally, previvors believe seeking and sharing information with their family members and friends is also important. Previvors reported a sense of responsibility to share the information with those around them, yet they often struggled with how to disclose their genetic test results and subsequent health decisions. Jessica states her familial responsibility: “I felt like it's important for me to get involved and find out everything about this because I need to be able to help Hannah [my niece] make some tough decisions” (p. 8). Some previvors noted receiving great support after sharing. Meanwhile, others recounted that sharing strained their family relations, and in some cases, relationships were ended altogether. One particular concern for previvors was sharing health information with their children. As such, many previvors conducted research and talked to other previvors to learn the best approach for disclosing their genetic test results to their children. For example, Chloe communicated this concern when she said: “The biggest anxiety was I have kids and I got to tell them I'm doing these surgeries. How do I explain it?” (p. 7).

Trust and comfort in information sources

The third theme to emerge from the data presents the ways in which previvors perceive information sources. Previvors reported the need to trust the information sources that they utilized. This perception derived from the belief that many information

sources are unreliable or biased, which causes frustration and confusion. In other words, trust was a prerequisite for feeling comfortable in using the information source for decision making. Previvors' key information sources included the following: medical professionals, Internet/media, and social support. The following sections describe the trust/comfort, or lack, that previvors experience with each of the key information sources, with exemplar quotes included.

Medical professionals

The first source was medical professionals. Medical professionals were a key source of information to previvors. Many previvors expressed strong relationships with doctors; some even had their physician's cell phone numbers. Previvors emphasized the importance of having a personal connection to their medical professionals, which enhanced their trust for the professionals and gave them confidence in the information the professionals provided. In other words, if the previvor trusted the medical professional, she was more likely to act on the provided information. For instance, Sophie noted: "I'm just kind of follow the provider's lead, that there's kind of—assuming that they're covering everything that's important, which is usually true, but it isn't necessarily always true" (p. 11).

In contrast, and as discussed earlier, many providers were not always knowledgeable about HBOC, which made previvors critically reflect on the information. Maggie said it this way: "I questioned the ability and the agenda of a lot of doctors. And in my own experience in my area, that is saturated with medical knowledge in cutting edge research. I still find doctors that aren't knowledgeable. So it's definitely being choosy about source" (p. 14). Although previvors can mistrust certain medical professionals, they also acknowledge their medical professionals' clinical expertise in healthcare.

Internet and the media

The second source was the Internet/media. Previvors found that much of the available online sources were "cloudy", with a few reputable websites that they were comfortable using. For example, Charlotte stated: "I think I didn't want to go online and do an exhaustive search of all the information because I felt that that was—It's just an unfiltered barrage of information that I wasn't sure if I could handle" (p. 11). One important issue that produced discomfort and distrust with online sources was how the media sexualized breast cancer. Mia mentions this when she said: "I also feel like I've been living with blinders on because breast cancer is super I think sexualized and a lot about the breast. We don't say that on anything else. We don't say, 'Save the liver.' Or like we say, 'Save the person.' Why is it with breast cancer -- even ovarian cancer, we don't say, 'Save the ovaries' we say, 'Save the person.' In breast cancer we say, 'Save the tatas,' or 'Save the boobies'" (p. 17). Some previvors noted their appreciation of Angelina Jolie's disclosure of her positive *BRC A* test result, because they felt it produced more information about *BRC A* and HBOC. Yet at the same time, others felt that she should say more because many of the online personal stories, such as blogs, could be "confusing and contradictory." Overall, previvors wanted to use the Internet for information, but also understood that issues of reliability and credibility exist.

Social support

The third source was social support. Previvors described using support groups as supplemental information sources, after consulting their medical professionals. Previvors believed support groups were a more relatable source of information, as opposed to online clinical data. However, sometimes the information shared during social support meetings made previvors feel uncomfortable because they feared similar issues might happen with them. Previvors directly stated that they felt they could trust the information from the support groups because it was "practical information" from someone who has experienced it firsthand. For example, Charlotte mentioned: "I felt like getting the information from the genetic counselor and my doctor was beneficial but I think more the emotional support and knowing like the reality of stuff and what is my life going to look like and that came more from the FORCE group" (p. 16).

Stage of life

The fourth theme to emerge from the data was previvors' perceptions of information needs related to their stage of life. Previvors navigated and interpreted HBOC information based on whether they were young adults, mid-life, or later life. Young adults include previvors in their 20's and 30's, but who have not yet had children and are not married. The following paragraph describes their specific needs and struggle to find information specific to their young age. Previvors in mid-life have established relationships and sometimes children, but are pre-menopausal. The Mid-life category below describes how their information needs changed, sometimes in relation to their careers/relationships and children. The later life category includes previvors who have well established lives and are post-menopausal. This section explains how their information needs are no longer relative to child-bearing or their careers. Exemplar quotes are included for each stage of life.

Young adult

The first category was young adulthood. Young adulthood refers to previvors who were not married and/or did not have children. Previvors in their early 20's and 30's who do not have children struggled to identify relevant information about *BRC A*.

Some previvors reported their medical professionals did not know how to advise younger *BRC A*-positive patients. For instance, Sophie explained: “When I first – met with just like my regular OB/GYN last summer and told her that we were thinking of starting a family but we were going to look into IVF and PDG first and she was like, she thought it was really great that we were doing it but she was so surprised that we were in that position because she was like, I have never met anyone who found out that they had *BRC A* mutation before they had kids” (p. 18). Previvors during this stage of life discuss the difficulty of receiving insurance coverage for increased cancer surveillance, due to their young age. In addition, many young previvors expressed the loneliness associated with testing positive for *BRC A* because they did not know many other young women going through similar experiences. Young previvors reported often avoiding social support group meetings because they are not “tailored” to their age. Finally, younger previvors who had established romantic relationships found it easier to seek out HBOC information, because they felt like they were in a more stable situation.

Mid-life

The second category was mid-life. Mid-life previvors had established romantic relationships, oftentimes with children, but were pre-menopausal. In this stage of life, previvors’ information needs related to coping with the decisions they had made or were planning to make as it related to preventative surgery. On one hand, mid-life previvors expressed that sometimes they found it easier to make preventative health decisions because they already completed their families and had partners to support them in the recovery process. For example, Chloe stated: “I was glad I didn’t know about my positive *BRC A* until I had already had my kids because that would be a hard time and maybe that’s why it was easier for me” (p. 18). On the other hand, mid-life previvors explained that their careers and family demands also made it difficult to cope with their genetic predisposition and undergoing preventative surgeries.

This was illustrated by Kenzie when she stated: “When I was teaching, I hated it and I would always be like, ‘Wow! If I got cancer now, at least I’d get some time off.’ But now it’s like, ‘Okay. If I get cancer now, I could probably still handle my classes. I’ll try to get to my internships.’ It’s literally always in my mind because I know it’s such a huge possibility. And really, I do want to get breast surgery but I just can’t right now with my schedule” (p. 5). Other information needs for mid-life previvors included coping with early on-set menopause after undergoing a preventative oophorectomy and disclosing their *BRC A* genetic mutation to their children.

Later life

The last category was later life. Previvors in this stage of life were in well-established relationships, were often retired, and were post-menopausal. While receiving *BRC A* positive genetic test results did not go away with time, later life previvors did explain that their information needs changed. Previvors in later life articulated that it was easier to make decisions about undergoing preventative surgeries to reduce their HBOC risk, because they no longer were concerned about careers and/or child-bearing. For instance, Iris stated: “I had the oophorectomy right away so that really wasn’t -- that to me that was a no brainer. I wanted to do that because that was my biggest fear and I really didn’t need my ovaries anymore at that point because of my age” (p. 12).

In sum, previvors viewed health information as power, and also acquired a sense of responsibility to share identified health information with others including previvors, family members, and friends. The types of information sources previvors turned to were determined by their perception of trust and comfort with the information source, as well as their stage of life. The main valued source of information for previvors was their medical professionals.

DISCUSSION

Addressing information as power

The most important finding of this study was that previvors viewed information as a source of power. Although participants admitted being overwhelmed with information seeking and decision making at times, overall previvors believed information was essential to be in control and feel empowered. This finding extends previous research examining breast cancer patients, which found women diagnosed with breast cancer were primarily concerned with receiving comprehensive information in a timely fashion in order to feel empowerment.¹⁴ It is important to note that this previous research was conducted in Iran, although the need is reflected among previvors interviewed in this study as well.

Addressing the responsibility of medical professionals

The primary source of information—regardless of the quality or quantity—for patients immediately after receiving a diagnosis are the medical professionals involved in the diagnosis. This interaction can be over the phone, through a letter, and in person. There is not only a perceived responsibility by previvors for medical professionals to provide adequate information, but also a responsibility for medical professionals to provide, at the very least, reliable sources of information to patients. Specifically, the findings of this study indicate that medical professionals need to have more information regarding HBOC to provide previvors with. Having to explain what your diagnosis means to your medical provider creates a sense of distrust/discomfort among previvors, since it is the provider’s responsibility to educate and empower patients. A recent study which used an interactive risk

assessment tool to effectively increase knowledge about HBOC, collect family history, and spark patient-provider discussions about HBOC screening, shows that interactive tools are useful for communicating HBOC information but are not by any means a replacement for the patient-provider discussions that are essential to successful health outcomes.¹⁵ It is important to note that this population of previvors turns to the Internet/media as sources of information when the information provided by medical professionals is not adequate, but that the internet/media should not be a replacement for patient-provider discussions. For instance, articles on Angelina Jolie's decision to undergo PBM could influence *BRCA*-positive women who are seeking information online.¹⁶ However, these articles emphasize Jolie's gender identity as a sexual icon, partner, mother, and humanitarian.¹⁶ *BRCA*-positive previvors need reliable health information that is unbiased from their medical professionals or reputable health sources, unlike the information provided through unfiltered Internet/media articles.

Addressing the function of support groups

The current study also demonstrates the function of support groups and previvors' perceptions of the relationships/information obtained through support groups. Previvors turn to support groups for emotional support, personal experience, and other relevant information. Support groups are very central to the previvors' experiences and information seeking journey. Studies suggest the support group dynamic as one that alleviates frustrations with medical professionals, while also offering emotional and experiential information in a trustworthy and safe environment.¹⁷ This study also discusses women seeking information regarding early menopause, because physicians provide limited knowledge and internet/media was contradictory.¹⁷ These are similar to the issues revealed in the data that indicate young previvors are not provided enough information regarding the consequences of early menopause.

Addressing the role of the previvor

Finally, this study addresses the role of the previvor and the perceptions of previvors' lived experiences. Although every previvor in this population used social support, there are nevertheless drawbacks and flaws with support groups. These flaws are particular to the stage of life that the participant is experiencing in relation to *BRCA*. Previvors felt out of place in their support groups due to the fact that they were the youngest members. A study conducted on young previvors, ages 18–24, notes that these women felt vulnerable and pressured to make decisions, although there were no well-defined guidelines for screening and prevention options for this population of young women.¹⁸

Disclosure varies based on stage of life, specifically depending on whether the previvor has kids, a stable relationship, or a career. They describe disclosure as something that is important, yet difficult. This is noted in a study conducted on family communication of *BRCA* results where age may affect a patient's decision to communicate results and information to family, because parents also try to protect children from anxiety producing information.¹⁹ Another study highlights the struggle of non-married carriers and the anxiety and fear that is present before disclosing their results to their partners, although most receive positive support after disclosure.²⁰ It is essential that previvors are provided with the means to communicate their HBOC information to those around them, specifically those that the diagnosis could have immediate importance to such as children and siblings, or other relatives.

The current study reveals the following about previvors' perceptions about HBOC health information: 1) previvors desire information to enhance control and create empowerment; 2) previvors desire information sources that are reliable and relevant to their present situations; and 3) previvors' information needs vary based on their stage of life.

CONCLUSION

Limitations & Future Directions

In summary, this study delves into previvors' perceptions of HBOC information by analyzing qualitative interview transcripts. While previous research indicates information assists in managing uncertainty, this research study does not investigate the well-being of the interviewed previvors. Instead, the aim of this study is to present previvors' perceptions of information and highlight the gaps in information or information delivery as identified by previvors. The study emphasizes the sense of power that reliable information can provide previvors. It also reveals the need for medical professional education in regards to *BRCA* and HBOC. The main limitation of this study is the sample. The interview participants are all educated with either some or extensive college completed. Additionally, the sample is not very ethnically diverse, with primarily White participants and a few Hispanic participants.

At the same time, this study contributes to the field of health communication and hereditary cancer in three ways. First, the study demonstrates the importance of patient perspectives in understanding health information. Not only does this study show that medical professionals are helpful information sources for previvors, but so too are support groups and the Internet/media. Second, previvors' emphasis on information as a source of power suggests that medical professionals should assist previvors in the information seeking process especially as it relates to their stage of life. Finally, given this study's findings, it is clear an educational intervention tool would be helpful for previvors and their medical professionals.

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PRESS SUMMARY

Women who test positive for a *BRCA* mutation are at increased risk for developing hereditary breast and ovarian cancer (HBOC) during their lifetime, and are frequently referred to as previvors. This study identifies previvors' perceptions regarding HBOC health information. Analysis revealed previvors view health information as power and sense a responsibility to share identified health information with others including other previvors, family members, and friends. The types of information sources previvors turn to are determined by their perception of trust and comfort with the information source as well as their stage of life. The main valued source of information for previvors was their medical providers. Therefore, it is essential for medical professionals to be knowledgeable about *BRCA* and provide HBOC information to these women so they can make informed health decisions.