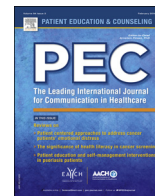




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# “When information is not enough”: A model for understanding *BRCA*-positive previvors’ information needs regarding hereditary breast and ovarian cancer risk

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### ABSTRACT

**Objective:** To investigate *BRCA*-positive, unaffected patients’ – referred to as previvors – information needs after testing positive for a deleterious *BRCA* genetic mutation.

**Methods:** 25 qualitative interviews were conducted with previvors. Data were analyzed using the constant comparison method of grounded theory.

**Results:** Analysis revealed a theoretical model of previvors’ information needs related to the stage of their health journey. Specifically, a four-stage model was developed based on the data: (1) pre-testing information needs, (2) post-testing information needs, (3) pre-management information needs, and (4) post-management information needs. Two recurring dimensions of desired knowledge also emerged within the stages—personal/social knowledge and medical knowledge.

**Conclusions:** While previvors may be genetically predisposed to develop cancer, they have not been diagnosed with cancer, and therefore have different information needs than cancer patients and cancer survivors.

**Practice Implications:** This model can serve as a framework for assisting healthcare providers in meeting the specific information needs of cancer previvors.

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## 1. Introduction

*BRCA1* and *BRCA2* carriers are at significantly increased risk to develop breast and ovarian cancer; depending on age, *BRCA1* carriers have a 40–87% chance of developing breast cancer and a 22–65% chance for ovarian cancer, while *BRCA2* carriers have an 18–87% chance of developing breast cancer and a 10–35% chance for ovarian cancer [1]. Since the identification of the *BRCA1* and *BRCA2* genes, hereditary breast and ovarian cancer (HBOC) researchers have argued for increased attention toward patients’ information needs regarding their diagnoses and risk management strategies [2–7]. While existing research has explored cancer patients and survivors’ information needs and decision-making preferences generally [10–13], the information needs of *BRCA*-

positive, unaffected patients are likely to be distinct from cancer patients and survivors. *BRCA*-positive, unaffected patients are often referred to as previvors. According to FORCE, the organization that coined the term, previvors are individuals who are survivors of a predisposition to HBOC but have not been diagnosed. Previvors can be individuals who carry a *BRCA* mutation or who have a significant family history of HBOC ([www.facingourrisk.org](http://www.facingourrisk.org)).<sup>1</sup>

Previvors have unique psychosocial and health-related concerns and needs in order to effectively manage their HBOC risk [14]. For example, previous research indicates after testing positive for *BRCA* previvors experience uncertainty, which cannot be completely eliminated because the risk for developing cancer is

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<sup>1</sup> Facing Our Risk of Cancer Empowered (FORCE) coined the term previvor in 2000 after a member stated she needed a label for being at a high risk for HBOC. Since then, it has been adopted by patients, healthcare providers, and researchers, and in 2007, it was one of *Time* Magazine's top 10 buzzwords.

always present [15,16]. Uncertainty produces detrimental effects on patients' health such as emotional distress, poor decision-making, and lower quality of life [17,18]. One effective strategy for managing uncertainty is information [19–21]. Information assists patients in understanding their situations, increases their knowledge, heightens their sense of control, and enables them to make informed health decisions [19,22,23].

What little research investigating *BRCA*-positive, unaffected patients' health experiences focuses on genetic counseling and testing and medical decision-making. This body of research has found previvors undergo genetic testing when there is a significant family history of HBOC [24,25] and then must make complex preventative health and family decisions [25–27]. However, to the best of our knowledge, no studies have examined previvors' specific information concerns and needs as a strategy for managing uncertainty. This gap in the research is problematic because the management of uncertainty is essential to make informed health decisions. Therefore, the purpose of this study was to identify previvors' information needs in order to inform the development of an educational intervention to manage uncertainty and promote uptake of appropriate prevention activities.

### 1.1. Theoretical framework

This study was framed by the Theory of Motivated Information Management (TMIM). According to the TMIM [28], individuals actively seek and manage information about health threats through information providers (i.e., healthcare provider, romantic partner, family member, or friend) in order to reduce undesirable emotions caused by uncertainty (i.e., anxiety, fear, worry). Because the first step in understanding how seeking and managing information may assist previvors in coping with their cancer-related uncertainty, the following research question guided this study: *What are previvors' information needs?*

## 2. Methods

### 2.1. Recruitment and data collection

Following IRB approval, a purposive sampling strategy was utilized, recruiting previvors via social media (i.e., Facebook and Twitter) [29]. Interested participants emailed the third author to schedule an interview. Eligible participants were: (1) *BRCA*-positive, (2) not diagnosed with cancer during their lifetime, (3) female, (4) over 18-years old, and (5) English speaking.

Telephone, semi-structured interviews were conducted between October and December of 2015. Semi-structured interviews employ a predetermined list of questions to guide the conversation, while also providing latitude to add information during the interviews [29]. The first and second authors developed the initial interview guide, and then two genetic counselors and two previvors, not interviewed for the study, provided feedback. After interview guide was revised based on the feedback, two mock interviews to test the guide were completed; the interview guide was again revised based on testing (Requests for the interview guide may be directed to the first author). Interviews ranged between 22 and 90 min (mean interview length = 56.40 min). The first and third author, trained in qualitative research methods, conducted the interviews. In appreciation for their time, interview participants received \$30 gift cards.

### 2.2. Data analysis

Interviews were audio-recorded and transcribed verbatim by a professional transcription service and checked for accuracy by study team members. Pseudonyms were used to protect previvors'

identities. The transcripts resulted in a total of 496 single-spaced pages of data, which were analyzed using the constant comparison method of grounded theory whereby three stages of coding are completed: open coding, axial coding, and selective coding [30]. In other words, the data were analyzed until a substantive theory was developed [31,32]. In the first stage, open coding, data were categorized into codes – a label that summarized the previvors' responses – by engaging in micro, line-by-line analysis [30,33]. In the second stage, axial coding, codes were grouped together in an attempt to understand previvors' lived experiences [32]. To ensure trustworthiness, "in vivo" codes were used, which encompassed the previvors' own language and words to describe their experiences [30]. In the last stage, selective coding, alike codes were collapsed, subthemes were identified, and a codebook was constructed [34]. The themes that emerged from the interview transcripts served as the units of analysis and were detected based on Owen's [35] three criteria: recurrence, repetition, and forcefulness.

Inter-coder reliability was calculated at two points during the analysis process. First, two trained coders independently coded 10% of the interview transcripts using the codebook. Krippendorff's alpha was 0.926. During mid-analysis, Krippendorff's alpha was calculated a second time to check for coder drift ( $\alpha=0.843$ ). Although some drift occurred, coders were still within acceptable limits of reliability ( $\alpha=0.7$ ). Lastly, to increase the credibility and consistency of the research findings, each research team member kept a reflexivity journal, and member checks were performed to ensure results resonated with participants [30].

## 3. Results

### 3.1. Participants characteristics

The purpose of this study was to investigate previvors' information needs after testing positive for a deleterious *BRCA* genetic mutation. A total of 25 participants completed an interview (Table 1). The majority was age 40 and younger ( $n=15$ ; 60%), white ( $n=24$ ; 96%), non-Hispanic ( $n=23$ ; 92%), not of Ashkenazi Jewish Heritage ( $n=17$ ; 68%), married ( $n=17$ ; 68%) and most had a graduate degree ( $n=11$ ; 44%). With regard to clinical characteristics, the majority was tested 3 or more years prior ( $n=15$ ; 60%), had a *BRCA1* mutation ( $n=14$ ; 56%), and made the decision to undergo preventive surgeries ( $n=19$ ; 76%).

Qualitative analysis of previvors' experiences revealed a theoretical model for understanding previvors' information needs. Specifically, a four-stage model was developed based on the data: (1) pre-testing information needs, (2) post-testing information needs, (3) pre-management decision information needs, and (4) post-decision information needs. Two recurring dimensions of desired knowledge also emerged within the stages—personal/social knowledge and medical knowledge. Table 2 provides an overview of the stages (Fig. 1 Fig. 1).

### 3.2. Stage 1: Pre-testing information needs

#### 3.2.1. Medical knowledge

Medical knowledge prior to genetic testing involved their healthcare providers' and office staff's knowledge about *BRCA* and cancer. Previvors discussed the importance of having knowledgeable providers, articulating their decision to undergo genetic testing was directly related to their providers' knowledge. For example, Sabina (54-year old, *BRCA2*-positive) talked about how her oncologist was "very, very knowledgeable about research-related *BRCA* mutation." In contrast to Sabina's experience, her brother went to his primary care physician (PCP) to discuss his *BRCA* status, and his doctor told him "Men can't get breast cancer."

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