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ORIGINAL RESEARCH

"It was an Emotional Baby": Previvors' Family Planning Decision-Making Styles about Hereditary Breast and Ovarian Cancer Risk

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Abstract Women who test positive for a *BRCA* genetic mutation are at an increased risk for developing hereditary breast and ovarian cancer and have a 50% chance of passing on their genetic mutation to their children. The purpose of this study was to investigate how women who test positive for a *BRCA* mutation but have not been diagnosed with cancer make decisions regarding family planning. Analysis of interviews with 20 women revealed they engage in logical and emotional decision-making styles. Although women want to be logical to reduce their hereditary cancer risk, emotions often complicate their decision-making. Women experience fear and worry about a future cancer diagnosis, yet also desire to create a family, particularly having children through natural conception. That is, women negotiate having preventative surgeries in a logical doctor-recommended timeframe but also organize those decisions around emotional desires of motherhood. Overall, this study demonstrates the complex decisions women who test positive for a *BRCA* mutation must make in regards to genetic testing timing, family planning, and overall quality of life.

Keywords Hereditary breast and ovarian cancer · Decision-making · Genetic risk · Disease risk · Genetic testing · Family communication · BRCA1, BRCA2 · Qualitative research

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Introduction

"*My children will never have to say, 'Mom died of ovarian cancer.'*" ~ *Angelina Jolie*

On March 24, 2015, Angelina Jolie, an actress, filmmaker, and special envoy of the United Nations High Commissioner for Refugees, wrote an op-ed for *The New York Times*, detailing her most recent preventative surgery to reduce her hereditary breast and ovarian cancer (HBOC) risk (Jolie Pitt 2015). In 2013, Jolie tested positive for *BRCA1*—a genetic mutation which increases her lifetime risk for developing HBOC and thus she underwent a prophylactic bilateral mastectomy. Two years later, after receiving concerning blood results, she underwent a bilateral salpingo oophorectomy in order to reduce her ovarian cancer risk. Individuals, like Jolie, are often referred to as previvors—individuals who are genetically predisposed to HBOC but have not yet been diagnosed with cancer (Friedman et al. 2012).[1]

Women who test positive for a *BRCA1* genetic mutation have a 40 to 87% lifetime risk for developing breast cancer and a 22 to 65% lifetime risk for ovarian cancer, while those who test positive for a *BRCA2* genetic mutation have an 18 to 87% lifetime breast cancer risk and a 10 to 35% lifetime ovarian cancer risk (Mavaddat et al. 2013). Additionally, such individuals have a 50% chance of passing on the genetic mutation to their children (Vadaparampil et al. 2009). Thus, many previvors grapple with family planning and reproductive

[1] While this term is commonly used by individuals who test positive for a *BRCA* genetic mutation, not all *BRCA*+ individuals identify with this term; however, for the purpose of this study, we use the term as a large majority of our participants identified with it.

decision-making (Friedman and Kramer 2005; Vadaparampil et al. 2009). While previous research has examined the types of personal risk-reducing decisions women make after testing positive for a *BRCA* mutation (e.g., preventative surgeries, Hesse-Biber 2014; Hoskins and Greene 2012; Westin et al. 2011), little is understood about how women who test positive for a *BRCA* mutation make health decisions, especially regarding family planning options (Howard et al. 2011; McCullum et al. 2007). Therefore, the purpose of this study was to investigate how previvors make decisions regarding family planning.

Family Planning and Reproductive Decision-Making

Family planning is the act of deciding the number of children to have and the spacing in which to have them. Issues of family planning include, but are not limited to, reproductive decision-making, contraception, infertility, prenatal testing, and other health concerns. Hence, the process of family planning is communicative, personal, and sensitive (Rauscher and Durham 2015). In general, women have a variety of reproductive options including personal pregnancy, surrogacy, in-vitro fertilization, and adoption. Researchers have examined family planning and reproductive decision-making in a variety of different health contexts such as Huntington's Disease (Downing 2005; Klitzman et al. 2007), Cystic Fibrosis (Myring et al. 2011), Multiple Sclerosis (Alwan et al. 2012), HIV/AIDS (Matthews et al. 2013), and cancer (Chung et al. 2013; Clayman et al. 2013). Yet most of this scholarship focuses on reproductive decision-making process rather than the negotiation of personal health risk *and* reproductive concerns. Therefore, the present study investigates the ways in which previvors make decisions regarding family planning after testing positive for a *BRCA* genetic mutation.

Negotiating Personal Risk-Reduction of HBOC and Making Family Planning Decisions

After testing positive for a *BRCA* genetic mutation, previvors have three main health options—increased surveillance, chemoprevention, and preventative surgeries (Dean 2016). Increased surveillance involves clinical breast screening (i.e., MRIs and mammograms), transvaginal ultrasounds, and CA-125 blood tests (Burke et al. 1997; Evans et al. 2009).[2] Chemoprevention encompasses the use of medication in order to reduce the risk or delay the development of HBOC. Preventative surgical options include a prophylactic bilateral mastectomy (PBM), a prophylactic bilateral salpingo-oopherectomy (BSO), and/or a hysterectomy.[3]

While the above health options may reduce one's personal risk for developing HBOC, they also may complicate decision-making about family planning (Quinn et al. 2009). Women who test positive a *BRCA* mutation may desire to undergo preventative surgeries because such procedures lower hereditary cancer risks; however, such decisions often end the chances of conception. For example, a BSO lowers a woman's ovarian cancer risk by 80% or more as well as her breast cancer risk by 50% (Friedman et al. 2012), yet she is no longer able to have children. Furthermore, while a PBM reduces a woman's breast cancer risk by 90% or more (Metcalfe et al. 2004), she is no longer able to breastfeed. Thus, women who test positive for a *BRCA* mutation must have conversations and make difficult decisions regarding family planning.

Furthermore, women who test positive for a *BRCA* genetic mutation have a limited window for completing their family (Chan et al. 2016). Previous research indicates women experience a compressed family life cycle—accelerating their childbearing plans while trying to manage their personal HBOC risk (Donnelly et al. 2013; Rubin et al. 2014). Werner-Lin (2008) points out, "the experience of creating a life plan that integrates the possibility of early illness and death is out of synch with normative developmental tasks of establishing intimate relationships and the start of family planning" (p. 427). However, it is unclear how women who test positive for a *BRCA* mutation make and prioritize these decisions—a key goal of the present study.

In addition to negotiating decisions about preventative surgeries and family planning, women who test positive for a *BRCA* mutation also negotiate how to accomplish their family planning goals in light of their HBOC risk. For instance, these women are often concerned about passing on their genetic mutation to their children (Quinn et al. 2010b), and thus, they may consider using assisted reproductive technologies (ART, Quinn et al. 2010a). ART consists of a variety of medical treatments and laboratory procedures with the end goal of pregnancy. Examples of ART include in vitro fertilization (IVF), preimplantation genetic diagnosis (PGD), embryo cryopreservation, and gestational surrogacy (for a detailed review of ART see Quinn et al. 2010a). At the same time, these women also have the option to have children naturally; women who decline ART report it might delay or even reduce their chances of becoming pregnant quickly (Rubin et al. 2014).

In short, making such decisions is emotionally charged (Hoskins and Greene 2012), and individuals' family and personal beliefs regarding HBOC influence their approach to

[2] According to the National Comprehensive Cancer Network (NCCN) guidelines on genetic/familial high-risk assessment for hereditary breast and ovarian cancer, although there may be some circumstances where healthcare providers may find ovarian screening helpful for patient care, overall data do not support routine ovarian screening.

[3] While the NCCN currently does not recommend women who are carriers of a *BRCA* mutation undergo a preventative hysterectomy, some women do consider this as a health option.

decision-making (Werner-Lin 2007, 2008). For example, Werner-Lin (2008) found women who test positive for a *BRCA* mutation with a family history of a HBOC related cancer were motivated to have children quickly in order to undergo preventative surgeries. Similarly, Rubin et al. (2014) also found, after learning their genetic predisposition, women accelerated their childbearing plans in light of their "complex family dynamics and histories" and their "*BRCA* clock" (p. 163). Ultimately, these women's primary concern was to prevent their own risk of HBOC and not repeat past family cancer patterns. Overall, knowing one's increased lifetime risk for developing HBOC "opens a Pandora's box of dilemmas regarding reproductive decision making" (Friedman and Kramer 2005, p. 85).

Utilizing Decision-Making Styles and Approaches

Existing research regarding decision-making styles in cancer care largely assumes individuals who are diagnosed with cancer and/or test positive for a *BRCA* mutation adhere to their healthcare providers' prevention and treatment recommendations due to their "expert knowledge," therefore following a "rational" decision-making model (Forde 1998; Glanz et al. 2002; Hesse-Biber 2014; Rodney et al. 2004). Indeed, many healthcare providers expect their patients to comply with their recommendations after discovering their HBOC risk (Pilarski 2009). Yet recent research has found individuals who test positive for a *BRCA* mutation do not always adhere to a "rational" decision-making model. Hesse-Biber (2014) learned that instead of making medical decisions based on medical or statistical analyses of risk, women who test positive for a *BRCA* mutation make decisions in a "nexus of decision-making," which encompasses family cancer experiences and a social support network made up of family, friends, and online relationships.

Adding to this "nexus of decision-making," other possible factors include perception of cancer risk, healthcare service characteristics, gender roles, and the nature of cancer risk-reducing options (d'Agincourt-Canning 2006; Hesse-Biber 2014). For instance, by conducting interviews with individuals who tested positive a *BRCA* mutation regarding their decisions about preventative surgeries, Howard and her colleagues (2011) identified five decision-making styles—snap, intuitive, deliberative, deferred, and if-then decision-making. These styles were characterized by particular decision-making approaches, which included the following: looking inward, paying attention to emotions, taking time, relying on intuition, engaging with others, making sense of numbers, and weighing pros and cons. In sum, it seems women make choices based on the "context of one's whole life." (de Vries-Kragt 1998, p. 79). As such, this study seeks to extend previous research beyond personal preventative decision-making to examine family planning as an important component of previvors' decision-making experience.

Research Question

Based on the reviewed literature and previous calls to examine contextual factors for decision-making (Rubin et al. 2014), the purpose of this study was to investigate how women make decisions regarding family planning after testing positive for a *BRCA* genetic mutation. Specifically, we asked the following research question: *How do previvors make decisions regarding family planning?*

Methods

Recruitment and Participants

Given the study's purpose to understand previvors' decision-making experiences, qualitative research methods were employed (Hesse-Biber and Levy 2006; Lindlof and Taylor 2011; Merriam 2009). After receiving IRB approval from Texas A&M University, participants were recruited at the 2015 Annual Facing Our Risk of Cancer Empowered's (FORCE)[4] Hereditary Cancer Conference. Purposive sampling techniques were used by hosting a table at the conference's Exhibit Hall (Merriam 2009). The authors distributed flyers describing the study's purpose, participant criteria, and interview procedure. Recruitment criteria included the following: (1) received positive *BRCA* genetic test results before completion of family planning, (2) be at least 18-years old, (3) have a committed partner, and (4) had a conversation with a partner about family planning. Potential participants signed a voluntarily list to be contacted after the conference to set up an interview time. A week following the conference, the second author sent emails to the potential participants to determine if they were still interested in conducting an interview. It is important to note that the authors did not have any prior relationship with the participants. For a detailed overview of participants' characteristics, refer to Table 1.

Procedures

Both authors—trained in qualitative research methods with extensive expertise in interviewing—conducted in-depth, semi-structured interviews with previvors (Lindlof and Taylor 2011, See Fig. 1 for the complete Interview Guide). Interviews were conducted over the phone since participants were from a variety of geographical locations within the United States. Interviews lasted between 24 and 68 min (Mean interview length = 43.47 min) and were audio recorded with participants' permission. The final sample size was contingent upon theoretical saturation, meaning that the authors

[4] FORCE originally conceptualized the term previvor in 1999 when one of their members expressed a desire to have a label to identify with.

Table 1 Previvors' Characteristics ($N = 20$)

Participant characteristic	Number
Mean age of participant	35.5 years (Range: 24–48)
Ethnicity	
Non-Hispanic/White	20
Ashkenazi Jewish	3
Annual household income	
< $25,000	3
$50–75,000	2
$75–100,000	5
> $100,000	9
Prefer not to answer	1
Educational level	
Some college	1
Bachelor's degree	11
Master's degree	7
Technical school	1
Mean time since receiving genetic test results	7.5 years (Range: 9 months to 16 years)
Type of *BRCA* Mutation	
BRCA1	12
BRCA2	8
Children	
Had children	8
Did not have children	11
Had frozen embryos	1
Marital status	
Married	13
Common law marriage	1
Single	3
Single with serious romantic partners	3
Preventative Surgeries	
Preventative bilateral mastectomy	12
Preventative salpingo-oopherectomy	5
Have not undergo preventative surgeries	7

continued interviewing participants until no new patterns emerged (Morgan et al. 2002). Data saturation occurred at the 15th interview, and five more interviews were conducted to validate saturation. Following each interview, the authors wrote research memos, noting important and relevant responses to the interview questions. Last, in accordance with IRB procedures, pseudonyms are used throughout the results to protect participants' identities.

Data Analysis

Interviews were recorded and transcribed by a professional transcription service. After the data were compiled, the authors engaged in the constant comparison method as described by Lindlof and Taylor (2011). The first stage is open coding whereby the authors categorized the interview data into codes. The second stage is axial coding, which involves grouping the codes together (Corbin and Strauss 2007). To ensure trustworthiness of the data, when possible, "in vivo" codes (i.e., the participants' own language) were used (Lindlof and Taylor 2011). The third stage of coding encompassed consolidating and collapsing the codes by identifying key properties of the codes (Geertz 1973). Following these three stages, the authors had an in-depth conversation about the data—identifying the main themes in the interview transcripts. Because the themes (i.e., codes) served as the units of analysis, a codebook was then developed and revised. The themes were assessed based on "thematic salience" using Owen's (1984) criteria recurrence, repetition, and forcefulness. The first author then used the codebook to recode all the transcripts, and the second author reviewed the results independent from this procedure to probe further and question any interpretations. Also, to further understand the prominence of previvors' decision-making styles, frequency counts were included in the analysis (see Table 2, Fisher et al. 2014). Finally, the authors kept a detailed audit trail to ensure the results' credibility, transferability, and consistency (Lincoln and Guba 1985; Lindlof and Taylor 2011).

Results

The purpose of this study was to investigate how women who test positive for a *BRCA* genetic mutation make decisions regarding family planning. After testing positive, previvors reported two major health decisions—when to have children and when to have preventative surgeries—that were guided by logical and emotional decision-making styles. Although previvors wanted to be logical to reduce their HBOC risk, emotions complicated their decision-making. Previvors experienced fear and worry about a future cancer diagnosis yet also desired to create a family, particularly having children through natural conception. In other words, previvors negotiated having preventative surgeries in a logical doctor-recommended timeframe but also organized those decisions around emotional desires of motherhood. We first describe previvors' logical decision-making style.

Logical Decision-Making

The first decision-making style previvors engaged in when making family planning health decisions was logical. Logical decision-making encompassed analyzing one's current situation (i.e., cancer incidences in the family, stage of life), seeking relevant family planning information from healthcare providers, and then rationally weighing the advantages and disadvantages of each possible health decision. Logical decision-making included two properties—timeline for preventative surgery and

Fig. 1 Interview Guide

Demographic Questions
1. State your age.
2. What ethnicity do you identify as?
3. What is your household income?
A. < 25,000 B. 25-50,000 C. 50-75,000 D. 75-100,000 E. > 100,000
4. State the highest level of education you have completed.
5. What year did you undergo genetic testing?
6. Do you have any children? How many?
7. What type of mutation have you tested positive for?
8. What is your marital status?
9. Have you undergo any preventative surgeries? If so, what surgeries have you had?
10. Please provide a brief narrative of the background of hereditary cancer in your family.

Open-Ended Content Questions
(1) Describe what it was like for you to be diagnosed with a gene mutation?
--How did you feel?
--Who did you talk to about it? Describe one of the first conversations you had about it.
--Were/are there people you don't talk to about it? Why or why not?
(2) What are your thoughts on family planning now that you know about your mutation?
--Family planning means any conversations related to having or not having children
--What do you consider to be your options for family planning?
--What must you take into consideration now that you have a genetic mutation?
--How did you come to the conclusions you came to?
--Who did you talk to? Why them? What advice did they give you?
(3) How do you and your partner talk about family planning?
--Describe one of these conversations
--What decisions have you made? What are the issues you have to consider?
--How have preventative surgeries factored into these decisions?
--How has passing genes to children factored into these decisions?
--Describe the last time you talked to your partner about family planning
--Do you anticipate any changes in your decisions or those of your partner?
(4) How have your relatives reacted to your family planning decisions? Provide examples.
--How did they learn about it?
--How did you discuss it with them?
(5) How did your friends react to your family planning decisions? Provide examples.
--How did they learn about it?
--How did you discuss it with them?
(6) Who else do you talk to about your family planning decisions?
--What do they say?
--Are there people you avoid talking to about it?
(7) Describe any conversations you've had with healthcare providers about family planning.
(8) What advice would you have for newly diagnosed female previvors in terms of family planning conversations?
--Communication with partner/family/friends/etc.

pressure from healthcare providers. We begin by discussing timeline for preventative surgery.

Timeline for Preventative Surgery The first property was a timeline for surgeries. Previvors explained their family planning decisions were intertwined with when they should have preventative surgeries. While preventative surgeries significantly reduce previvors' HBOC risk (e.g., a PBM reduces one's breast cancer risk by 90% or more, Metcalfe et al. 2004), these decisions end the chances of conception and/or breastfeeding. Previvors engaged in logical decision-making by making a logical timeline for having preventative surgeries and future children. In other words, the primary concern for previvors who engaged in logical decision-making was decreasing their personal risk for HBOC.

For example, Callie (a 37-year old, married *BRCA1* previvor) shared how she and her husband discussed when to have a PBM and a second child by weighing all their options. She explained,

> "I guess our conversations about family planning also related to having the prophylactic surgery. So, in talking about when is the ideal timing for the prophylactic surgery, we talked about would I want to be able to try to have another child that I could breastfeed before having the surgery…Then we talked about how I could have the surgery first and then still have another child, but I wouldn't be able to breastfeed."

Callie further explicated that if she chose to have another baby, before undergoing a PBM like her healthcare providers recommended, she would have to wait at least six months after giving birth to have the surgery. This period of waiting caused concern with Callie and her husband because she would be that much older with a high risk of developing breast cancer. She clarified,

> "If [I] tried to keep within the timeframe, then I would have two very small children and trying to manage a recovery would be more of a challenge—So figuring

Table 2 Previvors' Decision-Making Styles

The two decision-making styles emerged in previvors' conversations about family planning,	which involved these dimensions,	and surfaced this prominently in previvors' accounts.
Logical Decision-making	Timing and timelines for undergoing preventative surgeries (e.g., PBM, oophorectomy, both) and pressure from healthcare providers	(n = 85)
Emotional Decision-making	Biological time clock, hope for the future, guilt associated with passing on gene to children, and pre-implantation genetic diagnosis (PGD)	(n = 167)

n refers to the frequency that the decision-making style emerged in previvors' family planning conversations

out the timing of the surgery [was] related to family planning."

In addition to creating a timeline for preventative surgery, previvors also described how *BRCA* created a sense of urgency to undergo preventative surgeries to reduce their HBOC risk. Leann (a 36-year old, married *BRCA1* previvor) illustrated it this way.

> "When it came down to looking at timing and biological clock as it relates to *BRCA*—that urgency—it definitely backed up the time that we were looking at wanting to get pregnant…But then the thought was as soon as we were done having kids that I would look at the surgery. And then looking at the timing and my age compared to my aunt's age [who was diagnosed with breast cancer in 40s], it made sense with BRCA to only have two [children] and then move on with surgeries."

Molly (a 32-year old, married, *BRCA2* previvor) articulated a similar experience:

> "A lot of it was trying to prioritize, do we finish our family before I have the mastectomy or do I have the mastectomy before we finish our family? Because there was never a question that I was going to have the mastectomy. It was just a matter of when. I mean that was really the majority of the conversations, and most of it was, 'We're going to have the surgery first because I just [can't] live with the uncertainty [of] when is it going to hit me.'"

Pressure from Healthcare Providers The second property was pressure from healthcare providers. Several previvors reported their providers had strong recommendations on when to have their preventative surgeries and when to have children. Brooke's (a 33-year old, *BRCA2* previvor in a common-law marriage) healthcare provider advocated for a PBM before trying to have a baby. She noted her doctor said, "You need to plan your mastectomy. You are putting yourself at too high a risk doing in vitro fertilization (IVF) when you haven't had a mastectomy." Brooke continued saying that her doctor was clear that she did not have clinical data to back up this opinion, but she felt very strongly that Brooke should undergo a PBM first. Brooke reported that her doctor stated,

> "I want you to do the mastectomy because what's going to happen is we're going to inject you full of hormones. You're going to get pregnant. You're going to have nine months of hormones, and you're going to be sitting in chemo when your child is two years old."

After contemplating her doctor's opinion, Brooke decided she trusted her doctor and would go through with the mastectomy before trying IVF.

Along the same lines, Lexi (a 38-year old, single *BRCA1* previvor) explained how her doctor encouraged her to have an early pregnancy in order to complete a preventative oophorectomy.

> "Initially I was doing fertility preservation…But my doctors advised me that I should probably, because of my age, and some of my numbers [referring to past surveillance results], that I should not delay trying to get pregnant. But I kind of have to see what I get still. I can't predict anything right now. But if all goes well, then I'll probably try to get pregnant by the end of the year."

In addition to having opinions about when to have children, many healthcare providers also emphasized previvors needed to have children by a particular age so they could then have surgeries. For example, Jen (a 24-year old, *BRCA1* previvor in a committed relationship) stated that her healthcare providers told her she was "getting close to that cut-off point." Although previvors' "cut-off" point varied somewhat based on their age and relationship status as well as when their female family members were originally diagnosed with HBOC, most previvors reported their providers recommended age 40 as the ideal age to be done with having children and then undergo preventative surgeries.

In sum, previvors engaged in logical-decision making to make family planning decisions in a rational doctor-

recommended timeframe. Indeed, sometimes previvors wanted to be logical in their management of their HBOC risk so much so that they decided not to have children at all or stop having children after learning their *BRCA* status. One example of this is Whitney—a 40-year old, married *BRCA2* previvor. She explained, "After getting the *BRCA* status, for me I think that kind of made me think that that was the decision made for me, that I wouldn't have children. Because I didn't want a mutation to be passed onto another generation of our family."

Emotional Decision-Making

The second decision-making style previvors engaged in was emotional decision-making, which invoked emotional responses (i.e., fear, worry, hope, longing, guilt) as driving factors for making family planning health decisions. Emotional decision-making included three properties—biological time clock, passing on the *BRCA* mutation, and hope for the future. Many previvors described how their emotions, rather than rational thought, informed when they decided to have children and when to have preventative surgeries. Indeed, several previvors expressed sentiments similar to Kristie (a 44-year old, married *BRCA1* previvor) who said, "I don't think we would have our fifth [child] if it weren't for the *BRCA* mutation. The emotions involved really affected my decision-making. It was an emotional baby, not a baby made from logically thinking." We first discuss the biological time clock.

Biological Time Clock Emotional decision-making has three properties. The first property was the biological time clock. Previvors who engaged in emotional decision-making organized their plans to have preventative surgeries around their plans to have children. This was in contrast to logical decision-making. In other words, the primary concern for previvors who engaged in emotional decision-making was having children. Older previvors in committed relationships tried to have as many children as possible before having surgery, whereas, younger, single previvors struggled with fitting preventative surgeries around their family planning.

For example, Jen (a 24-year old, *BRCA1* previvor living with her partner) described the personal pressure she feels to have children soon in order to undergo preventative surgeries. Jen explained that since her mother was diagnosed with cancer at age 42 she should have surgery at age 32 because the recommendation is to have surgery about ten years prior to the earliest cancer diagnosis in the family. She said,

> "It's a little stressful because does that mean that I have to be [done having] all my kids by then? Usually [you] don't have such a timeline when you need to be done having your children…I mean my sister who is 28 and doesn't have a boyfriend yet, and, so there is that little bit of pressure in terms of [family planning]."

Jen continued on sharing that she would like to have biological children naturally; however, her current partner wants to wait until they are married for at least four years before having children. Yet waiting four years would put Jen at 28-years old, which only leaves four years to have children before undergoing surgery at 32, and she wants multiple children.

Britney (a 28-year old, single *BRCA2* previvor) echoed this emotional distress that comes with making decisions about family planning and preventative surgery. She explained that as she has grown older she feels like her "time is running out," which has loosened up her self-imposed restrictions on family planning. Originally, Britney had planned to do pre-implantation genetic diagnosis (PGD) in order to "have kids without a mutation." However, because she is still single and without children, her desire to have kids is now more important than her hesitation about passing on her genetic mutation. In fact, Britney clarified how the older she gets the more willing she might be to extend her timeline for undergoing a preventative oophorectomy in order to have children. "I am incredibly emotionally attached to my ovaries and my uterus," she said, which is influencing her decision-making.

This was also the case for Kristie. As noted above, Kristie's decision to have her fifth child was "purely emotional." Kristie's gynecological-oncologist recommended having her ovaries and uterus removed at age 38. Yet the closer Kristie moved toward that age, the more she started to experience sadness. She lamented,

> "I just hated to close that door. Hated to lose my fertility. Losing my breasts was a lot easier than my ovaries. Losing my ovaries meant a lack of hormones, a lack of fertility. It was just difficult. I guess I wanted to squeeze everything I could out of them."

Passing on a *BRCA* Mutation The second property of emotional decision-making was guilt for passing on a *BRCA* mutation. Previvors talked about how they struggled with the idea of passing on their genetic mutation to their children. For instance, some previvors reported sadness and discomfort after learning they were pregnant due to guilt about passing on a *BRCA* mutation. This was Corrine's experience (a 41-year old, married *BRCA2* previvor). She exclaimed,

> "When I did my pregnancy test I remember crying when I saw the positive test because I thought, 'My God, what have I done? This is just the most selfish thing I've ever done.' I rang up my friend, a really, really close friend of mine, and I said, 'I'm pregnant,' and I was in tears and saying, 'I think I've done something horrible. Am I a bad mum?' I just felt horrible."

This emotional struggle about not passing on their genetic HBOC risk often led previvors to consider PGD. Previvors who learned about their *BRCA* genetic mutation prior to children or during their family planning contemplated still having children naturally without assisted reproductive technologies (ART) and engaging in ART in order to stop the hereditary nature of cancer. For example, after finding out she was pregnant, Leah (a 43-year old, married *BRCA2* previvor) realized she was uncomfortable about passing on the *BRCA* mutation because "the mutation not only affects one person, but affects the entire family as a whole… I couldn't see a reason to pass it on if I had a choice."

Lexi's conversation with her brother further articulates this emotional struggle. Lexi (a 38-year old, single *BRCA1* previvor) recounted how her brother became angry at her when she informed him she was considering not undergoing PGD.

> "So my brother was kind of angry with me when I told him that I was, for a few days, [I was] considering not doing PGD, just IUI,[5] and rolling the dice. And he got kind of angry that I was willing to take that risk. And that kind of made me jump back a little bit…Because if I have a child without doing PGD, I think it's something that I'll always think about and worry about whether she has my mutation or not, and I won't be able to know until she decides sometime in adult life whether she wants to do it [referring to genetic testing] or not herself."

However, Lexi was the only previvor who decided to do PGD. The majority of previvors (90%) expressed desires to have a natural conception, explaining they would only consider PGD if there were identified fertility issues. PGD was viewed as "extreme" and a means for creating a "comfort baby," "Hollywood baby," or "science project baby." This viewpoint was especially cognizant for previvors who already had some children or who did not know about their *BRCA* mutation until after having children. Molly shared this perspective:

> "We decided we were going to just hope it happened naturally. If we had to do fertility treatments down the road anyway, we would have looked into the PGD then, but since we ended up not needing to go that route anyway – we were hoping to just go naturally versus having to do all that."

Hope for the Future The last property was hope for the future. Several previvors conveyed their persistent hope for future scientific and medical advancements for cancer prevention and treatment. Although it may seem like this property would fall under logical decision-making due its emphasis on advancements, instead, such decision-making was emotionally framed because previvors explained that their decisions were based on emotional hope, not rational thought.

First, previvors discussed how their hope for the future assisted them in making personal family planning decisions. Leah (a 43-year old, married *BRCA2* previvor) recounted an emotional conversation with her husband regarding future medical advancements and passing on her genetic mutation.

> "I think his [referring to her husband] opinion at first was, "Well, we have other things wrong with us, so this is just one bad thing that we know about that we would be passing on. Maybe medicine will be more advanced once we have a child, if the child has the mutation." So that was his take on it, [but] as I said, my opinion kind of changed over time, and I began to realize that I really didn't want to pass on the mutation."

So while Leah was concerned about passing *BRCA2*, and ART was an option to stop HBOC in her family, ultimately the couple decided not to undergo PGD because they hoped the future would bring better treatments for cancer. Lacey (a 48-year old, married *BRCA1* previvor) described similar emotional thinking, "I made a point that we all have something, and that at least they can test for this now, and that maybe in 20 or 30 [years] there will be a lot of medical advances and better options." In other words, previvors acknowledged that there were ways to avoid passing on their genetic mutation, but they did not use those means because of their hope for the future.

Second, previvors explained that the possibilities of future medical advancements will also assist their children in the future. For instance, Molly (a 32-year old, married, *BRCA2* previvor) confidently said,

> "We'll have solutions for them. The solutions that are already available are better than what was available 30 or 20 years ago, and so by the time our kids are old enough to have to really worry about it [referring to HBOC], hopefully there will be even better solutions and options for them."

Macie (a 31-year old, married *BRCA1* previvor) further supported this reiterating, "Medicine is only advancing, maybe by the time that they [referring to her kids] are in their 20s, there will be different options for them than there were for me 3 or 4 years ago."

Important here though is that previvors employed this decision-making style (i.e., placing hope on future cancer prevention and treatment options) while also engaging in logical decision-making (i.e., undergoing preventative surgeries in order to reduce their HBOC risk). In other words, previvors often

[5] Intrauterine insemination (IUI) refers to the fertility treatment whereby a sperm is placed directly into a women's uterus in order to increase the likelihood that many sperm will reach the fallopian tubes and result in a pregnancy.

engaged in emotional decision-making about children, but employed logical decision-making regarding personal HBOC risk. For example, Lexi (a 38-year old, single *BRCA1* previvor) explained this emotional struggle between hoping for better options in the future and feeling guilty about passing on the *BRCA* mutation by recounting a conversation she had with a *BRCA1+* cousin. Although Lexi's cousin underwent a PBM because she wanted to reduce her personal genetic risk of HBOC, she did not want to pursue PGD. Lexi said,

> "She felt like in 30 years there would be better options, and so on, and so forth, and that it was a risk that she was comfortable with taking. I didn't really want to offend her, but I disagree… We just try to be respectful of each other's differing viewpoints as much as possible on that matter."

Lexi further reflected on previvors hope for the future saying, "A lot of times the reason they give is they just assume that there will be better options for their son or daughter by the time they reach adulthood, and there is no guarantee of that. There [are] just no guarantees of anything."

In short, in addition to logical decision-making, previvors also engaged in emotional decision-making when making family planning health decisions. Although previvors desired to be logical, following their healthcare providers' recommendations for having children and undergoing preventative surgeries, many explained how their emotions would trump rational thought. Overall, these decision-making styles reveal a difficult struggle for previvors, determining to listen to one's own personal desires of motherhood while managing clinical recommendations for reducing one's HBOC risk.

Discussion

This study identified previvors' decision-making styles about family planning. These results demonstrate the complex family planning decisions previvors grapple with after testing positive for *BRCA* and the ways in which they try to make those decisions. First, we discuss the results, followed by limitations, practice implications, and research recommendations.

The results of this study revealed, after testing positive for a *BRCA* genetic mutation, previvors must decide when to have children and when to have preventative surgeries, and these decisions are guided by logical and emotional decision-making styles. More specifically, logical decision-making prioritized decreasing their personal risk of HBOC and thus undergoing preventative surgeries over having any (or more) children, while emotional decision-making prioritized having children by extending their preventative surgery timeline and in so gambling with their personal HBOC risk.

To begin, our findings reinforce previous research articulating a tension between cancer risk management (i.e., preventative surgeries) and life goals (i.e., having children, Donnelly et al. 2013; Rubin et al. 2014; Werner-Lin 2008), yet reveals previvors' willingness to push their preventative surgeries back in order to have (more) children. This is in contrast to previous research that has found that women who test positive for a *BRCA* mutation were less likely to want more children after learning their genetic test results (Smith et al. 2004; Woodson et al. 2014). This finding also relates to other reproductive decision-making in other genetic contexts. For example, Myring and her colleagues (Myring et al. 2011) found Cystic Fibrosis (CF) carrier couples who already had a child or pregnancy affected with CF were more likely to have another pregnancy, while CF carrier couples who had a healthy child first were less likely to consider another pregnancy because of their concern for the child's risk. Future research may consider comparing and contrasting several life-threatening genetic conditions about reproductive concerns.

Underlying previvors' prioritization of childbearing over personal risk management is a sense of urgency and heightened desires of motherhood. While previous research notes single women who test positive for a *BRCA* mutation experience urgency to find a partner in order to have a family (Werner-Lin 2008), this research demonstrates the urgency relates to having the children over finding a partner. In our study, previvors experienced urgency to have children early if possible, but when that was not possible, they considered extending their preventative surgery timeline in order to have children even at the expense of their own personal HBOC risk. This finding makes sense given a systematic review examining women's decision-making about risk-reducing strategies for HBOC which found women with children were more likely to undergo preventative surgeries like a PBM than those who did not have children (Howard et al. 2009). Moreover, this sense of urgency is particularly important because women who test positive for a *BRCA* mutation report their healthcare providers focus more on personal risk reduction (e.g., preventative surgeries) in consultations rather than issues of family planning; even when genetic counselors and social workers discuss reproductive issues, oftentimes, it is communicated indirectly and without substantial medical expertise (Vadaparampil et al. 2009). Thus, the results of this study indicate a need to counsel women considering genetic testing, especially younger women who have not completed their childbearing, on reproductive and fertility decisions related to genetic testing.

Another key finding of this study was previvors' feelings of guilt regarding passing on a *BRCA* genetic mutation. This concern about passing on a mutation is consistent with aforementioned literature (Quinn et al. 2010b). In a survey of women at risk for HBOC who were of reproductive age, 90% expressed their concerns about passing on their mutation

(Staton et al. 2008). Additionally, a more recent survey investigating how women's knowledge of their *BRCA* genetic status influenced their reproductive decision-making found 17% would not have children due to a fear of passing on the gene and 10% would not have children due to the concern that the child might develop cancer in the future (Chan et al. 2016). Yet concern for passing on a genetic mutation is not only in the HBOC context. Klitzman and his colleagues (Klitzman et al. 2007) found individuals at risk for Huntington's Disease (HD) experienced similar feelings of guilt and occasional blame for passing on their genetic predisposition to their current children or possible future children.

Given this concern for passing on a genetic predisposition, one might think previvors would undergo measures to reduce that risk through ART; however, previvors in this study emphasized wanting to have children naturally despite the fact that using ART like PGD would eliminate the 50% chance of passing a *BRCA* mutation to their potential children. This finding is especially interesting as many previvors chose to undergo preventative surgeries to reduce their personal risk of HBOC. As such, it seems previvors in this study wanted to have children naturally without fully considering how this decision may impact their future children.

Women who do consider PGD do so under the following conditions: when they are aware of PGD as ART; when they desire to have children or more children; and when they believe PGD is an appropriate way to decrease their children's HBOC risk (Vadaparampil et al. 2009). However, while PGD allows women and their partners to select non-*BRCA* positive embryos (Quinn et al. 2010b), the decision-making process is complex, as many individuals have ethical and moral concerns about selecting embryos (for example, see, Krahn 2009; Noble et al. 2008; Wang and Hui 2009). Furthermore, few studies have assessed women's attitudes and experiences regarding PGD (e.g., Staton et al. 2008; Quinn et al. 2009), and those studies that do examine perceptions of reproductive decision-making find while 59% of women believe PGD should be offered to individual who test positive for a *BRCA* mutation only 35% would consider it (Chan et al. 2016). Thus, this qualitative study provides deeper insight into these statistics, revealing previvors hold many negative interpretations about PGD. Future research may continue exploring women's justifications for not utilizing PGD. Moreover, healthcare providers may work to better understand their patients concerns about ART in order to better assist them in the family planning decision-making process.

A final important finding was that previvors cope with the possibility of passing on their genetic mutation to their children by holding onto "hope for future" medical and scientific advancements. This finding is also supported by previous research (Donnelly et al. 2013; Friedman and Kramer 2005). In a qualitative study with women who test positive for a *BRCA* mutation regarding their attitudes towards reproductive genetic testing but who did not have children yet, Ormondroyd et al. (2012) found the women's perceived severity of HBOC on reproductive decisions influenced their attitudes. For example, some women mentioned prevention and treatment options for individuals who test positive for a *BRCA* mutation would surely improve in the future. In another study—which extended Ormondroyd et al.'s (2012) work—Donnelly and her colleagues (Donnelly et al. 2013) found eighteen of their 25 participants (72%) "expressed a strong belief in the future development of medical science and its ability to alleviate cancer" (p. 1009). Yet, the present study extends such research as hope for the future was a component of emotional decision-making rather than logical decision-making. In other words, this emotional belief mediated previvors' rational thoughts regarding family planning decisions. Furthermore, this finding demonstrates that previvors hold the same concerns about their future children developing cancer as cancer patients do (Quinn et al. 2010a).

Study Limitations

While this study provides insight on family planning decision-making in the HBOC context, it is not without limitations. One limitation was the homogenous nature of the sample. Most participants were Caucasian, well-educated, and fairly affluent. Also, the results of this study were likely influenced by recruiting participants at a conference solely devoted to teaching individuals about HBOC. In other words, conference attendees were already interested in HBOC and preventative health management options. In addition, the participants had monetary means to attend the conference. Thus, it is conceivable these factors influenced the experiences they shared. A second limitation was the lack of gendered differences as this study focused on women's HBOC decision-making experiences. Future research may examine men's decision-making experiences and account for how such differences may influence both men and women's perceptions of genetic risk, decision-making, and family planning.

Practice Implications

The results of this study may aid genetic counselors in assisting previvors with decision-making. First, we hope the results show how emotions and logic affect family planning decision-making and provide additional information that may assist genetic counselors and other healthcare providers in effectively facilitating conversations about family planning with their clients, client's partners, and/or client's family members. Second, and along these lines, it is important that during pre-genetic testing counseling sessions genetic counselors discuss reproductive decision-making, family planning options, and possible feelings about passing on one's genetic mutation to children alongside personal risk-reducing health decisions.

Research Recommendations

Finally, we suggest two important next steps for this avenue of research. First, future research should specifically examine why previvors chose to undergo preventative surgeries to reduce their personal HBOC risk but do not choose to screen for a *BRCA* mutation through ART like PGD. Second, since previvors reported healthcare providers being integral to their logical decision-making, future research should examine providers' perceptions regarding preventative surgeries and family planning. Understanding the reasons behind providers' medical advice would assist in creating clearer guidelines and improve interactions between providers, patients, and their partners. Last, given the complex nature of decision-making, it may be valuable to develop educational materials for healthcare providers, women who test positive for a *BRCA* mutation, and their family members describing logical and emotional decision-making to assist in effective decision-making regarding family planning.

Conclusions

Overall, this study extends previous research (Donnelly et al. 2013; Ormondroyd et al. 2012; Rubin et al. 2014; Werner-Lin 2007, 2008), revealing the ways in which previvors grapple with family planning decisions. The findings show—after testing positive for *BRCA*—previvors negotiate having preventative surgeries in a logical doctor-recommended timeframe while also organizing their decisions around emotional desires of motherhood.

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Compliance with Ethical Standards

Conflict of Interest Authors Marleah Dean, PhD and Emily Rauscher, PhD declare they have no conflict of interest.

Human Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Animal Studies This article does not contain any studies with animals performed by any of the authors.

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