



“Where do I go? Who do I go to?”: BRCA Previvors, genetic counselors and family planning

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ABSTRACT

Objective: We sought to understand BRCA previvors' perceptions of communication with genetic counselors and other healthcare providers.

Methods: We conducted 16 qualitative interviews and utilized thematic analysis to develop patterns present in the narratives of previvors.

Results: Interviews with previvors suggest genetic counselors and other providers often make assumptions about previvors' family planning and treatment needs based on perceived gender, age, and sexual orientation.

Conclusion: BRCA patients require individualized attention when planning for their future and making healthcare decisions and we argue that implementing patient-centered care practices into the communication process can provide a higher quality of care.

Innovation: This study offers an innovative lens through which scholars and healthcare providers may examine the experiences of BRCA previvors as they seek adequate care. Asking previvors to explain their perceptions of conversations with genetic counselors and healthcare providers offers insight into the communicative process of seeking care rather than the health outcomes of the care itself. Our findings suggest biases among providers related to gender, age, and sexual orientation are concerning elements of family planning communication that potentially interrupt previvors' abilities to express their care needs in a safe environment. We argue for an increased awareness of, and advocacy for, more inclusive conversations regarding treatment and family planning decisions.

1. Introduction

Individuals found to carry a pathogenic variant in the genes *BRCA1/2*, sometimes referred to as *previvors*, often meet with numerous healthcare providers including genetic counselors, gynecologists, and oncologists throughout their journey. They rely on these and other sources to learn more about their genetic mutation, family planning and fertility options, and treatment possibilities, which largely include surveillance and surgery. Research on communication between genetic counselors and BRCA previvors is growing, yet still provides opportunities for exploration. A much larger body of research has explored the communication between genetic counselors and individuals who have received a cancer diagnosis or are receiving treatments, including a scoping review published in 2019 [1] highlighting the need to study the communication process in genetic counseling more deeply. Prior literature suggests genetic counseling tends to focus on biomedical information rather than psychological support of patients [1]. In addition, patients' needs for personalized information regarding their diagnosis, family dynamics, and treatment options may not always be met by genetic

counselors [2]. In a study of breast and ovarian cancer patients, Jacobs and colleagues [2] argued that research is needed to better understand communication by oncology professionals, including genetic counselors.

We begin to answer this call, and extend agency to previvors, with an exploratory study investigating BRCA previvors and their experiences with genetic counselors and other members of their healthcare team. BRCA previvors, along with most precision medicine patients, have specific needs when meeting with genetic counselors and other providers. Sharing previvors' experiences with healthcare providers like genetic counselors, gynecologists, and oncologists through qualitative interviews such as those used in this study can help educate scholars, healthcare providers, genetic counselors and professionals and policymakers on how to improve engagement with this growing population.

1.1. Genetic counseling and patient-centered care

Genomic communication scholarship has called for innovative lenses through which to understand precision medicine decisions made by

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BRCA previvors, including an increased focus on patient-centered care and communication [2–4]. Patient-centered care is designed to manage the concerns many scholars have noted are central to the previvor experience like uncertainty, information exchange, emotional well-being, and self-management [3,5,6]. In a recent article on enhancing patient-centered care within precision oncology, Chou and her colleagues [7] note communication is critical for those being genetically tested for hereditary breast and ovarian cancer. Such patients are often struggling with feelings of uncertainty [8–10] in understanding their diagnosis and in making decisions based on their results. Genetic counselors and other providers can help patients manage their uncertainty by addressing their specific care preferences as well as concerns like financial insecurity, misinformation, and the possibility of changing treatment modalities when necessary [7,8]. There are documented psychological impacts of genetic testing for *BRCA* patients [11–13] and patient-centered care and communication is critical to ensure previvors' needs are met.

In a qualitative study of *BRCA* previvors' experiences with genetic testing and treatment planning, Hesse-Biber [5] found previvors did not make decisions specifically based on statistical data provided by their genetic counselor. Instead, they filtered those data through a broader lens of personal experiences and preferences. Genetic counselors must understand those personal preferences to offer the highest quality of care for previvors. Patient-centered care within precision medicine and genetic testing, as described by Arora and colleagues [4] needs to take a whole-person approach rather than focusing on the patient's genes alone.

While important, most prior scholarship has analyzed quantitative communication outcomes such as patients' uncertainty, anxiety, and stress after communicating with counselors, rather than the communication process itself [1]. Qualitative studies are needed to analyze perceptions of the process of communication in visits between *BRCA* previvors, genetic counselors, and other providers on their healthcare teams to ensure the highest quality care throughout the previvor journey that is meeting the needs of previvors.

1.2. Family planning for *BRCA* previvors

Precision medicine and genetic testing for *BRCA* previvors has many benefits but requires strong communication between patients and providers particularly around patients' personal and family planning needs [8]. Family planning is the act of deciding how many children to have and how to space out pregnancy, keeping in mind fertility issues, contraception, prenatal testing, and other health concerns. Family planning is a central topic within genetic counseling sessions for *BRCA* patients as decisions about managing cancer risk (i.e., prophylactic oophorectomy) might also impact reproductive decisions [14,15]. However, family planning communication scholarship is still quite limited with regards to navigating the individual preferences of patients. Most literature notes the importance of family planning as well as the struggle many go through in the process of making decisions regarding their reproductive health [9,15,16], but research detailing the process of how patients and genetic counselors communicate about family planning is scarce.

There is often an assumption that *BRCA* previvors want to get married, have kids, and plan for a family once diagnosed. However, a recent study of single, unmarried Korean *BRCA* mutation carriers found that 25.3% of those surveyed no longer wanted to get married and 36.2% who previously wanted to bear children no longer want them [17]. Family planning scholarship is often presented through a normative, cisgender and heterosexual lens, leaving out others experiencing previvorship. Additionally, there is minimal research on how the age of *BRCA* previvors impacts their family planning and treatment choices [15,17]. These previvors may not interact with genetic counselors in the same way as others and research is needed to detail the experiences of those patients so counselors and other healthcare providers understand the specific needs of all patients.

Therefore, this study asks:

RQ1: What were previvors' perceptions of communication with genetic counselors and other healthcare providers about their diagnosis and treatment plan?

RQ2: What were previvors' perceptions of communication with providers and experiences within the healthcare system related to family planning?

2. Method

2.1. Study design

To examine *BRCA* previvors' experiences with genetic counselors and other healthcare professionals throughout their process of diagnosis, surgery, and recovery, we used an exploratory, qualitative interview approach. The data were collected as part of a larger study that examined reasons for social media content creation by previvors [3] although these data were not previously analyzed. The Institutional Review Board approved the study protocol (IRB_00144720).

2.2. Recruitment and eligibility

This study recruited individuals living in the United States who have been found to carry a *BRCA1* or *BRCA2* mutation and identify as woman with the pronouns she/her or a non-binary person with the pronouns they/them. Of the total participants ($n = 16$), 15 were women and one was non-binary. However, the non-binary individual noted that they are often perceived as female and have "woman" listed as their gender on their medical paperwork for insurance purposes. All participants were white presenting, but two identified as Hispanic and two identified as Ashkenazi Jewish, noting the importance of their ethnicity as related to their *BRCA* status, as one in 40 Ashkenazi Jewish women have a *BRCA* mutation [18]. All individuals had to be over the age of 18 and could participate regardless of where they were in their *BRCA* journey. Additionally, all participants must have been active on at least one personal social media account where they shared about their experiences publicly.

Individuals were recruited through both Instagram and TikTok. The principal investigator searched popular hashtags related to *BRCA* including: #brca, #brca1, #previvor, #brcagene, and #breastcancerprevivor. Once accounts populated, the researcher reached out to previvors who listed their email addresses publicly on their social media accounts explaining the project and requesting they respond if interested. Once individuals responded, they were scheduled for interviews and provided with the consent form.

2.3. Procedure

Eligible participants were scheduled for a virtual interview over Zoom. Verbal consent was requested again at the start of each interview before recording was initiated. All interview audio was recorded for accuracy and transparency for the duration of the interview. The interviews were based on a semi-structured interview format and topics included the previvor's experience with *BRCA* up until the day of the interview, their experience working with genetic counselors and healthcare providers through their journey, their activity on social media, and how they feel about the online communities surrounding *BRCA*. Each of the interviews lasted between 45 and 60 min and sessions were transcribed verbatim by a professional transcription company. Participants received compensation in the form of a \$50 gift card.

2.4. Analysis

Thematic analysis [19,20] was implemented by the principal investigator and supported by a graduate assistant (GA). This method was recently applied to the study of *BRCA* previvorship as a label of identity [21] and to explore how previvors share about their experiences on Instagram [3]. The transcripts were manually coded by the principal investigator and the GA for patterns related to previvor's experiences with healthcare professionals, including genetic counselors. We elected to follow the two-stage review process recommended to maintain the rigor of the method, including an initial round of open coding, followed by a discussion of the primary

patterns developed. Then, both the principal investigator and the GA completed another round of focused coding to ensure the themes reflected the content. The aim of this analysis is not only to summarize the data, but to identify and interpret features [20], therefore the findings in this article only touch on one aspect of previvorship within a much larger discussion of how *BRCA* previvors experience genetic testing and interact with healthcare professionals. All direct quotes provided in the findings are anonymized.

3. Results

3.1. Communication: Genetic counselors more helpful than other providers

Participants noted genetic counselors were helpful in the process of finding other healthcare professionals necessary for the previvors' journey and preparing them for the physical repercussions of their treatment decisions. However, they were not ready for the mental, emotional, and social aspects experienced by previvors after testing positive for *BRCA*. Additionally, previvors noted that while their genetic counselor knew about *BRCA*, physicians often didn't know as much, and some hadn't heard of it at all (INT03; INT04), resulting in previvors worrying about the quality of their care. Some previvors even felt like their providers didn't want to learn about their diagnosis or personalize their care (INT02). Previvors shared that they felt unprepared for what was ahead of them in their previvor journey.

Participants noted that other healthcare providers often did not appear to hold much knowledge about *BRCA*, leaving previvors feeling wary about their diagnosis and treatment plan as well as unwelcome in their provider's office. One shared that while on a visit to her provider, the nurses treated her poorly when they found out she was having a prophylactic mastectomy. "They were so like 'oh you don't have cancer, you're fine'" (INT03). The assumption that *BRCA* previvors don't have cancer, and therefore, are "fine" is harmful and dismissive toward previvors' feelings of fear and uncertainty related to their diagnosis. This may lead to a distrust in medical providers.

Additionally, even previvors who had positive experiences with physicians, still felt like something was missing.

What I got from the care team...even though my doctors were very nice, and very caring, it was from the medical perspective, it missed that humanistic feeling, that connection with people, and the emotional piece of it was just missing. Even with the genetics counselor, I think I thought from her I would get that emotional piece, but I definitely...I didn't. (INT16)

Feeling unsupported emotionally by members of their care team, some previvors said they would be searching for new physicians for future treatment. One previvor agreed that their care was missing a personalized touch where they were seen and heard as an individual, not as just another person with *BRCA*.

I wish (personalization) was more thought of. I'm also at a point where I'm thinking about the ovarian cancer piece of this and I feel very lost in that component of things and I'm like where do I go? Who do I go to? I know that my doctor is not going to be the person that I need to talk to, really at the end of the day. (INT06).

As some providers and medical staff may not understand the complexities of *BRCA*, they may also make assumptions about the type of care previvors are receiving. Even those tangential to the medical intervention process, such as front-desk staff may make assumptions that impact the experiences of previvors. For example, one participant shared a story about going to get her first mammogram after being diagnosed.

I walked in and was like, "Hey. I have an appointment. I'm here for my mammogram." And (the receptionist) looked at me and she was like, "How old are you?" I was like, "Twenty-three." And she was just like, "And you're having a mammogram?" And I was like, "Yes. I have an

appointment." And she just started asking me these questions and like, she was not pleasant to talk to. And so finally I put my paperwork down on the thing. I slammed it down. I said, "I'm *BRCA1*." And she goes, "Oh." And I'm like "Why?" That right there is just incredibly frustrating because even if a woman just wanted to get checked just because she had a feeling or whatever, regardless of what her age is, like if she's, like, 20 and just wants to come in and get checked, she should be able to do that (INT14).

The questioning *BRCA* previvors receive when attempting to seek care may also dissuade them from engaging further with a provider's office.

When asked to describe interactions with genetic counselors and other healthcare professionals, many participants shared positive experiences. As one said, "My genetic counselor was supreme. She got me through the process. She helped me find doctors" (INT03). Another participant (INT08) shared similar feelings saying, "The genetic counselor...she was phenomenal. I absolutely loved her. I actually am kind of sad that she wasn't...I wish she could have been one of my more normal doctors" (INT08).

Many participants shared similar sentiments in that they wished their genetic counselor played a larger role, as they were often more helpful than the other healthcare professionals on their treatment team. For example, another previvor said, "To find a gyno who is well versed in that is really hard. Like, I'm very lucky to have found one, but it was a challenge to get to her." (INT06). This previvor said she has heard many stories of gynecologists not knowing what *BRCA* was, and her provider not only knew what it was, but collaborated with the previvor by listening to her concerns and paying attention to the information she had found online.

Finally, a non-binary previvor detailed the experience they had with their genetic counselor regarding filing paperwork:

The genetic counselor that I originally saw...she was fantastic, and was very helpful with information and telling me who she preferred provider-wise to see with somebody my age, my gender everything like that because like on medical papers, I'm not (listed as) non-binary just because the insurance that I hold is known for having issues with that, with covering procedures that are gender coded (INT12).

They went on to say they felt very lucky to have a genetic counselor that understood their specific needs, however, they had heard stories from other previvors about feeling pushed toward societal norms. They continued, "I think in my case just, in general, the healthcare system here is incredibly inclusive and patient-focused, like they really listen" (INT12).

3.2. Family planning: Assumptions of identity and treatment desires

When discussing family planning, some participants perceived their communication with genetic counselors to be negative, specifically related to identity, societal norms, and expectations regarding marriage and children. One participant (INT06) shared that she feels like some providers automatically assume all female-presenting patients are heterosexual and will marry a cisgender man and have children.

I rolled my eyes because the questions I got over and over again from people who kept—especially like genetic counselors, people who were really pushing me on like "Are you sure you're making the right decision?" was because they're like "Well, you haven't had kids yet and you might want to breastfeed," and I'm like "I don't want kids and even if I do, they don't need to have breastmilk from my breasts." Like, I just didn't give a fuck and the amount of people who care so much about this...I just couldn't understand it. It couldn't compute (INT06).

Another participant (INT13) said she understood why the assumptions happen, as in the United States, most assume that every woman is going to have a child or wants children. And another previvor said it wasn't just the genetic counselor who made assumptions about her future goals surrounding marriage and children. "It was also the oncologist. I felt like

everyone was asking me when I wanted to have kids, and I wasn't at a place then...I knew I wanted kids, but I wasn't able to answer that in my early 20s" (INT16).

Family planning conversations are designed not only to help *BRCA* previvors decide when to have kids, but also whether they want kids at all. As *BRCA* previvors can be diagnosed quite early in life, some say they were frustrated while interacting with their care team. For example, one young participant noted that she didn't like how the conversation was centered around building a family, versus being alive. "I'm thinking more about the fact that regardless of having a family if I don't do these things I'm not going to be here for my family. So that's really what's more important to me is me being here versus the family I'm creating" (INT09). Another participant agreed, saying "(It was) extremely frustrating for me, especially as a 22-year-old with no clear plans to get married or have kids. It really...it was almost like...it felt like fearmongering now that I'm out of it" (INT09).

4. Discussion and conclusion

4.1. Discussion

This study found that while genetic counselors and other providers offered valuable information to patients, previvors felt unprepared emotionally to take on their diagnosis and unsure of whether they would receive a high quality of care. They believed genetic counselors and providers gave incomplete information that left them confused and afraid of what was to come. Providers also made assumptions about previvors' identity and family planning based on perceived gender, sexual orientation, and age.

In response to RQ1, we found most previvors perceived their communication with genetic counselors to be positive overall, especially when previvors took the time to advocate for themselves as a patient. However, specific interactions were perceived as negative by previvors throughout their office visit experiences. Feelings of frustration and distress occurred throughout the previvor experience, as suggested in a similar study [2], from meeting with genetic counselors to receiving treatment. Our study found that even those tangential to the medical intervention process, such as front-desk staff at medical offices and hospitals, impact the experiences of previvors.

In response to RQ2, previvors said they felt pushed toward assimilating with societal norms in appointments with genetic counselors and other providers. The tendency for genetic counselors to assume a patient's identity and life goals based on their perceived gender, sexual orientation, and age can be harmful for *BRCA* patients, putting them in a position where they may be encouraged to disclose personal and private information to correct the assumptions of the genetic counselor. *BRCA* patients need care that is personalized to them to reduce the possibility of psychological harm [1,10–12,21]. Currently, there is a lack of research on identity-inclusive language and conversation tactics for providers to implement when discussing treatment and family planning options with *BRCA* patients. A recent case study reviewed an experience treating a young trans-feminine *BRCA* patient [22]. Even as a child under 18 with *BRCA*, the genetic counselor and healthcare providers respected the patient's autonomy and identity by including them in all decisions, listening to their perspective, and committing to the obligation of clinicians to "do no harm." This case demonstrates how ethical principles and implementing patient-centered care can be used to help guide providers and manage uncertainty for *BRCA* patients related to their identity and more research is needed to craft proper guidelines around working with *BRCA* patients in this capacity.

Practicing patient-centered care would also encourage counselors to ask about family planning rather than making assumptions about patients' preferences and values. Recent studies have argued providers require more effective education regarding specific subgroups and their needs [23]. When genetic counselors meet with a feminine-presenting patient, they may assume pronouns, sexual orientation, and the desire of their patient to have

children [24]. Pre-screening *BRCA* patients with surveys about pronouns and identity and communicating with the patient in an initial meeting about their life plans might mitigate assumptions. For younger *BRCA* patients meeting with genetic counselors, psychosocial needs are an important focus when meeting with genetic counselors and family planning. In a previous study, young *BRCA* patients noted psychosocial distress as a factor of family planning much more frequently than was recognized by genetic counselors [25], and as *BRCA* patients receive diagnoses earlier in life, providers must consider how their age may impact their treatment and family planning decisions. Finally, patient-centered care not only pertains to the specific provider a patient is seeing but must be threaded through a patient's entire experience with the healthcare system. Understanding that each *BRCA* previvor is an individual with specific needs for personalized care will only serve to support that patient in their previvor journey [2,4].

While strengths of this study include giving voice to *BRCA* previvors and their experiences, there were some limitations. First, the interviews were conducted over Zoom due to COVID-19 limitations and geographical distance between the researchers and participants, limiting the interviewer's ability to fully connect with the participant. Video interviews limit the interviewer's ability to respond to body language and utilize the participant's physical response to questioning as a guide for future questions. Additionally, the differences in geographic location of each participant may be a limitation considering the access to healthcare varies widely across the United States [26]. Second, participants were recruited through Instagram and TikTok keeping in line with the larger study objectives. The algorithm present on both platforms most likely pushed the most popular *BRCA* previvor accounts to the surface, leaving out valuable participants with smaller follower counts. This also meant most participants were white or white passing. This mirrors similar studies which found very little social media content created by and for Black previvors and other previvors of color [3]. We recognize the limitations of this study as the inclusion criteria was specific to the larger project and thus overlooked previvors' experiences with healthcare providers who do not share about their journey on social media. Future studies should explore these community members' perceptions of communication with genetic counselors and other healthcare providers.

4.2. Innovation

This study offers an innovative lens through which scholars and healthcare providers may examine the experiences of *BRCA* previvors as they seek adequate care. By examining the communicative process of seeking *BRCA* care rather than the health outcomes of the care itself, we provide an innovative approach to investigate previvors' perceptions of communication with genetic counselors and other members of their healthcare team. This study increases knowledge around the communication processes of previvors and gives them agency by allowing them to openly share their personal experiences. Specifically, our findings suggest biases among providers related to gender, age, and sexual orientation are concerning elements of family planning communication that potentially interrupt previvors' abilities to express their care needs in a safe environment. We argue for an increased awareness of, and advocacy for, more inclusive conversations regarding treatment and family planning decisions. This study also informs the actors we've noted throughout the study including genetic counselors, other healthcare providers, and policymakers. Scholars should continue to conduct studies that explore the relationship between *BRCA* previvors and providers to ensure previvors are receiving inclusive communication surrounding family planning and treatment options.

5. Conclusion

This article provides an innovative look at *BRCA* previvors' perceptions of communication with genetic counselors and other healthcare providers. Interviews with previvors suggest genetic counselors and healthcare team members often make assumptions about previvors' family planning and

treatment based on perceived gender, age, and sexual orientation. *BRCA* patients require individualized attention when planning for their future and making decisions about their healthcare and implementing patient-centered care practices into the communication process can provide a higher quality of care. Future research should continue to give agency to *BRCA* previvors, especially those from marginalized groups, to reduce assumptions surrounding treatment options and family planning.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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