

## Building the Cancer Family: Family Planning in the Context of Inherited Breast and Ovarian Cancer Risk

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Deleterious *BRCA1* and *BRCA2* gene alterations significantly elevate a woman's risk of developing hereditary breast and ovarian cancer. A simple blood test can identify the presence of a *BRCA* gene alteration in a patient's DNA. Increasingly, individuals pursuing genetic testing to identify these alterations are also involved in family planning and parenting young children. However, the challenges unique to *BRCA* gene alteration carriers of reproductive age are just beginning to be studied. This investigation identifies the influences of family medical histories and genetic testing on reproductive choices and examines the meanings of family planning and parenting in the context of genetic medicine.

23 female *BRCA* gene alteration carriers of reproductive age were recruited from an urban hospital and an Internet-based support community. Each participant completed an open-ended interview and constructed a medically focused family genogram. Interviews addressed family experiences with cancer, perceptions of cancer risk, and beliefs about family development. Interviews were transcribed verbatim and analyzed using the *Listening Guide* (Gilligan, Spencer, Weinberg, & Bertsch, 2003) to identify key relationships and meaning structures. Participants had no personal history of cancer.

Emergent themes included balancing risk management with family planning, weighing possible advances in cancer prevention with desire for biological children, and anticipating implications of a parent's carrier status for children. Findings will aid in developing research and clinical protocols to integrate risk management with family planning. Research attention to partners, health care access, and reproductive technologies is considered.

*Keywords:* *BRCA gene alterations, hereditary breast and ovarian cancer, cancer risk management, family planning, parenting*

Young adulthood, perhaps more so than any other period of development, may be the most critical time to consider the impact of genetic testing on coping and quality of life. Recent literature on hereditary breast and ovarian cancer has identified unique medical and psychosocial challenges faced by healthy young adults, specifically women, living with inherited cancer risk (e.g., Kenan, Arden-Jones, & Eeles, 2006; Werner-Lin, 2007). This literature suggests cancer risk may be highest before menopause (Evans, Skrzynia, Susswein, & Harlan, 2005-2006) when screening and preventive measures have a significant impact on reproductive capacity and quality over a longer period of time than for older women (Friedman & Kramer, 2005).

Young adulthood is frequently characterized by building a life structure to include a variety of emerging relational, family, and career identities (Arnett, 2000; Carter & McGoldrick, 1999). The

experience of creating a life plan that integrates either (a) the possibilities of early illness and death to cancer, or (b) the pursuit of risk reduction measures that significantly constrain pathways to parenthood is out of synch with normative developmental tasks of establishing intimate relationships (Hoskins, Roy, & Peters, 2008) and the start of family planning (Werner-Lin, 2008).

A growing number of *BRCA* gene alteration carriers (hereafter, *BRCA* carriers) of reproductive age are asymptomatic. Without a standing cancer diagnosis, genetic testing results remain entirely predictive, leaving patients with ambiguous risk information. In the absence of definitive risk information, patients frequently lean on heuristics, or cognitive shortcuts, embedded in their family histories with cancer to guide expectations about vulnerability (Kenen et al., 2006; Werner-Lin, 2007). These expectations inform decisions about family planning and cancer risk management. Risk-reducing surgery, specifically to prevent ovarian cancer, dismantles the reproductive system, halting fertility. Although couples may experience some fluidity in making reproductive decisions (Patenaude, 2004), perceptions of imminent cancer risk, whether suggested or confirmed through genetic testing (Werner-Lin, 2007), may push

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childbearing before individuals and couples are ready or may prevent couples from having the children they had hoped for. Alternatively, remaining childless may present a more compelling risk for young patients, limiting uptake of preventive measures. Thus, fertility and family planning are uniquely and intricately tied to the process of cancer risk management for patients of reproductive age.

The young adult women under investigation in this study are part of the first generation of *BRCA* carriers who are actively involved in family planning. They have the power to make choices about cancer prevention and family planning that integrate family medical histories (Werner-Lin & Gardner, 2009) with the possibilities offered by genetically enhanced medicine. This investigation addressed the following research question: How are family illness histories and positive genetic testing results integrated into life planning for *BRCA* carriers of reproductive age? This article seeks to identify the influences of family medical histories on reproductive beliefs, behaviors, and intent for these young patients. Through the presentation of medical family genograms and participant quotes (using pseudonyms), this article links family planning beliefs and behaviors to the meaning of family experiences with cancer and genetic testing.

### Profile of *BRCA* Alterations

Deleterious *BRCA1* and *BRCA2* gene alterations (also commonly called mutations) increase a woman's risk of developing hereditary breast and ovarian cancer. Either biological parent can carry and pass on the alteration to a child, and each child of a *BRCA* carrier has a 50% chance of inheriting the gene alteration. *Penetrance*, the proportion of *BRCA* carriers who will manifest symptoms, varies widely based on factors such as the particular alteration (Sorlie et al., 2003), the ethnic group under investigation, and the method of recruitment of the study sample (e.g., Olopade et al., 2003; Struwing et al., 1997). Early large-scale family case studies that used clinic-based samples to identify and isolate the *BRCA* genes recruited patients with dense family histories and isolated mutation strains. These retrospective studies found that by age 50 years, between 50% and 73% of *BRCA* carriers developed breast cancer, and nearly 30% developed ovarian cancer (Easton, Bishop, & Ford, 1995; Ford, Easton, Bishop, Narod, & Goldgar, 1994). In the last decade, research with community- and population-based samples has expanded these risk estimates to address families with limited *cancer density* (i.e., the rate of cancer expression in a given population). These studies suggest that by age 70 years, an estimated 14% to 87% of female *BRCA* carriers will develop breast cancer, and 10% to 68% of these women will develop ovarian cancer (Antoniou, Pharoah, & Narod, 2003; Szabo &

King, 1997). Given that limited research addresses the variety of risk factors that scatter alteration carriers across this extraordinarily wide risk spectrum, clinicians continue to look at family histories as predictors of risk.

Screening methods, particularly for ovarian cancer, are imperfect. Noninvasive measures to detect ovarian cancer in its early stages are not well proven (Evans et al., 2005-2006). As a result, approximately 75% of ovarian cancers are diagnosed with advanced staging, at which point the 5-year survival rate is only 8% (Gaarenstroom, van der Hiel, & Tollenaar, 2006). Further, preventive measures provide no guarantees and many significantly affect quality of life (Lostumbo, Carbine, Wallace, Ezzo, & Dickersin 2004; Lux, Fasching, & Beckmann 2006; Meiser, 2005). Noninvasive procedures such as breast self-examination and transvaginal ultrasound promote early detection. Chemoprevention can reduce breast and ovarian cancer risk by up to 50%. *Bilateral prophylactic mastectomy*, the surgical removal of breast tissue, can reduce breast cancer risk by more than 90% (Black & Smith, 2005-2006; Edlich, Winters, & Lin, 2005). *Bilateral prophylactic salpingo-oophorectomy*, the surgical removal of ovaries and fallopian tubes, reduces ovarian cancer risk by more than 85% and stops ovulation and estrogen production, which substantially lowers lifetime risk of breast cancer for premenopausal women (Mokbel, 2003; Rebbeck, 2002). Although these risk-reducing surgeries nearly eliminate ovarian cancer risk and significantly diminish breast cancer risk (Mokbel, 2003; Rebbeck, 2002), they remain imperfect solutions to preserving health; Risk-reducing oophorectomy induces surgical menopause (Rebbeck, 2002), dismantles the reproductive system, and increases lifetime risk of osteoporosis and heart disease (Kauff et al., 2008). Further, removal of the ovaries profoundly affects quality of life; ramifications of the procedure may drastically alter sexuality (Oktay, 1998) and identity both physiologically and psychologically (Black & Smith, 2005-2006; Goodwin, 2000; Meiser et al., 2000; Samuel & Ollila, 2005-2006; Stiefel, Lehmann, & Guex, 1997). A recent review demonstrated that in the year following genetic testing, between 0% and 54% of unaffected carriers pursued bilateral prophylactic mastectomy, and between 13% and 54% of unaffected carriers pursued bilateral prophylactic salpingo-oophorectomy (Wainberg & Husted, 2004). For those *BRCA* carriers who did not immediately complete surgery, the majority showed significantly increased rates in the uptake of breast screening and an overall decline in ovarian screening. These rates may reflect the lack of demonstrated efficacy of standard ovarian cancer screening tools. It is of note that women choosing preventive surgery are electing to reduce their cancer risk whereas those

pursuing surveillance are relying on early detection in the hopes of precluding cancer mortality (Schwartz, Peshkin, Tercyak, Taylor, & Valdimarsdottir, 2005).

### Literature Review

#### Pathways to Risk Reduction and Cancer Prevention

Genetic testing for hereditary breast and ovarian cancer offers knowledge of a potential future diagnosis to families that generally have considerable experience with cancer (Erblich, Bovbjerg, & Valdimarsdottir, 2000; Peters & Biesecker, 1997; Werner-Lin, 2007). Genetic testing may provide a young woman with a sense of increased control over her inherited risk by minimizing uncertainty and by opening avenues to pursue advanced and targeted preventive medical care (Gooding, Organista, Burack, & Biesecker, 2006). However, after testing, *BRCA* carriers must make crucial, and frequently distressing decisions, about how to monitor their health (Erblich et al., 2000; Schlich-Bakker, ten Kroode, & Ausems, 2006). Predominant models of health behavior suggest health decisions are “rational” when informed by a combination of a risk-benefit calculus, pressures from and modeling of important others, beliefs about control and mastery, and available resources (Gehlert, 2006). Although socially focused models of health behavior and decision making exist, these models were designed well before the genetic revolution and are proving insufficient in the examination of individual and family experiences with hereditary disease. These models do not take into account the importance of family histories in shaping cognitive representations of the illness experience long before the individual experiences a diagnosis, a scenario in which grief, self-concept, and relational dynamics are tied intimately to illness expectations.

Distress and anxiety continue to be clear and consistent predictors of uptake of prophylactic surgery (Metcalf, Lynch, Ghadirian, & Nadine, 2004). Psychological morbidity decreases substantially after bilateral prophylactic mastectomy (Hatcher, Fallowfield, & A'Hern, 2001; Metcalfe et al., 2004; van Oostrom et al., 2003) and bilateral prophylactic salpingo-oophorectomy (Tiller et al., 2002), suggesting risk-reducing surgery is effective in lowering both cancer risk and emotional distress. However, the field is still in the process of identifying factors that contribute to increased distress following genetic testing. Personal and family histories and beliefs about vulnerability and risk must be factored into assessments of distress for women choosing among the varied risk management options (Patenaude, 2004; Werner-Lin, 2007). This assessment approach is supported by mounting evidence that a family history of cancer may inform disease expectations (McDaniel, Rolland, Feetham, & Miller, 2006), underlie perceptions of risk and associated distress (Hallowell,

2006; Patenaude, 2004; Werner-Lin, 2007) and guide decisions made by women to manage their cancer risk (Babb et al., 2002; Meijers-Heijboer et al., 2000; Miller et al., 1999). A study by Hallowell, Statham, and Murton (1998) of women completing genetic testing found the majority of patients who discussed prophylaxis with their genetic counselor focused on the type of surgery that corresponded to their family histories with cancer. For example, women with family histories of breast cancer asked about risk-reducing mastectomy rather than oophorectomy (Hallowell et al., 1998). Similarly, Babb and colleagues (2002) found that women who had an extensive family history of ovarian cancer were more likely than other *BRCA* carriers to elect risk-reducing oophorectomy rather than less invasive ovarian screening.

Further, decisions about risk-reducing surgery are made with consideration of the impact and burden on important relationships with children, partners, and extended family members. In addition to lowering cancer-related fear and distress, completion of risk-reducing surgery enables women to fulfill childcare obligations and to protect children from the pain of parental loss by decreasing mortality (Hallowell et al., 1998). Taken together, these findings suggest that the decision to pursue various risk management pathways is influenced by a *BRCA* carrier's family history, concerns about risk, and beliefs about and hopes for the future for self and family.

#### Family Planning and Inherited Cancer Risk

Women considering risk-reducing surgery face a variety of psychosocial and psychosexual challenges that shift in salience as they move through the life course or experience changes in their family's cancer profile (e.g., experience a new diagnosis or cancer-related death). Among these challenges is mapping a timeline that balances quality of life priorities with distress about cancer risk and its management. The identification of time as a significant factor in deciding when to complete surgery suggests a developmental or life cycle perspective is crucial to a holistic understanding of hereditary cancer risk management. A life cycle perspective on human growth suggests individual and family development progresses through normative, sequential stages with anticipated psychosocial tasks and changes (Borysenko, 1996; Carter & McGoldrick, 1999). For young *BRCA* carriers, partnering and family planning—normative tasks of early adulthood—may be significantly threatened by perceptions of impending cancer risk or the realities of experiencing and treating a cancer diagnosis (Decruyenaere et al., 1996; Werner-Lin, 2007). This notion is supported by evidence suggesting *BRCA* carriers who are nurturing small children are more likely to exhibit increased distress over longer

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periods of time than *BRCA* carriers with older children or no children (van Oostrom et al., 2003).

Empirical and clinical evidence has demonstrated the decision to pursue genetic testing is linked to early adult life cycle transitions (McDaniel, 2005), specifically to inform family planning (Decruyenaere et al., 2007; Denayer et al., 1999; Evers-Kiebooms, Nys, & Harper, 2002). The timing of prophylaxis is linked to these life cycle stages; Women wanting to preserve fertility to complete childbearing may elect to postpone risk-reducing oophorectomy, seeing it as a viable option only for older women or those who have completed childbearing (Hallowell et al., 1998; Werner-Lin 2008). In the interim, mastectomy may be the best choice to reduce risk, and therefore distress, particularly because mastectomy does not interfere with childbearing. Thus, women choosing risk-reducing mastectomy are more likely to be younger than those pursuing oophorectomy (Botkin, Smith, & Croyle, 2003) and are more likely to have both young children and extensive family histories of breast and ovarian cancer (Lodder et al., 2002; Meijers-Heijboer et al., 2000; Scheuer et al. 2002).

Technological advances in genetic medicine provide new measures to reduce risk across a variety of personal and social dimensions. These advances offer hope for patients with extensive histories of illness and loss. The purpose of this study was to further illuminate the links between perceptions of cancer risk couched in family histories, reproductive decision making, and cancer risk management for young women living in this “risk society” (Beck, 1992; Webb, 2005) who have completed genetic testing. Although many of the studies mentioned above began addressing this connection, very few were designed specifically to investigate young adult women or to address the

specific challenges of managing cancer risk while pursuing important family development goals. This investigation aimed to fill this gap by interviewing women in their childbearing years who are actively facing these challenges.

### Method

#### Sample

Twenty-three participants were recruited over 6 months using purposive and convenience sampling. The majority ( $n = 19$ ) came from an online, nonprofit organization providing information and support to women with hereditary breast and ovarian cancer concerns; the rest ( $n = 4$ ) were recruited from the cancer risk clinic at a large, Midwestern, urban, teaching and research hospital. Recruitment criteria included the following characteristics: participants were (a) women; (b) *BRCA1* or *BRCA2* gene alteration carriers testing positive at least 6 months before the interview; (c) English-speaking; (d) between ages 21 and 35 years old, which are the boundaries for young adulthood as set by Carter and McGoldrick (1999) and with 35 years also representing the age at which pregnancy risk begins to increase in the general population; (e) not currently pregnant, and (f) not diagnosed with cancer. All participants had completed some college, and many had completed postgraduate degrees. All participants were White and of mixed Eastern or Western European descent. The extent of participants’ exposure to cancer and cancer-related losses varied across the sample, but remained consistent with hereditary breast and ovarian cancer expression rates. The decisions women made about prevention and surveillance also varied within the group.

Table 1

*Number of Participants Reporting Surveillance and Prevention Behavior by Key Family Variables*

	Single/Dating ( $n = 4$ )	Partnered, No children ( $n = 7$ )	Partnered, With children ( $n = 12$ )
Lifestyle changes (e.g., diet, exercise)	4 100%	3 43%	1 8%
Increased medical surveillance	4 100%	5 71%	3 23%
Chemoprevention	0	0	0
Risk-reducing surgery: Bilateral prophylactic mastectomy	1 25%	2 29%	8 67%
Risk-reducing surgery: Bilateral prophylactic salpingo-oophorectomy	0	0	9 75%

**Data Collection**

All potential informants participated in a telephone screening to assure they met inclusion criteria. Twenty-three eligible women completed an informed consent process in compliance with institutional review board requirements. Data collection included semi-structured, open-ended, audio-taped interviews using a brief list of core questions with consistent prompts. Table 2 shows examples of questions in the interview guide.

When possible, interviews were completed in person ( $n = 16$ ) rather than by telephone ( $n = 7$ ). During the course of the audio-taped interview, the researcher and participant co-constructed a family genogram that

spanned at least three generations, focusing on health and illness experiences (Daly et al., 1999). Throughout the interview, salient medical and psychosocial details presented by participants were noted on the genogram by the researcher. At the end of the interview, the participant was invited to check the genogram for accuracy and needed additions. When interviews were conducted over the telephone, genograms were mailed to participants in advance. Each interview was approximately 2 hours in length, and interviews were conducted in a place chosen by the participant, frequently their homes. Participants received \$25.00 gift cards to compensate them for their time and contribution. All audiotapes of interviews were transcribed and then coded by the author.

Table 2  
*Example Questions from Interview Guide*

Core Question	Sample Prompts
What does it mean for you to have (had) family members with cancer?	-Tell me about your family’s experiences with cancer. -What does it mean to have (had) a (mother, sister, grandmother, aunt, cousin) with cancer? -Are your understandings of and experiences with cancer influenced by spiritual, religious, or cultural understandings of illness and healing?
What does it mean for you to have a <i>BRCA1/BRCA2</i> alteration?	-Have any of your relationships changed since you learned your test results? -What do these results mean for you and your family/partner?
Has your thinking about the future shifted since you learned you have a <i>BRCA1/BRCA2</i> alteration?	-Have you taken measures to decrease your risk? -How were these measures decided upon? -Who was involved in these decisions?
Thinking about your family history with cancer and your risk, what does it mean for you to be a wife or mother?	-Do (did) you or your partner have fears or hesitation about marriage or having children? -Did you feel any pressure to accomplish life goals more quickly? -What relationships or responsibilities are important for you right now in your thinking about cancer? -Does knowledge of the <i>BRCA1/BRCA2</i> gene factor into your life plans?

**Data Management and Analysis**

The collection of medical family genograms aided the project in a number of ways. First, the genograms facilitated the initial interview experience by allowing the participant and researcher to collaborate on the concrete task of building a representational model of the participant’s family experience. Second, genograms provided a snapshot of family life to the researcher, and were useful in sorting participants by salient medical or family features to facilitate building significant categories of data and to confirm patterns and findings. Third, the genograms provided a unique and immediate way to engage in member checking. Member checking is frequently employed to enhance trustworthiness by requesting feedback and verification from participants (Padgett, 2008). In this study, member checking involved

showing the participant how their family story was captured on the genogram and inviting them to make corrections, additions, or deletions.

The *Listening Guide* (Gilligan et al. 2003) is a qualitative data analysis method designed to highlight the impact of relational and personal meanings on experience. The method involves a series of readings of, or “listensings” to, the interview text (Gilligan et al., 2003). Using this method, coding the transcribed interviews involved three discrete steps. First, an initial series of readings revealed three broad areas that corresponded to the design of the interview guide: (a) individual and family experiences with illness and genetic testing, (b) meanings and beliefs about cancer and inherited risk, and (c) individual and family development. The second step involved a series of three sequential and focused readings of each transcript. Each

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domain above guided one of these readings. During these focused readings, salient codes that emerged from the data were defined. For example, in this stage of data management, codes reflecting aspects of “time” emerged as significant across all three domains (see Table 3). Readings for family experiences with cancer revealed consistent reference to the time in the participant’s life that a loved one was diagnosed with cancer (e.g., during the participant’s childhood, adolescence, or young adulthood). Readings for the meaning and beliefs about

cancer and inherited risk revealed participants had concrete beliefs about when they might experience a cancer diagnosis should their genetic vulnerability go unchecked by preventive methods. Codes reflecting elements of time appeared across all transcripts, and were selected for inclusion in data analysis for two reasons: (a) these codes reflected an unexplored dimension of coping with genetic testing and (b) these findings might suggest meaningful avenues for targeted interventions across the life cycle.

Table 3  
*Codebook Excerpt*

Domain	Code	Definition	Participant Quotes
Experience of cancer in the family	Timing of cancer diagnosis in participant’s life cycle	Impact of loved one’s cancer diagnosis at varied stages of participant’s youth/adulthood.	<p>(parent diagnosed before participant was 10 years old, discussing chemotherapy): <i>I could not fathom why my mom would be fine at home, she’d go to the hospital and come home sick. It did not make sense in my mind at all.</i></p> <p>(parent diagnosed when participant was in puberty): <i>It’s a very strange age to have all this happening. I was just coming into being a woman, and I was just about to get my period... She was being taken out of having female organs and being a woman. ...It was a pivotal year.</i></p> <p>(parent diagnosed when participant was a young adult): <i>I was able to talk to her about other things and be more of a friend to her than when I was 12.</i></p>
Meaning of cancer and genetic risk	Beliefs about the timing of a future cancer diagnosis: danger zones	Point at which a person’s perception of the risk of developing cancer increases dramatically.	<i>...probably in my thirties...I mean my family has been sort of consistent in the forties but they do say it gets earlier.</i>
Life Cycle/ Developmental	Timing of diagnosis in patient’s life cycle	Timing of a cancer diagnosis in the life cycle of the affected family member.	<i>My mom was the first one to get it, quote on quote, young.</i>

The third step in data analysis involved compiling categorical summaries across participant narratives based on these codes. Identifying areas of overlap between the three broad themes provided the most insight into how young women integrate genetic testing and family experiences with cancer as they construct their lives and make health decisions. Categorical summaries distinguished participants from one another based on a variety of demographic and medical history data. For example, completion or intent to pursue various preventive measures distinguished, albeit

incompletely, women who hoped to have biological children from those who had completed childbearing or were not interested in having children.

### **Trustworthiness**

Research using qualitative methods must be rigorous, coherent, and trustworthy (Riessman, 1998). Coherence addresses the extent to which the analysis is cohesive and integrated (i.e., “hangs together”), demonstrating rigorous analysis and methodological interpretation. The completion of genograms during the interview process allowed for immediate confirmation

with participants that their stories were accurately captured, allowing for member checking to enhance the trustworthiness of findings (Golafshani, 2003). The author maintained detailed memos of impressions, connections, and meanings found in the data throughout analysis. By providing a consistent place to collect these thoughts, much like the genogram provides a single place to capture a person's family history, the researcher's detailed notes preserved continuity throughout analysis.

### Findings

#### Balancing Acts: Managing Family Planning and Cancer Risk Management

Family planning is a fundamental part of cancer risk management for *BRCA* carriers in their reproductive years. The desire to preserve fertility to enable childbearing was a distinct priority for participants. However, electing to preserve fertility meant significantly limiting ovarian cancer prevention. Ovarian cancer was perceived to be "sneakier" and "more elusive" than breast cancer, due in part to the limitations of available screening methods. Relying on early detection for ovarian cancer was unsettling, yet to preserve fertility, this was the only acceptable option. Internal and external pressures (from family and physicians) to complete risk-reducing oophorectomy pushed participants to make family planning decisions before they felt prepared. Judith, age 33, said,

*What if I'm choosing wrong? It's not that I feel the need to have children as much as I resent feeling the pressure, having to decide. Because I'm looking at my results through the lens of how they affected my mother, I feel pressure to decide now.*

Consistent with Hallowell's (1998) findings, participants with family histories of breast cancer discussed their breast cancer risk in greater detail than ovarian cancer risk. Similarly, those with family histories of ovarian cancer discussed ovarian cancer risk in greater depth than breast cancer. This risk focus speaks to the value of a multigenerational lens in assessing risk interpretation. Judith addressed this risk focus, identifying her mother's medical trajectory as a guide for interpreting her genetic testing results and her desire to have a third child. She weighed the decision for a third child against her growing sense of urgency to complete her surgeries and remain alive and healthy for her two older children. She eventually decided to give up her dream of another child because she was approaching the critical age of her mother's diagnosis and death.

Judith's experience, like that of other participants, was characterized by her need to find a livable balance between managing her risk and her family planning

priorities. Gwen, like Judith, felt the pressure of a timeline to complete her surgeries. Gwen was partnered and fit her childbearing plan into a prepared medical timeline:

*We got married when I was 25 and got pregnant 2 months later. That July, I had my ovaries removed. And then in January, my goal was to have all this done by the time I was 32, I had double mastectomy with reconstruction.*

The process of achieving balance between family planning and risk management was also frequently contemplated against elevated distress at first receiving testing results and having limited preventive options. Gillian, a 35-year-old, had genetic testing after she had completed childbearing because that is when she was first presented with the possibility. She said,

*If I had this test prior to having kids, I would have had a much harder time because I couldn't do anything to reduce my risk—and, that period between testing and being able to do the surgery, I don't know how I would have survived.*

Participants who completed prophylactic surgery identified the period between testing and surgery as the most worrisome. Many were pregnant and having children during this period and cancer risk was a present, ongoing concern. Participants who found themselves in this gray area between testing and surgeries talked about being preoccupied with their cancer risk and their ability to find a mate with whom to build a family quickly.

Mothers in the sample, such as Judith, Gwen, and Gillian, uniformly pursued surgery explicitly to remain healthy and alive for their children. This need was particularly salient for participants who had experienced their mother's illness and death. As participants approached *danger zones*, that is, particular ages at which they perceived their cancer risk to increase substantially (Werner-Lin, 2007), the need to make definite decisions became crucial. One participant shared this comment:

*Had I gone through genetic testing when it first became available, I would have had a way different reaction because I was not done having kids. I couldn't have gone for surgery. Just the timing worked out. I was 99% sure I wasn't going to have a third baby, and when this [BRCA test results] came back, I was like, no way.*

For a small number of participants, protecting children from parental loss meant curtailing further childbearing to ensure sustained health. These participants had lost their mothers during early

childhood, and were approaching the age of their mother's initial cancer diagnosis, which was a significant and emotionally charged anniversary age (Gabriel, 1992).

Having at least one biological child allowed women to pursue surgeries with fewer regrets or resentment. Participants without biological children, or those committed to bearing more biological children, worried about having the opportunity before surgery or a cancer diagnosis made childbearing impossible. Jessica, age 28, was single at the time of our interview. Her mother survived an ovarian cancer diagnosis in her forties, while Jessica was in puberty. Jessica did not believe a diagnosis would be lethal, but she did have concerns that the psychological impact of her mother losing breasts and ovaries while Jessica was developing them might affect her ability to become pregnant. She also worried about developing cancer during a pregnancy and the need to make impossible choices. Jessica commented,

*It's a race against time, and my biggest fear of the whole gene is that I'm not going to be able to have children because I'm going to get ovarian cancer. I feel like I have to give them [ovaries] up at 40, and there's no guarantee it'll go the way that I want it to.*

Together, these findings speak to the importance of the timing of genetic testing in the life cycle. This timing remains crucial to the psychosocial experience not only of adjusting to genetic testing results but also to pregnancy and family planning.

**"This Gene Dies With My Generation!"**

Overwhelmingly, concern about passing on the altered *BRCA* gene to children was less pressing than the desire to have biological children. This finding may represent a sampling bias because all participants were *BRCA* carriers, all decided to participate in this study, and many were recruited from a support community that regularly discusses these issues. A group who had not pursued genetic testing or who elected not to participate in this investigation might make very different choices. However, participants in this study discussed the belief that cancer is becoming easier to detect and treat, and they uniformly expressed faith in the next generation of technological advances to help their children navigate these decisions with greater ease. Karly, age 33, said,

*I felt a little hesitation when I first found out my results. I felt, "What does it say about me that I know I have this mutation and I still want to see children that were part me and part my husband?" And then after I had (my son), I learned that these are little, amazing,*

*wonderful creatures that have many facets to their life. And that made it easier.*

For Karly and others, having children helped participants understand themselves as multifaceted. This perspective supported the value of their own lives as *BRCA* carriers and validated their choices to have children with similar risk estimates.

Although reproductive technologies, such as preimplantation genetic diagnosis with in vitro fertilization, may provide greater control over genetic inheritance, no participant explicitly mentioned this technology. The extent of participant knowledge about preimplantation genetic diagnosis at the time of this study was unknown, although two participants mentioned technological possibilities they considered promising. Michelle, the mother of two young girls said,

*I wish they would have tested me, then said, "Okay, you have this gene, so when you decide to have a child, we will remove that gene from you so they can't get it.*

Although preimplantation genetic diagnosis is more commonly used for childhood onset disorders, its use for adult onset disorders such as Huntington's disease and some inherited cancers is becoming more common (Offit et al., 2006). Similar to the choice between prevention and early detection, genetically enhanced reproductive technologies enable prevention not only from inherited cancer risk but also from the distress of genetic testing and the medical decisions this group of *BRCA* carriers is facing. Tracy, age 26, commented on her struggle with this distinction:

*[My fiancé] seems pretty determined that he wants my eggs tested prior to us getting pregnant. By the time [our kids] would have to worry about it, who knows what's going to be available? But to be on the absolute safe side we'll probably end up going that route just to make sure this gene dies with my generation.*

**Shifting Lenses: Focusing on the Children**

A significant distinction between findings from participants with and without children was the mothers' concern for the quality of their children's experiences. Many of the mothers had experienced parental illness and death in early and middle childhood and, therefore, were committed to protecting their children from the same devastating losses. For this group, carrying the *BRCA* alteration meant the salient risks to their own children were unique. Amy, 34 years old and mother of two small children said,

*It's not the stranger that might pull up in a car, it's losing family members or illness*

*that might come. Those are the things that I talk about with them.*

Further, mothers saw genetic testing and the availability of preventive options as an opportunity to change the family's illness narrative from one of loss to one of hope and survivorship. Testing and surgery enables choice, which increases quality and quantity of life. Cara, age 34 years, talked about the experience of growing up with an emotionally distant mother, one she believed never learned to nurture after losing her own mother at a young age. Two generations later, Cara acutely felt the loss of her grandmother, through her mother, and she wanted her children to have a different experience.

*My mother lost her mother so young...she's not very emotionally connected to me. I want to be there for my children, so they have an example when they have kids...so I'm doing whatever it takes to be around.*

### **Limitations**

A methodological concern with this project was the author's dual role as interviewer and coder. Consistent supervision and mentoring by seasoned qualitative researchers as well as active, ongoing participation in a qualitative methods work group helped to balance these roles. Although decisions made with respect to genetic testing and prevention involve processes spanning years, the design of this investigation was cross-sectional, capturing only a snapshot of experience at a single point in time. Ideally, future investigations will follow women such as these through genetic testing, family planning, and decision making about risk management, and in whatever order those experiences occur.

Sampling was constrained by participants' genetic status. This criterion limited the range of experiences across a broader spectrum to those who had completed genetic testing. Therefore, women excluded from this sample included those opting not to go through gene testing at present, perhaps because they were waiting until after completion of childbearing. Further, the overrepresentation of participants recruited from the online support community may represent a unique population that is highly and uniquely engaged in cancer risk reduction, and thus more interested in participating in such an investigation. However, because this population is actively reaching out to a supportive community, this sample provided interesting insights for helping professionals. Although the absence of an ethnically, racially, and socioeconomically diverse participant pool reflects the populations who have completed genetic testing and agree to participate in research, future projects must consider alternative recruitment methods more consistent with increasing these aspects of diversity.

Recruiting a diverse study sample will better enable researchers to speak to a broader range of patient experiences to inform genetic counseling and direct social work practice, particularly as genetic testing becomes more conventional and widely available.

### **Implications and Recommendations**

After completing genetic testing, young women face significant psychosocial challenges in managing their cancer risk while adequately attending to tasks that are developmentally appropriate to early adulthood. This study provides evidence that family planning must be balanced with cancer risk management in a way that attends to both the patient's family history and future. This history is defined by the patients' multigenerational family legacy of illness and loss. The future attends to issues of survivorship, parenthood, and the quality of children's experiences of family life. Medical recommendations about early detection and prevention must attend to developmental issues. For this population, these recommendations must integrate family planning priorities to provide realistic risk management options and assuage disease-specific distress for young patients.

### **Direct Practice Implications**

Planning for children involves identifying and preparing for the challenges children will face as they grow, both in having parents with identified genetic alterations and in possibly carrying that alteration themselves. Therefore, the risks to children are not purely biological. Rather, participants described a host of equally powerful psychosocial risks, including the potential distress children may feel about carrying the altered *BRCA* gene and the possibility of a parent's early death to cancer. Genetic counselors and social workers in direct practice should attend to the ways complicated and unresolved grief over parental loss to cancer in early childhood (Werner-Lin, Biank, & Rubenstein, 2010) may resurface as patients engage in building their own families.

Technological advances might mitigate some of these challenges. As *BRCA* carrier parents pursue preventive surgeries, they significantly lower their chance of developing hereditary cancers. This reduced risk, in turn, lowers the chance that their child will experience early parental illness or death, which is a powerfully formative psychosocial experience. However, as technological advances suggest new choices, such advances also suggest new risks and sacrifices (Webb, 2005). For a number of women in this study, choosing preventive surgery to maximize their health for existing children meant forgoing plans to continue childbearing. This sacrifice allowed young women control over the illness legacy they were building in their families of procreation (Werner-Lin & Gardner, 2009).

As clinicians engage with this grief work, by naming these dilemmas and identifying the residue of early loss in these decisions they can free patients to make medical decisions that attend to the possibilities offered by genetic medicine (Werner-Lin & Gardner, 2009). Theoretical models that address the dynamic nature of childhood loss over the life course are absent from the genetic counseling literature. Intervention models general to psychosocial oncology focus on coping and adaptation with a current diagnosis, and are not appropriate to decision making dilemmas in the face of anticipated cancer risk. However, online communities have proliferated as young, healthy *BRCA* carriers reach out to bridge pockets of isolation in search of others facing similar dilemmas (Werner-Lin, 2008). Interventions that target the specific developmental needs and dilemmas of *BRCA* carriers of reproductive age are needed. These interventions should incorporate group modalities wherever possible to build communities that support and validate the struggles of this burgeoning population. Ideally, as the number of young patients pursuing genetic testing grows, such interventions can be tested and integrated in standard care in genetic risk clinics.

### Research Implications

As a group, women who were married with children at the time of the interview had greater personal exposure to cancer and had experienced a greater number of significant personal losses than participants who were single and without children. These characteristics (i.e., married and having children) are strong predictors of genetic testing uptake (Meiser, 2005); therefore, these characteristics may be overrepresented in the population of known *BRCA* carriers. It is possible that these differences in cancer exposure encouraged the young women interviewed to pursue marriage and childbearing with greater speed and urgency than their single counterparts. As mentioned earlier, longitudinal research can investigate the impact of categorical differences in participants' family histories with cancer over a broader spectrum of time in the cancer journey. Such research should address how developmental and family variables influence decision making.

Because of limited resources, this study was unable to interview male *BRCA* carriers, non-carrier partners, and other important relations in the lives of female *BRCA* carriers. Yet, reproductive decisions are rarely made outside of relational contexts, and future research must address not only the ways couples negotiate family planning and inherited cancer risk management but also the ways important others, such as affected mothers or sisters, become involved in the balance between family planning and cancer risk management.

Participants universally cited hope for a generation of powerful new technological developments in cancer detection and treatment to help children carrying the *BRCA* gene alteration. These advances will minimize the biological risk to children over their lifetimes. Among these advances are genetically enhanced assisted reproductive technologies such as preimplantation genetic diagnosis. This procedure permits couples to pursue in vitro fertilization with an additional genetic testing stage to identify embryos for transfer that do not have the *BRCA* gene alteration. Although preimplantation genetic diagnosis offers the hope for halting transmission of mutated genes, the procedure is costly, unregulated, and presents a host of ethical, relational, and social challenges that must be examined from a transdisciplinary and bioethical perspective (Rubin, Werner-Lin, Stern, 2009). The extent to which young adult *BRCA* carriers in their childbearing years are even aware of these technologies is just beginning to be studied (Quinn et al., 2009). Given that participants in this investigation were less concerned about passing on the altered gene to their children than they were about the ability to have biological children, it is unclear what investment this population will have in these developing reproductive technologies. The potential for these technologies to mitigate the unique risks faced by children of *BRCA* carriers certainly warrants further investigation.

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