

“IT’S NOT IF I GET CANCER, IT’S WHEN I GET CANCER”:
EXPLORING PREVIVORS’ MANAGEMENT OF UNCERTAINTY FOR
HEREDITARY CANCER IN CLINICAL ENCOUNTERS

A Dissertation

by

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ABSTRACT

The purpose of this dissertation study was to identify previvors' sources of uncertainty and strategies for managing uncertainty and understand how previvors' uncertainty influence what type of preventative health decisions they make and how those decisions affect their subsequent sense of uncertainty. A previvor is an individual who is highly predisposed to breast and ovarian cancer due to a genetic mutation called BRCA1/2. Previvors have a 44 to 87 percent risk of developing cancer during their lifetime. Consequently, previvors live in a constant state of uncertainty—wondering not if they might get cancer but when—and must make certain preventative health decisions to reduce their cancer risk.

To understand previvors' health experiences, thirty-four, semi-structured interviews were conducted with female previvors. Participants were recruited through Facing Our Risk of Cancer Empowered's (FORCE) social media pages. Interviews were recorded and transcribed. The constant comparison method was employed to code the interview transcriptions, and the interview transcripts' themes served as the units of analysis.

First, analysis revealed two main uncertainty sources for previvors—medical uncertainty and familial uncertainty. Medical uncertainty types include the unknown future, peaks and valleys associated with medical consultations, and personal cancer scares. Familial uncertainty encompasses traumatic family cancer experiences and being a mother and being present in children's lives. Second, four uncertainty management

strategies—seeking clinicians as an informational source, seeking clinicians as a partner for decision-making, seeking clinicians as an emotional support, and seeking referrals from clinicians for emotional support—were identified as ways previvors try to manage their uncertainties. Ultimately, previvors’ uncertainty sources and uncertainty management strategies impacted their health decision-making with preventative surgeries as the most common health decision.

Overall, the purpose of this research was to gain insight into previvors’ uncertain health experiences in order to improve patient-centered communication between previvors and clinicians and ultimately better previvors’ health and well-being. This research contributes to the literature by extending the exploration of uncertainty management to a new population, reinforcing the belief that chronic uncertainty should be managed not reduced, supporting health and illness uncertainty theories, and providing practical recommendations for clinician-patient communication.

DEDICATION

“Do one thing every day that scares you.” ~ Eleanor Roosevelt

I dedicate this dissertation to those who challenge me to live these words and to those who have supported me in those actions. May I continue to follow Eleanor’s advice every day of my life.

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CHAPTER I
INTRODUCTION AND LITERATURE REVIEW

“Cancer is still a word that strikes fear into people’s hearts, producing a deep sense of powerlessness. But today it is possible to find out through a blood test whether you are highly susceptible to breast and ovarian cancer, and then take action.”

~ Angelina Jolie

On May 14, 2013 Angelina Jolie, an Oscar winning actress, film director, and humanitarian, wrote an op-ed for *The New York Times*, called “My Medical Choice.” In this article, she disclosed that she “carr[ies] a ‘faulty’ gene, BRCA1, which sharply increases [her] risk of developing breast cancer and ovarian cancer” (par. 2). Having this gene mutation in addition to her family history of cancer means she has an 87 percent risk for developing breast cancer and a 50 percent risk for developing ovarian cancer during her lifetime. Because of this gene, Angelina decided to “be proactive and to minimize the risk as much as [she] could” (par. 5) by undergoing a prophylactic double mastectomy.¹ Doing so remarkably reduced her risk for breast cancer from 87 percent to 5 percent (Jolie, 2013)!

Angelina Jolie is not the only woman who has made this medical decision. In 2004, Jessica Queller, a writer and producer for the TV shows “Gilmore Girls” and “Gossip Girl,” discovered she had the BRCA1 gene mutation and a few years later had a

¹ A prophylactic double mastectomy is the surgical removal of one’s natural breasts in order to prevent a cancer.

prophylactic mastectomy (Queller, 2008). In 2012, Sharon Osborne, the wife of Ozzy Osborne, former “X Factor” judge, and now co-host of CBS’s “The Talk,” revealed her prophylactic double mastectomy decision after learning her high risk for breast cancer (“Osbourne Mastectomy,” 2012). And most recently, Miss DC and a 2013 contestant for Miss America, Allyn Rose, revealed she intends to have a prophylactic mastectomy after completing the 2013 pageant (“Rose Mastectomy,” 2013).

Angelina Jolie, Jessica Queller, Sharon Osborne, and Allyn Rose are examples of previvors. A *previvor* refers to an individual who is highly predisposed to breast or ovarian cancer due to a genetic mutation called BReast CAncer1 (BRCA1) and BReast CAncer2 (BRCA2) (Friedman, Sutphen, & Steligo, 2012; Roth Port, 2010). The term “previvor” was coined by the organization Facing Our Risk of Cancer Empowered (FORCE) in 2000. FORCE is a non-profit organization that seeks to improve both previvors and their family members’ lives through raising awareness and educating individuals about hereditary cancer and advocating for advancements in cancer prevention, detection, treatment, and quality-of-life (“Mission,” 2013).

Having an organization that focuses on assisting previvors and their families make informed decisions about their health are essential for several reasons. For one, previvors’ stories emphasize the fear, the anxiety, the waiting, and the unknown. Previvors experience and must deal with multiple and daily triggers of uncertainty about their future. Previvors contemplate their own genetic risk, agonizing over what to do given new information about their genetic make-up.

Experiences like these raise important questions. What does a previvor's health experience look like? Is it different than a breast or ovarian cancer patient or a survivor? How does it feel to have, as many women put it, "ticking time bomb boobs?" What petrifies a previvor more—losing one's femininity through the removal of her breasts or ovaries or not being around to watch her children grow up? And how does a previvor deal with not knowing what her future path will encompass?

Angelina, Jessica, Sharon, and Allyn's stories exemplify one pathway for answering these questions. For these four women, the pathway included finding out whether or not they had a high genetic risk for developing breast and ovarian cancer at some point in their lives, and when that risk was confirmed, they decided to proactively minimize their risk by undergoing prophylactic or preventative mastectomies (Jolie, 2013; Queller, 2008; "Osbourne Mastectomy," 2012; "Rose Mastectomy," 2013).

However, this is not the only pathway for coping with a terrifying and uncertain future of hereditary cancer. In addition to preventative surgeries, individuals may also choose to ignore their family history of breast and ovarian cancer and not even be tested. Or individuals may be tested, and then once they discover they have a positive genetic mutation, they may choose to completely ignore the results and try to not worry about their high risk. Or lastly, individuals may discover they are positive BRCA gene carriers but not opt for prophylactic surgeries and instead engage in measures such as increased detection or even chemoprevention. In short, individuals make decisions about their uncertain futures in many different ways (Friedman, Sutphen, & Steligo, 2012; Roth Port, 2010).

The purpose of this dissertation is threefold. First, I seek to identify previvors' types or sources of uncertainty. Second, I want to learn what strategies previvors utilize to cope with those uncertainties, and finally, I seek to understand how previvors' uncertainties influence what type of health decisions they make and how those decisions affect their subsequent sense of uncertainty.

What is a Previvor?

A *previvor* is an individual who is highly predisposed to developing breast or ovarian cancer due to an inherited genetic mutation called BReast CAncer1 (BRCA1) and BReast CAncer2 (BRCA2), commonly known as “the breast cancer gene.”² The BRCA gene was discovered in the mid-1990s, and these mutations are inherited. Testing positive means the following:

- You inherited a genetic mutation from one of your parents.
- You have increased risk for breast, ovarian, and other cancers.
- Your biological siblings have a 50 percent chance of having the same mutation.
- Your cousins, aunts, uncles, and other blood relatives (on the side of the family from which you inherited the mutation) may have the same mutation.
- Your biological children have a 50 percent chance of inheriting your mutation (Friedman, Sutphen, & Steligo, 2012, p. 67; (see Appendix C for a list of technical terms).

² BRCA gene mutations are only responsible for causing approximately five to ten percent of breast cancers and 12 percent of ovarian cancers.

An individual's risk is the key to understanding one's chance of developing breast and/or ovarian cancer during one's lifetime. A risk factor is anything that makes an individual more susceptible to developing a disease than other individuals (Roth Port, 2010). Individuals are more likely to have a positive BRCA gene mutation and thus have an increased risk of developing cancer if one or more of the following controllable risk factors (e.g., weight, diet, physical activity, alcohol consumption) and/or uncontrollable risk factors are true (e.g., gender, age, race/ethnicity, genetics). I first discuss the risk factors that are not in an individual's control.

Gender, age, race/ethnicity, and genetics are the first four uncontrollable risk factors. According to Friedman, Sutphen, and Steligo (2012), first, simply being a woman enhances the risk for developing breast and ovarian cancer, although men can also be diagnosed with breast cancer and are at risk if they carry the gene mutation. Second, an individual's age influences the likelihood of acquiring abnormal changes in one's breast or ovaries. In other words, one's risk increases with age. The third uncontrollable risk factor is race/ethnicity. Individuals of Ashkenazi Jewish heritage are the most likely to develop breast cancer followed by, but not too closely, White or Caucasian women and then African-American women (2012).

In addition to these demographic risk factors, a fourth risk factor is genetics. Though a small number of breast and ovarian cancer diagnoses are due to a genetic mutation, individuals who test positive for either the BRCA1/2 gene mutation have a high risk for developing cancer in their lifetime. An individual's chance of having a positive gene mutation is higher when any family member has had either ovarian,

primary peritoneal, or fallopian tube cancer at any age, or if a male family member has been diagnosed with breast cancer despite age, and/or if there are multiple diagnoses in a family on the same side (Friedman, Sutphen, & Steligo, 2012).

The sixth risk factor, according to the same authors, is personal health and cancer experiences. Being diagnosed with cancer in one breast increases the likelihood of acquiring cancer in the other breast or even a different part of the original breast. Also, abnormal breast biopsy results increase risk of breast cancer. For instance, a woman who finds benign breast cells often raises her risk because the cells proliferate, meaning they multiply quickly. Additionally, personal radiation exposure increases a woman's risk of developing cancer because it can cause cancer especially when exposed during adolescence (2012).

The seventh risk factor is a woman's breasts and hormones. Breast density and hormone levels enhance the likelihood of being diagnosed with breast cancer in one's lifetime. A woman who has dense breasts has more breast tissue to fat and thus is more likely to develop cancerous cells. Also, hormone-related issues are a risk. The more estrogen in a woman's body increases the likelihood that mutated breast cells will grow cancerous (Friedman, Sutphen, & Steligo, 2012).

Finally, Roth Port (2010) explains a few of the risk factors that women may have some control over. For one, gaining weight as an adult in post menopause increases breast cancer risk. So individuals who exercise regularly can reduce their breast cancer risk because exercising lowers the estrogen levels in the body and also helps control fat

content. Further, a low-fat diet can also reduce an individual's risk. Lastly, limiting consumption to one drink a day can also slightly reduce one's breast cancer risk.

Yet even with all of these known risk factors, it is difficult to determine the exact amount of one's risk for developing breast and ovarian cancer. Currently, there is no specific way for experts to determine a woman's "exact" risk because it is difficult to calculate due to the many possible uncontrollable and controllable risk factors (Bylund et al., 2012; Roth Port, 2010). It is still unclear why some people have mutations and are diagnosed with cancer while others have the mutation and never contract the disease. Furthermore, specialists cannot predict when cancer may develop for individuals with a genetic mutation or how those individuals may respond to different types of treatment. Nevertheless, discovering BRCA1/2 gene mutations is "important in identifying high-risk individuals and finding ways to reduce their breast and ovarian cancer risk" (Friedman, Sutphen, & Steligo, 2012, p. 12).

Presently, specialists can only offer women and their families a vague range between 44 to 87 percent risk for developing cancer (Roth Port, 2010). According to recent estimates, individuals who test positive for BRCA1 have a 55 to 65 percent risk for breast cancer and a 39 percent risk for ovarian cancer, while individuals who test positive for BRCA2 have around a 45 percent risk for breast cancer and an 11 to 17 percent risk for ovarian cancer (Chen & Parmigiani, 2007; Howlader et al., 2013). Again, these statistics vary based on uncontrollable and controllable factors such as family history of cancer. However, researchers hope and believe that sooner than later they will be able to assess women's individual risk more precisely (Roth Port, 2010).

In summary, a *previvor* refers to an individual who is highly predisposed to developing breast and ovarian cancer during one's lifetime due to the genetic mutation BRCA1/2. Having one of these genetic mutations in addition to understanding personal risk factors assists in revealing a previvor's likelihood of being diagnosed with cancer. Nonetheless, even with recent scientific advancements in genetics and cancer, previvors still do not know their exact risk because of the various risk factors associated with cancer. Thus, a previvor's life is ridden with uncertainty.

Why Uncertainty?

Uncertainty manifests in many different ways for previvors. As noted previously, previvors experience uncertainty and fear about an unknown diagnosis and must face daily reminders of the high possibility of developing cancer. Moreover, after discovering one's genetic predisposition, previvors must then wrestle with how to protect their health and secure their future. So often in an attempt to cope, previvors engage in different types of strategies for reducing and managing their uncertainties, yet with each coping strategy, it becomes clear that being a previvor means one is never quite free of an uncertain future. Such a conclusion points to the importance of examining uncertainty within this particular population and how it is people come to manage the uncertainty.

Research reveals that within medical encounters uncertainty cannot ever be entirely eliminated (Epstein & Street, 2007), and inadequately managed uncertainty in clinical encounters can have detrimental psychosocial effects (Neville, 1998). When uncertainty is managed poorly, and an individual has inadequate coping resources and

mechanisms, emotional distress often results (e.g., anxiety, stress, depression, etc.) (Arora, 2003; Lee, 2006; Lien, Gau, Hsu, & Chang 2009; Shaha et al., 2008; Stewart, Lynn, & Mishel, 2010). Other negative consequences of uncertainty in cancer care include loss of control or sense of control, low resourcefulness, and lower quality of life (Andreassen et al., 2005; Dirkson, 2000; Dunn et al., 1993; McWilliams, Brown, & Stewart, 2000).

Additionally, uncertainties regarding illness can complicate relationships with clinicians, family members, friends and even coworkers, which in turn can complicate treatment and aggravate the illness (Ford, Babrow, & Stohl, 1996). Uncertainty can cause anxiety for clinicians and patients as well as lead to patient dissatisfaction and decision regret (Bosk, 1980; Curley et al., 1989; Johnson et al., 1988; Katz, 1984; Hershey & Baron, 1987). Uncertainty also interferes with patients' ability to construct meaning about illness-related events, resulting in poorer decisions and psychosocial adjustment (Christman et al., 1988; Fuemmeler, Mullins, & Marx, 2001; Mishel, 1999; Wong & Bramwell, 1992). Finally, uncertainty can diminish standards of quality care, contribute to malpractice claims, and complicate the informed consent process (Beresford, 1991; Eddy, 1984; Eddy & Billings, 1988; Gutheil, Bursztajn, & Brodsky, 1984; Mirvis & Chang, 1997). Hence, there is a need to explore and understand the nature of uncertainty and the strategies that can assist previvors in managing uncertainty.

Unfortunately, despite psychological and physical morbidity associated with uncertainty, little is known about what clinicians can do to reduce distress and anxiety related to uncertainty. Thus, this dissertation expands understanding about managing

uncertainty in cancer care to a new population—previvors. Through this research, I hope to provide clinicians with specific ways to assist previvors in coping and tolerating uncertainty about a future cancer diagnosis and present previvors with information about managing uncertainty in order to make health-related decisions. Now that I have explained what it means to be a previvor and why it is important to examine previvors' management of uncertainty, I turn to discussing relevant literature to the present topic.

Literature Review

In this section, I seek to accomplish three objectives. First, I define uncertainty, noting theories of uncertainty management and sources for uncertainty. Second, I discuss patient-centered communication especially as it relates to managing uncertainty in clinical encounters. Third, I discuss different strategies for managing uncertainty.

It is important to note that even though I am interested in previvors' management of uncertainty in clinical encounters, it is necessary to have a broad understanding of uncertainty in cancer care. As such, in my literature review, I draw on relevant research about cancer patients and cancer survivors as well as cancer previvors. I first define uncertainty, explaining three important uncertainty management theories of health and illness.

Uncertainty and the Management of Uncertainty

Uncertainty fluctuates through cancer stages (Mishel et al., 2003), and often it cannot be completely eliminated (Epstein & Street, 2007). Individuals diagnosed with cancer often experience significant emotional distress and uncertainty, which can have negative impacts on patient health outcomes (Arora, 2003). For example, cancer

patients must deal with an overwhelming amount of medical information and then make difficult treatment decisions (Epstein & Street 2007). Cancer survivors experience uncertainty and anxiety at the end of the treatment when moving into the survivorship phase (Becze, 2009; Epstein & Street, 2007). Cancer previvors are faced with uncertainty and emotional distress because of a possible future cancer diagnosis and must make decisions regarding genetic testing as well as possible preventative actions and lifestyle changes (Pasacreta, 2003). These are but a few examples of medical decisions that include unknown or uncertain clinical evidence regarding possible risks and benefits that guide clinical decisions (BMJ Clinical Evidence, 2007).

Uncertainty Defined

Uncertainty is inherent in health contexts and has been conceptualized in several different ways. Originally, uncertainty was conceptualized as something that needed to be (and could be) reduced or eliminated (Babrow & Kline, 2000; Berger & Calabrese, 1975; Bylund et al., 2012). From this perspective, uncertainty is viewed as a “dispreferred state,” and individuals can reduce such cognitive and behavioral uncertainty states through passive, active, and interactive strategies (Berger, 1987; Berger & Calabrese, 1975).

Yet after subsequent studies, scholars have realized that uncertainty is more complex than previously thought (Bylund et al., 2012; Epstein & Street, 2007). Since then other scholars in medicine and communication have grappled with defining uncertainty, building on its original definition especially as it relates to information. Broadly, uncertainty exists when an individual believes certain aspects of a situation

(e.g., health illness or issue) is ambiguous, inconsistent, too complex, unknown or unclear, and/or unpredictable or random; when information is inconsistent or even unavailable; or when the individual is insecure about the amount of information and thus knowledge she has about the situation or issue (Babrow, Hines, & Kasch, 2000; Babrow, Kasch, & Ford, 1998; Brashers, 2001; Mishel, 2005). From this perspective, uncertainty is a state of knowledge that an individual possesses or lacks (Babrow, Hines, & Kasch, 2000; Babrow, Kasch, & Ford, 1998), and the lack of information is, to some degree, independent of the knowledge an individual possesses. In other words, though an individual may have all possible information on a particular issue, she may still feel uncertain (Brashers, 2001).

Uncertainty is also defined based on the probability that an event might occur (Babrow, 1992). Individuals experience uncertainty when the “likelihood of the event occurring or not occurring becomes equal. If multiple alternatives are possible, uncertainty is highest when all events seem equally probable” (Brashers, 2001, p. 479). Similarly, an important component of uncertainty for Han (2013) is probability, which refers to randomness of possible future outcomes and events. So uncertainty is “the subjective consciousness of ignorance,” or a “‘metacognition’—a thinking about thinking—characterized by self-awareness of incomplete knowledge about some aspect of the world” (p. 16S).

The above viewpoints of uncertainty clearly reveal a bias towards information. Much of research on uncertainty assumes uncertainty stems from a lack of information, but uncertainty can also be created by too much information or when information that is

available has multiple interpretations (Epstein & Street, 2007). This point reinforces the idea that uncertainty cannot simply be reduced, but sometimes must be maintained or even increased in order to preserve and/or produce psychological well-being and good health (Brashers et al., 2000; Epstein & Street, 2007).

Despite varying definitions of uncertainty, there are three important theories to consider that seek to explain the nature of uncertainty in the health care context—the theory of uncertainty in illness (Mishel, 1988), theory of communication and uncertainty management (Brashers et al., 2000, 2003), and problematic integration theory (Babrow, 1992). I first describe Mishel’s theory of uncertainty in illness.

Theories of Uncertainty in Health

The theory of uncertainty in illness states uncertainty is produced when an individual’s present experience regarding the nature of illness lacks a complete cognitive representation. In other words, some component(s) of the illness event are missing such that an individual does not have a sufficient understanding of factors related to her health and well-being (Mishel, 1988). There are three important components of this uncertainty. The first component, symptom pattern, refers to an individual’s ability to recognize symptom patterns regarding her intensity, frequency, predictability, and expected outcomes. Event-familiarity, the second component, is the ability to organize an illness event within the context of a time and place. Lastly, event-congruence refers to an individual’s ability to comprehend an illness-related event and understand the probability of the outcome occurring.

Thus, according to this theory, when a patient like a previvor is uncertain, she is

not able to form cognitive representations for her illness due to little or no information, knowledge, or experience with the symptoms, her significance, and/or how to manage the problem (Mishel, 1988; Mishel & Braden, 1988). Failure to effectively manage this uncertainty can result in poor decision-making, negative psychosocial consequences, and lower quality of life (Christman et al., 1988; Fuemmeler et al., 2001; Mishel, 1999; Wong & Bramwell, 1992). Yet in order to effectively manage the uncertainty, previvors need to perceive their clinicians as credible sources for information in helping them comprehend and make meaning out of their potential illness and the best course of therapeutic action (Mishel, 1990). Individuals may also rely on other resources for understanding and interpreting issues related to their health including the Internet, print, audio, or video materials, friends and family, and cultural and religious beliefs (Sparks & Villagran, 2010). In short, according to theory of uncertainty in illness, the relationship between uncertainty and stress is influenced by the vagueness of illness events and a lack of comprehensible and coherent information (Mishel, 1984).

The second theory speaks to communication and uncertainty management. According to Brashers and his colleagues (2000), uncertainty management means making specific choices based on the perceived threat and information. In other words, individuals assess their uncertainty in order to determine potential harm and benefits. Such assessments are intertwined with emotions such as anxiety and worry but also hope and optimism. Individuals' assessments and emotional responses then produce possible routes of behavior and psychological actions to manage the experienced uncertainty.

There are two main types of uncertainty management—information seeking and

information avoidance (Brashers et al., 2003). Though both strategies can assist in managing uncertainty, each has their own purposes. The goal of information seeking is typically to reduce uncertainty, whereas the goal of information avoidance is to retreat from overwhelming or distressing information. For instance, previvors might seek genetic testing to gain information about their possible high risk for cancer, while others might avoid genetic testing because they do not want to learn that information.

In this way, a key tenet of the theory of communication and uncertainty management is that uncertainty management is not equivalent to uncertainty reduction. For example, when the threat of information is perceived high, then individuals might seek out contrary information to then *increase* the uncertainty and ultimately reduce the threat (Brashers et al., 2000). In short, successfully managing uncertainty involves “the negotiation of identity, relationships, levels of knowledge, and physical and psychological well-being” (p. 81).

The last theory is problematic integration (PI) theory. This theory explains that individuals orient their lives in terms of expectations and evaluations; it seeks to understand how people seek information to manage their uncertainty when coping with an illness (Babrow, 1992, 1995, 2001). There are two main components of PI theory—probabilistic orientations and evaluative orientations. Probabilistic orientations refer to the likelihood an event or issue may occur in an individual’s lifetime, while evaluative orientations refer to the assessment of the desirability of a possible outcome. Evaluative orientations are rooted in emotions, but probabilistic ones are rooted in cognition. So problematic integration then occurs when the expectations individuals have and the

evaluations individuals think will occur are uncertain. Said differently, uncertainty arises when individuals' judgments about the likelihood of wanted or unwanted outcomes are incompatible (Babrow, 2001; Sparks & Villagran, 2010).

PI theory offers several advantages to understanding uncertainty in clinical encounters. One advantage is it provides clinicians with multiple explanations for different kinds of uncertainties that can coexist on many levels (Hines et al., 2001). For example, a cancer previvor may be uncertain about what preventative course of action to take (e.g., increased detection, chemoprevention, or prophylactic surgeries). This uncertainty may exist because, on one level, the previvor is overwhelmed with the amount of information provided for each preventative choice; while at the same time, she may be uncertain about whether the chosen option will reduce her risk of cancer. Second, PI theory assists in understanding the relational context of uncertainty as previvors and clinicians must work through the uncertainty together to achieve a shared understanding of the problem and ultimately take appropriate actions to address the problem. Third, it emphasizes the importance of communication as a resource for coping or managing uncertainty. In brief, PI theory explains that the emotional and cognitive aspects of uncertainty are managed, if not resolved, communicatively because clinicians and patients co-work to make sense out of the patient's health state and the best course of therapeutic action (Sparks & Villagran, 2010).

Taken together, these theoretical perspectives emphasize three important aspects of health-related uncertainty (Bylund et al., 2012). First, although uncertainty at any one point in time may be reduced and sometimes eliminated, more often it ebbs and flows

over time. For instance, a cancer previvor's uncertainty about a preventative choice may be reduced after the preventative course is completed; however, a different form of uncertainty may emerge when she is no longer actively participating in preventing the cancer and consequently worrying about the future. Second, people differ in their preferences for managing uncertainty such that sometimes individuals choose to maintain or even increase their uncertainty as a coping mechanism (Bylund et al., 2012). For example, a previvor may know her mother has tested positive for the BRCA1/2 gene mutation but decide not to be tested because she does not want to be burdened with the knowledge of having the mutation. Lastly, uncertainty cannot always be eliminated and therefore must be managed communicatively. Within these relationships, people will make various decisions to cope with and to manage the uncertainty in an effort to maximize their health and well-being (Epstein & Street, 2007). Thus, after conversations with families and clinicians, a cancer previvor may undergo genetic testing, engage in more diligent preventive and screening behavior, and ponder future prophylactic actions in an effort to achieve some peace of mind about a health condition that has an uncertain future.

Types, Reasons, and Sources of Uncertainty

To satisfactorily manage health-related uncertainty, it is important to understand the reasons and sources of the uncertainty. There are several sources that create uncertainty about cancer and other chronic diseases, much of which relate to the amount or quality of available information in that uncertainty; such uncertainty can be created by too little information, complicated or conflicting information, and/or too much

information (Brashers, 2001; Epstein & Street, 2007; Mishel, 1999; Shaha et al., 2008). First, there can be uncertainty related to the likelihood of future health states. Stochastic uncertainty refers to being uncertain about future outcomes or events related to an illness and/or its treatment (Edwards, Elwyn, & Mulley, 2002; Politi & Street, 2011; Politi, Lewis, & Frosch, 2013). For example, how likely is it that a previvor will develop cancer or that a cancer treatment can cure the disease. Second, ambiguity uncertainty is defined as uncertainty related to conflicting evidence or the strength of the evidence generating risk information. For instance, missing or inconsistent data, differences in study results, and conflicting clinical recommendations produce such ambiguity (Politi, Lewis, & Frosch, 2013; Politi & Street, 2011; Politi et al., 2007). Lastly, informational uncertainty is caused by unusable, inapplicable, or even unavailable scientific data in a clinical encounter that is a function of ambiguity (Politi, Lewis, & Frosch, 2013). For example, a treatment might be relatively new and thus clinical evidence lacking (Truog et al., 2008), and this unavailable data might cause clinicians to feel unprepared to talk about the new treatment with the patient (Brehaut et al., 2008; Davison et al., 2006).

Much of the current research on health-related uncertainty focuses on communicating risk. According to Roth Port (2010), there are two types of risk:

Absolute risk is the odds a person will develop breast cancer over a specific time period. For example, you can determine your odds in the next year, the next five years, or throughout your lifetime. So when you hear the well-known statistic that one in eight women will develop breast cancer during their lifetime, that's an absolute risk.

Relative risk shows the relationship between a risk factor and breast cancer by comparing a group of people who have that particular risk with people who don't (p. 36, emphasis in original).

Thus, in the clinical encounter, communication about uncertainty often focuses on helping patients understand their perceived risk. By doing so, clinicians and patients are able to explicate the different types of sources for uncertainties related to patients' likelihood of future health states.

Politi, Han, and Col (2007) identify the following sources of such uncertainty:

1) risk, or uncertainty about future outcomes; 2) ambiguity, or uncertainty about the strength or validity of evidence about risks; 3) uncertainty about the personal significance of particular risks (e.g., their severity timing); 4) uncertainty arising from the complexity of risk information (e.g., the multiplicity of risks and benefits or the instability of risks and benefits over time); and 5) uncertainty resulting from ignorance (p. 682).

Since then, Han and his colleagues (2011) have extended conceptions of health-related uncertainty to include the decision making process and medical and the organizational features of health care providers. According to Han et al., uncertainty exists on a continuum from disease-centered to patient-centered. Disease-centered uncertainty focuses on scientific or data-centered issues including diagnosis, prognosis, causal explanations, and treatment recommendations (e.g., risk information, probability of outcome). The next is practical or system-centered uncertainty related to the structures and care processes (e.g., what care does the previvor need and how does she

get it). Lastly, personal or patient-centered uncertainty refers to psychosocial and existential issues and concerns related to a patient's unique situation and how she perceives and manages the uncertainty (e.g., coping, preventive actions, spirituality).

Overall, health-related, unmanaged uncertainty is caused by several sources, centers around different illness issues, and produces negative outcomes. Uncertainty stems from potential unknown outcomes, ambiguous symptoms, the unpredictable course of the illness, the treatment and recovery's intensity and timing, and concerns regarding the cancer's long-term impact on social, cognitive, and emotional competence. Such uncertainty results in negative psychosocial effects including emotional distress, low quality of life, poor decisions, and loss of control. As such, clinicians and patients must communicate effectively to manage health-related uncertainty. Thus, I turn to discussing managing uncertainty as a function of patient-centered communication.

Patient-centered Communication Functions

Because uncertainty can be problematic when it is not managed, there is a need to effectively communicate about uncertainty in health contexts. To explore uncertainty, a functional approach to communication is helpful. Such approach focuses on the key tasks or 'work' communication must do well in order to achieve the interaction's goals (Street & de Haes, 2014).

While there could be any number of important communicative tasks in cancer care, Epstein and Street (2007) identify six key functions—effective information exchange, fostering healing relationships, responding to emotions, making quality decisions, enabling patient self-management, and with respect to this dissertation, managing

uncertainty. These key functions are especially important because they emphasize meeting patients' needs and impact health outcomes within the clinical encounter. Yet before I present this six-function model of patient-centered communication, it is important to note that these functions overlap and thus are not independent from one another. Consequently, I will talk about each of the functions within the context of the function managing uncertainty, as this is the most important function to the present dissertation.

The first function of effective patient-clinician communication is managing uncertainty (Epstein & Street, 2007). Uncertainty is significant in cancer care because outcomes occur close to diagnosis, and cancer is typically curable. Additionally, uncertainty manifests in several stages of cancer (Mishel et al., 2003). A cancer patient who receives a cancer diagnosis is uncertain about which treatment course to take. A cancer survivor ending treatment is uncertain about the possibility of recurrence. A cancer previvor is uncertain about which preventative course to take after testing positive for a genetic mutation.

Given these uncertainties are associated with the different stages of cancer, uncertainty is often irreducible and thus, clinicians must assist patients in managing their uncertainty instead. To manage uncertainty, clinicians can acknowledge uncertainty exists, frame information based on what is known and unknown, be empathetic and engage in active listening, and teach patients coping techniques to personally assist them in their day-to-day lives (Epstein & Street, 2007). Unfortunately, managing uncertainty is one of the least understudied and problematic elements of patient-centered

communication (Decker, Haase, & Bell, 2007; Epstein & Street, 2007; Politi & Street, 2011), and the specific strategies with which to manage uncertainties in cancer is poorly understood (Bailey et al., 2004; Mishel, 1999).

Each of the other patient-centered communication functions helps address issues related to managing and coping with uncertainty. For example, the second core function—information exchange (Epstein & Street, 2007)—is important to managing uncertainty as some sources of uncertainty are associated with information. Information exchange includes seeking or gathering information, giving information, verifying information, checking for understanding, and reaching agreement on medical decisions and plans (Cegala, Coleman, & Turner, 1998; Cegala, 1997). Both clinicians and patients must present and manage information with each other in order to reach a shared understanding of patients' health (Epstein & Street, 2007). Also, providing information enhances satisfaction, facilitates more participation, decreases anxiety, and increases coping abilities (Davidson & Mills, 2005; Arraras et al., 2004). In order to effectively exchange information, clinicians must learn patients' information needs, understand their health beliefs and values, and present clinical information in understandable ways (Epstein & Street, 2007).

For previvors, obtaining and understanding information from clinicians about their genetic risk can assist in managing their uncertainty about the possibility of a future cancer diagnosis (McCormack et al., 2011; Politi & Street, 2007). Information about risk probabilities, preventative options, and outcomes can assist previvors in making choices about their health risk. Furthermore, understanding information about what is

“known” versus “unknown” as it relates to cancer risk and the risks and benefits of different types of preventative options may also reduce future uncertainty (Epstein, Alper & Quill, 2004; Epstein & Street, 2007).

The third core function of effective clinician-patient communication is fostering healing relationships (Epstein & Street, 2007). Fostering such relationships between clinicians and previvors contributes to managing uncertainty by demonstrating to previvors that they will not be abandoned as well as showing them their clinicians will support them throughout their entire journey. To foster such relationships, patient-centered communication must build rapport and create trust between previvors, their families, and their clinicians.

Several factors can help produce strong relationships between clinicians and patients including trust, respect, shared understanding of roles and responsibilities, and clinician self-awareness and well-being. First, trust must be mutual. Patients trust their clinicians when they believe their clinicians are informative, include them in the decision-making process, and are sensitive to their concerns (Gordon, Street, Sharf, Kelly, & Soucek, 2006; Salkeld, Solomon, Short, & Butow, 2004). Second, building rapport, or connecting with patients through verbal and nonverbal communication, leads to satisfactory relationships (Tickle-Degnen & Rosenthal, 1990). Third, clinicians and patients must understand each other’s roles and responsibilities by learning and comprehending each other’s preferences (Krupat, Yeager, & Putnam, 2000). Lastly, clinicians should build partnerships, listen actively, ensure patient understanding, display empathetic nonverbal behaviors, and engage in joint agenda setting with the patient

(Street, Gordon, Ward, Krupat, Kravitz, 2005; Street, Voigt, Geyer, Manning, & Swanson, 1995; Williams & Deci, 2001). By fostering such relationships through these strategies, clinicians can help previvors cope and manage their uncertainty about the future.

The fourth core function is responding to emotions (Epstein & Street, 2007). Patients experience a variety of emotions during clinical encounters, and many are important to providing quality health care. For example, previvors who have a high risk of being diagnosed with cancer must constantly deal with its imminent threat and thus experience negative emotions such as fear, worry, frustration, depression, and anger. Because these emotional states can have negative effects on individuals' physical health and overall well-being, clinicians must first recognize and then respond to the emotions (Dean & Street, 2014).

To respond to emotions, clinicians can employ both verbal and nonverbal communication behaviors to recognize the displayed emotion, ask questions to understand the emotional state, communicate that understanding, and then respond with empathy and/or, depending on the degree of the emotion, provide referrals and engage in interventions (Epstein & Street, 2007). Unfortunately, clinicians have a difficult time identifying and thus assisting their patients in managing negative emotions due to a variety of reasons (Dean & Street, 2014). Some of those reasons include the following: not having the skills to recognize or respond to the emotions, thinking it is someone else's responsibility, or worrying that talking about the emotions will cause further distress for the patient (Butow, Brown, Cogar, & Tattersall, 2002; Ryan et al., 2005;

Zimmerman, Del Piccolo, & Finset, 2007). Yet, clinicians who work with previvors (e.g., oncologists, genetic counselors, gynecologists, etc.) must learn to overcome such challenges, acknowledge their role in identifying negative emotions, and enact the above strategies to enhance the recognition of emotional distress (Dean & Street, 2014).

The fifth core function is making decisions (Epstein & Street, 2007). Decision-making is essential to any patient-clinician interaction but especially those in cancer care. Previvors must make decisions about which preventative course to choose after testing positive for the BRCA gene mutation in order to help manage their anxiety about possibly developing cancer during their lifetime. Effective decision-making includes three main steps—information exchange, deliberation, and the final decision (Charles, Gafni, & Whelan, 1999). A high-quality decision includes identifying and understanding patients' preferences. However, clinicians often do not know their patients' needs and values, and patients may not know or understand all treatment options (Epstein & Street, 2007).

Furthermore, patients vary on the desired degree of participation in clinical interactions (Janz et al., 2004). Decision-making can either be paternalistic (e.g., the clinician decides), shared (e.g., the clinician and patient decide together), or informed (e.g., the patient decides given provided information from clinician and other sources) (Charles, Gafni, & Whelan, 1999). To enact patient-centered decision-making, clinicians should actively listen, set an agenda, check understanding, offer involvement opportunities, encourage patient participation, accommodate preferences, and communicate empathy and warmth (Epstein & Street, 2007). Engaging in such

strategies will assist previvors in enacting effective decision-making but also managing uncertainties about the many preventative health options.

The sixth function is enabling patient self-management (Epstein & Street 2007). Self-management is the perceived ability to self-manage one's illness through navigating the healthcare system, seeking information, coping with side effects, and finding help when needed (Bodenheimer, Wagner, & Grumbach 2002; Bodenheimer et al., 2002; Epstein & Street 2007). Management or enablement encompasses both tasks clinicians can perform for their patients that may eliminate barriers to self-management and strategies clinicians can engage in to assist patients in caring for themselves outside of the clinical encounter. Important here is the difference between information exchange and self-management. Self-management specifically emphasizes recommendations, instructions, and advocacy; whereas, information exchange includes sending and receiving content about a topic (Epstein & Street 2007).

Engaging in self-management skills can assist previvors in managing their uncertainty. For instance, clinicians may need to act or advocate on the behalf of their previvors in order to help them navigate the health care system (e.g., coordinate care, arrange referrals), support patient autonomy to enhance patient self-efficacy and motivation (Deci & Ryan, 1985), and provide guidance and skills as well as access to resources (e.g., Internet, health educators, or interactive media) (Epstein & Street, 2007). Doing so enables previvors to cope with the various uncertainties outside clinicians' offices and facilities.

In summary, patient-centered communication encompasses managing uncertainty, exchanging information, fostering healing relationships, responding to emotions, making quality decisions, and enabling self-management, and these functions of communication overlap and work together to achieve certain goals in order to meet needs and impact health outcomes, as demonstrated through the uncertain experience of previvors.

Communicative Strategies for Managing Uncertainty

From this patient-centered communication perspective, specific strategies can be derived in order to assist in tolerating, coping, and managing uncertainty (Babrow & Kline, 2000; Brashers, 2001; Politi & Street, 2011). Providing useable and meaningful information, offering support, and engaging in cognitive coping techniques are but a few examples of the different communicative strategies that can assist both clinicians and patients and their families in dealing with uncertainty (Epstein & Street, 2007). In this section, I categorize communicative actions for managing uncertainty into the following three types of strategies: 1) cognitive strategies, 2) affective strategies, and 3) behavioral strategies (McCormack et al., 2011).

Before discussing specific communicative strategies for managing uncertainty, it is important to note the quality of the patient-clinician relationship specifically as it relates to trust and shared understanding plays an important role in helping patients (and clinicians) manage uncertainty (Arora, 2003; Mishel et al., 2005; Politi & Street, 2007; Quill & Suchman, 1993). Engaging in patient-centered communication strategies such as validating patients' uneasiness with uncertainty, involving patients in decision-

making, and clarifying values and goals can assist in reducing the negative health impacts of communicating uncertainty (Han, 2013; Politi & Street, 2011). Furthermore, since patients and clinicians often differ in how they experience uncertainty (Richardson, Masse, Nanny, & Sanders, 2004), clinicians must acquire some insight, either directly or indirectly, regarding patients' preferences in order to determine how best to deal with both short-term and long-term patients' uncertainty (Hoff & Hermeren, 2011).

Cognitive Strategies for Managing Uncertainty

The first domain for managing uncertainty is cognitive. Cognitive strategies for managing uncertainty include skills such as cognitive reframing, problem solving, and the provision of information. These cognitive strategies target uncertainty caused by unexpected or inconsistent triggers and thus are important because they assist in creating shared understanding for why uncertainty exists (Mishel et al., 2005; McCormack et al., 2011).

Cognitive reframing is the ability to address concerns and issues from an optimistic perspective. Cognitive reframing skills include self-talk, relaxation, pleasant imagery, and distractions. By using these skills and strategies, cancer patients, survivors, and previvors can manage their uncertainty when it is triggered (Mishel et al., 2002, 2005). For example, a cancer survivor may feel heightened uncertainty when she hears a media story about breast cancer, or a cancer previvor might experience increased anxiety about possible cancer when attending her annual mammogram check-up. On the other hand, enacting problem solving then uses those learned cognitive coping skills to recognize and define concerns and produce possible solutions to those concerns (Mishel

et al., 2002, 2005). In short, these strategies are effective in managing sudden triggers of uncertainty such as recurrence (Mishel et al., 2005) and creating space for hope (Babrow, 2001; Frenkel, Ben-Arye, & Cohen, 2010).

In addition to cognitive reframing and problem solving, providing informational resources can be another way to manage uncertainty (McCormack et al., 2011; Politi & Street, 2007). Information resources are important in the management of uncertainty (Davison, Degner & Morgan, 1995; Mishel et al., 2005; Nanton et al., 2009; Neville, 1998; Schofield et al., 2003; Timmermans et al., 2004). Under situations of uncertainty, it is helpful not only to present information in clear, detailed, and understandable ways but also to clarify what is “known” versus “unknown” (e.g., risks and benefits of treatment options) (Epstein, Alper & Quill, 2004; Epstein & Street, 2007; Fagerlin, Zikmund-Fisher, & Ubel, 2011; McCormack et al., 2011; Schofield et al., 2003).

Additionally, presenting information about uncertainty in visual ways can also be beneficial (Han, 2013). Clinicians should provide information based on patients’ preferences, and patients should seek information based on their needs (Corbeil et al., 2009; Mishel et al., 2002). Important here is short-term uncertainty may often be alleviated with information, but long-term uncertainty may require teaching patients how to manage their uncertainty by creating time boundaries for how long the uncertainty might be tolerated (McCormack et al., 2011).

Affective Strategies for Managing Uncertainty

The second domain involves communicative strategies for managing individuals’ affective reactions to uncertainty. Affective strategies seek to address the emotional side

of uncertainty such as anxiety and distress (McCormack et al., 2011). Though affective strategies are less prominent in the literature on managing uncertainty, such strategies are still important because the ability to manage uncertainty is connected to patients' emotional states (Epstein & Street, 2007; Han, 2013).

One affective strategy to assist individuals in dealing with the negative emotions is through acknowledgement and validation (Dean & Street, 2014). Clinicians should seek to recognize the type of uncertainty being displayed and then acknowledge the emotional concerns regarding the uncertainty. To do this, clinicians can engage in techniques such as active listening (Razavi & Delvaux, 1997) and asking open-ended questions as they provide space for patients to elaborate on their concerns and worries (Street, 1991, 1992). Also, acknowledging uncertainty assists in validating the experience of uncertainty (Politi, Han, & Col, 2007), which may contribute to a sense of feeling known (Anderson et al., 2008; Street et al., 2009). By acknowledging uncertainty, clinicians and patients can come to a shared understanding of whether the uncertainty is reducible or irreducible and the reasons or sources of uncertainty (Epstein & Street, 2007; McCormack et al., 2011).

A second affective strategy is empathy (Dean & Street, 2014). Empathy is defined as the sharing and understanding of individuals' emotions and thoughts. Clinicians can be empathetic by demonstrating respect, acting as a partner, and providing supportive communication messages (Arborelius & Österberg, 1995; Eide et al., 2011). For example, clinicians can inquire about patients' concerns, demonstrate interest and understanding for their circumstances, and build rapport with them (Street, 1991, 1992).

A final affective strategy is offering coping resources like counseling services or social support groups (McCormack et al., 2011; Mishel et al., 2005).

Behavioral Strategies for Managing Uncertainty

The last domain for managing uncertainty is through behavioral strategies of self-care or self-management. Self-management is the perceived ability to self-manage one's illness through navigating the healthcare system, seeking information, coping with side effects, and finding help when needed (Bodenheimer, Wagner, & Grumbach, 2002; Bodenheimer et al., 2002; Epstein & Street, 2007). Such management includes both tasks that clinicians can perform for their patients, which may eliminate barriers to self-management, and strategies clinicians can engage in to assist patients in caring for themselves (Epstein & Street, 2007). Specific self-care skills for managing uncertainty related to cancer include the following: creating action plans, laying out contingencies, journaling, meditating on positive images, and engaging in positive thinking and calming self-talk (Mishel et al., 2005; Fatter & Hayes, 2013; Ullrich & Lutgendorf, 2002; Utley & Garza, 2011; Wagner et al., 2001).

Self-care skills are helpful in managing uncertainty in many different cancer stages. For instance, a cancer patient and her clinician may create a timeframe to assist in digesting the multiple treatment options and then come back together to discuss the options by a certain date. A cancer survivor and her clinician may construct a back-up plan to address if her breast cancer reoccurs; doing so may help manage some of the uncertainty about finishing treatment. Finally, a cancer previvor may engage in personal self-care skills such as journaling and mediating to deal with a possible future cancer

diagnosis due to a recommendation by her clinician.

In summary, managing uncertainty requires patient-centered communication between the clinician and patient. Cognitive, affective, and behavioral communicative strategies provide particular ways individuals may manage uncertainty. Cognitive strategies include cognitive reframing, problem solving, and providing information. Affective strategies encompass acknowledging and validating emotions, being empathetic and actively listening, and offering resources for coping. Lastly, behavioral strategies involve self-management skills such as creating action plans and meditating on positive images. However, despite these different strategies for managing uncertainty in cancer, much still needs to be learned about what particular strategies work for particular people. More specifically, there is a need to explore how particular people experience uncertainty and what strategies help them cope.

Research Questions

Thus, the goal of my dissertation is to describe, understand, and interpret previvors' health experiences regarding patient-centered communication especially as it relates to managing uncertainty. As such, this dissertation is guided by two main research questions:

- (1) What are the sources of uncertainty for previvors, and what types of strategies do previvors employ to manage their uncertainty in clinical encounters?
- (2) How do previvors' uncertainties influence their health decisions in clinical encounters?

Now that I have reviewed relevant literature, I discuss the methods I engaged in to answer my research questions.

CHAPTER II

RESEARCH METHODOLOGY

“My daughter doesn’t dwell on cancer, but I’ve heard her say, “It’s not if I get cancer, it’s when I get cancer.” She uses this phrase because she says it will help her, IF she gets cancer, to move forward quickly and positively. But, that’s a burden for a mother; one our family lives with.”

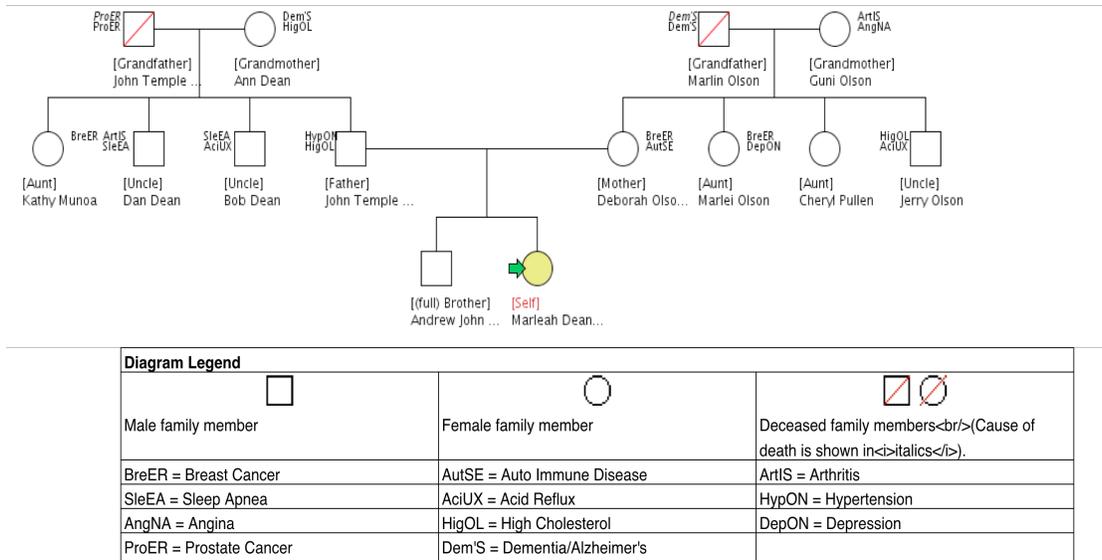
~ Deborah Olson-Dean

My mom is right. I still feel the effects of those early years. I hate hospitals. I hate blood. Needles. Doctors. The antiseptic smell. And, above all, I hate the sight of sick people with their families surrounding them, watching as their loved ones’ lives wither away. As the daughter of a 17-years old breast cancer survivor, I have always been interested in health communication. From a young age I watched my mother undergo breast cancer surgery, chemotherapy, hair loss, nausea, radiation, and reconstruction. Though scared, I was determined to be involved, as much as an eight year old could be. Now, as a previvor myself (BRCA2+), I am realizing just how much breast cancer rages through my family, and it is my passion for this topic that drives my research. Thus, in this section, I describe my research methods for this dissertation, highlighting my role as a researcher, the justification of qualitative methods, and data collection and data analysis.

My mother was diagnosed with breast cancer in 1997. One month earlier than my mom, my grandmother was diagnosed. Two years following, my Aunt, my mother’s

younger sister, was diagnosed. Since then both have tested positive for the BRCA2 gene. Later my other Aunt, my mother's oldest sister (the sister who has not fought breast cancer), researched and found out that my paternal great-grandma died of breast cancer at 35 years old, and my grandma's sister died after living with the disease for 20 years. Since then, my Aunt, on my dad's side, has been diagnosed (see Figure 1 for our family tree). For my family, breast cancer is not just a disease. For so long breast cancer has seemed to define how we live our lives.

Figure 1. My Family Health Tree



More recently, however, breast cancer is affecting my family and me in a different way. Instead of coping with family members who have had breast cancer and the associated perils, I now have to think about the future of my own immediate family. Since I found out I have the BRCA2 gene mutation, my husband and I have been discussing what our family plans might look like now. I always saw children in my

future, but in all honesty, I never thought much about the details. Now, I am being forced to do so. Do I risk possibly passing the mutated gene to a daughter, a son? When do we try to start having a family? Do I speed up my timeline in order to have children before having a prophylactic mastectomy and eventually an oophorectomy and hysterectomy? These are just a few questions that have been whirling around inside my head.

Given my own experiences and personal interest in this dissertation, I am aware that being a BRCA2 previvor will influence not only my conversations with my research participants but also my analysis of those interactions. I share this information in the spirit of self-reflexivity—constantly assessing how the researcher is affecting and influencing both the collection and analysis of data (Hesse-Biber & Leavy, 2006). Self-reflexivity is especially important in qualitative research because the researcher is the primary instrument for collecting and analyzing the data (Merriam, 2009). Furthermore, Lindlof and Taylor (2011) state reflexivity involves critical reflection about how the researcher, her participants, and the phenomena of interest influence and interact with each other. Thus, engaging in self-reflexivity will be important throughout my dissertation but especially qualitative data collection and analysis.

Justification for Qualitative Methods

Research inquiry should always direct the research method. So, in light of my research goals, qualitative research methods are most appropriate. I am interested in describing, understanding, and interpreting previvors' lived experiences, perceptions, and social constructions of life. Qualitative methods provide a way to understand how

individuals construct their world and the meanings they associate with such experiences (Hesse-Biber & Leavy, 2006; Lindlof & Taylor, 2011; Merriam, 2009). In addition, qualitative research recognizes specific patterns of multiple realities (Steubert & Carpenter, 1999). Interviewing previvors with different health experiences and decisions allowed me to identify certain pathways through which previvors construct their realities. Finally, qualitative methods in health communication can assist in understanding processes regarding healthcare (Britten, 2011). Therefore, qualitative methods enabled me to learn about the previvor community and possibly different pathways of coping with uncertainty and emotional distress (Lindlof, 1995).

Data Collection

After receiving Institutional Review Board approval and informed consent from my participants, I conducted semi-structured interviews with previvors. An *interview* is defined as “a process in which a researcher and a participant engage in a conversation focused on questions related to a research study” (deMarrais, 2004, p. 55). A researcher engages in this method of interviewing when she cannot observe participants’ behaviors, feelings, or interpretations of their worldview and when the researcher is interested in past events that cannot be replicated (Hesse-Biber & Leavy, 2006). Hence, it is through the dialogue or conversation between the interviewer and the interviewee that knowledge is produced and understood (Kvale, 1996).

Moreover, semi-structured interviews employ a predetermined list of issues and questions to guide the conversation, while also providing latitude to add information during the interviews (see Appendix A for my interview questions) (Merriam, 2009).

This style of open-ended interviewing enables the researcher to explore individuals' views and realities of life and ultimately generate theory (Reinharz, 1992). Additionally, semi-structured interviews create a more natural conversation between the interviewer and interviewee. So this type of interviewing is appropriate to learn about previvors' health experiences because it facilitates in-depth understanding and cultivates a comfortable environment for the participants (Lindlof & Taylor, 2011). In short, semi-structured interviewing enabled me to guide the interview conversation while also giving some control to the participants (Fontana & Frey, 1994).

Research Participants

Because the data for this dissertation draws upon previvors' health stories about managing their uncertainty, I interviewed 34 female previvors. The sample size is appropriate because the purpose of my research is to look at the "process" or "meaning" individuals attribute to their social situation (Hesse-Biber & Leavy, 2006, p. 70), not to generalize experience to *all* previvors.

There were two important criteria for identifying participants. First, the participants were women and, second, the women must have tested positive for either the BRCA1 or BRCA2 gene mutation. In addition to these two criteria, I originally desired the participants' preventative health decisions to vary because I wanted to understand the different ways previvors manage their uncertainty about their high risk for breast and ovarian cancer. For example, dominant categories of prevention for positive BRCA gene carriers include prophylactic surgeries (e.g., mastectomy, oophorectomy, hysterectomy), chemoprevention (e.g., drug tamoxifen), and increased detection (e.g.,

mammograms and MRIs and ultrasounds and CA125 tests every 6 months) (see Appendix B for a list of technical terms). The rationale for having women who had engaged in different health decisions is based on the idea that individuals respond in different ways to uncertainties in life. Yet even though I pre-screened the participants before conducting the interviews, the majority of women who were interested in interviewing with me had chosen preventative surgeries. To protect the participants, pseudonyms are used throughout the dissertation.

Participants' Demographics

The majority of women interviewed were Caucasian (e.g., 26 total). Yet in addition, one woman identified as Chinese; another identified as Ashkenazi Jewish; another identified as Caucasian and Colombian; another identified as Caucasian and Hispanic; and four women identified as Caucasian and Ashkenazi Jewish.

As for age, the majority of women were between 30-39 years old (e.g., 21 total). Additionally, six women were between 40-49 years old. Two were between 20-29 years old. Three women were between 50-59 years old, and finally two were between 60-69 years old.

Finally, 17 of the women have the BRCA1 gene mutation, and 17 of the women have the BRCA2 gene mutation. Also, 26 of my participants had undergone a preventative double mastectomy. 13 participants had undergone a preventative oophorectomy, hysterectomy, and sometimes both. Lastly, four participants are currently engaging in increased surveillance, and one woman is undergoing

chemoprevention (see Appendix C for the specific breakdown of the participants' demographics).

Recruitment

I recruited my participants through Facing Our Risk of Cancer Empowered's (FORCE) social media pages (e.g., message boards, Facebook, Pinterest). Sue Friedman, a former veterinarian and breast cancer survivor, founded this online, non-profit organization FORCE in 1999 under the belief that no one should go through hereditary cancer alone. Therefore, FORCE is committed to improving previvors and families' lives that are affected by hereditary breast and ovarian cancer.

I chose to recruit my participants from this organization for two main reasons—their important presence in the previvor community and their commitment to advancing research on hereditary cancer. First, FORCE coined the term “previvor” in 2000 when a community member stated she “needed a label.” As previously discussed, the term previvor refers to individuals who are highly predisposed to breast and ovarian cancer due to a genetic mutation and thus have different needs and concerns regarding cancer than the general population. Since 2000, the organization has been instrumental in educating individuals about advancements in cancer detection, treatment, and quality-of-life issues but most importantly cancer prevention. For instance, according to their website, FORCE has the following eight main mission objectives:

- To provide women with resources to determine whether they are at high risk for breast and ovarian cancer due to genetic predisposition, family history, and other factors.

- To provide information about options for managing and living with these risk factors.
- To provide support for women as they pursue these options.
- To provide support for families facing these risks.
- To raise awareness of hereditary breast and ovarian cancer.
- To represent the concerns and interests of our high-risk constituency to the cancer advocacy community, the scientific and medical community, the legislative community, and the general public.
- To promote research specific to hereditary cancer.
- To reduce disparities among underserved populations by promoting access to information, resources, and clinical trials specific to hereditary breast and ovarian cancer (“Mission,” par. 2).

These objectives demonstrate FORCE’s importance to the previvor community but also their commitment to research, which is discussed next.

The second reason I chose FORCE as the organization to recruit the participants is their commitment to research on hereditary cancer. According to their website:

FORCE recognizes the importance of collaboration between health care professionals, researchers, and lay advocacy groups, particularly regarding a rare disorder such as hereditary breast and ovarian cancer syndrome. We are committed to working together to assure the high-risk community and general populations receive up-to-date, credible information on hereditary breast and

ovarian cancer risk and management, and have access to the latest research and the best care” (“Information for Researchers,” par. 1).

Thus by recruiting through FORCE, I positioned my research and myself in a visible way, but more importantly, among individuals who are passionate about assisting others like themselves.

It is important to note that in exchange for recruitment advertising through FORCE’s social network, the staff encourages researchers to fund their own research costs such as outreach, consulting, advertising, or travel expenses. Furthermore, they also request an acknowledgement of their contribution to the research in any publication or presentation. I have adhered to both requests.

Data Analysis

After recruiting previvors willing to participate in this dissertation, I conducted semi-structured interviews to explore my specific research interests. To answer my research questions, I recorded and transcribed the interviews into a Word document. Then I used the constant comparison method to code my data (Glaser & Strauss, 1967; Lindlof & Taylor, 2011). I chose this method of analysis because it is considered the most prevalent and widely accepted way to code qualitative data (Glaser & Strauss, 1967; Lindlof & Taylor, 2002; Strauss & Corbin, 1990, 1994). To analyze my data, I engaged in open coding by sorting and tagging the data into themes. In other words, first, I categorized the data (Strauss, 1987). Second, I employed axial coding to refine the codes by grouping and relating the codes to each other (Corbin & Strauss, 2007).

Also, I wrote reflective memos throughout the study to record possible themes and notes (Glaser & Strauss, 1967).

The themes within the interview transcripts served as the units of analysis. A theme represents a cognitive schema set that can be used to conceptualize and understand ideas and relationships (Owen, 1984). Themes were detected based on Owen's (1984) three criteria—recurrence, repetition, and forcefulness. Recurrence refers to when there are at least two mentions of a general idea with the same meaning regardless of the words used. Repetition refers to repeated words, phrases, and sometimes sentences. The last criterion is forcefulness, which refers to the participants' vocalics (e.g., inflection, volume, pauses, etc.) that emphasize certain utterances as well as stress written phrases or words (e.g., underlining, italics, increased print, etc.).

Finally, I engaged in two strategies for increasing the credibility, transferability, and consistency of my research findings (Lindlof & Taylor, 2011). First, I wrote reflexivity journals. A reflexive journal is a helpful research tool because it allows the researcher to record key information about the study such as schedules, methodological decisions, questions of ethics, initial analyses, and other important decisions and notes for the study (Lincoln & Guba, 1985). Furthermore, a reflexive journal serves as an audit trail for data analysis to enhance transferability of my research (Lindlof & Taylor, 2011) as well as a place for researcher self-reflexivity.

Second, after completing my data collection and analysis, I conducted member checks with a sample of participants. I conducted member checks for two reasons. First, I wanted to ensure the participants are comfortable with the manner in which their

perspective was being portrayed in my analysis (Lindlof & Taylor, 2011), and second, I also wanted to determine if my participants felt the findings resonate with their lived experiences and thus provide communicative validity to my study (Hesse-Biber & Leavy, 2006). The member check process varied per participant. The majority of participants simply requested a summary of the findings to determine if they resonated with their experiences, while one participant wanted to review her whole interview transcription. Participants did indicate the findings accurately represented their health experiences.

CHAPTER III

FINDINGS

Research Question 1

Research question one asked what are the sources of uncertainty for previvors, and what types of strategies do previvors employ to manage their uncertainty in clinical encounters. Analysis revealed two main uncertainty sources for previvors—medical uncertainty and familial uncertainty. Medical uncertainty types include the unknown future, peaks and valleys associated with medical consultations, and personal cancer scares. Familial uncertainty encompasses traumatic family cancer experiences and being a mother and being present in children’s lives. I first discuss the sources of medical uncertainty.

Medical Uncertainty

“The Unknown Future”

The first type of medical uncertainty for previvors is “the unknown future.” Broadly, previvors grapple with an uncertain future. From deciding whether or not to undergo genetic testing to making health decisions after testing positive for the BRCA gene, previvors are uncertain, anxious, and fearful about what their future may bring. A common inter-dialogue for a previvor is: “Well, today I’m fine, but what about the future? What about my next mammogram or ultrasound?” In other words, previvors feel like knowing that they are at high risk is simply an “endless waiting game” for your “ticking time bomb boobs to go off.”

Jacklynn, a 34-year-old, Caucasian and Colombian BRCA1 previvor described what it means to have an unknown future.

As soon as I got the results of the BRCA test, I really felt like I went through the stages of grief—denial, being upset, being mad—and then once all of that passed, I started doing research and doing surveillance, but then after that first MRI, and the clinicians saying, ‘We think we see something.’ And then having the second [test], which didn’t confirm anything, I just felt like this ticking time bomb.

When am I going to get cancer? Some people can live with that, and it’s fine. But I’ve just been always an anxious person, so if I can just take care of something, I want to take care of it. And also talking to the doctor, he made me more aware that it’s not just an increased risk that I have, and then I was thinking about how young my aunt and uncle were when they died...Some people are wired to deal with it better, but I’ve never been good at that.

As exemplified here, first, Jacklynn illustrates her experience trying to deal with testing positive for the BRCA gene and the consequences it had on her future. Originally, she wanted to reduce her uncertainty about whether or not she had the gene, but after testing positive, she realized she now had to cope with a very high cancer risk. Said differently, testing positive led Jacklynn to experience uncertainty about a possible cancer diagnosis and fear about what the future might bring, which produced severe anxiety and distress.

In addition to the fear of a cancer diagnosis, previvors are also uncertain about when they might develop the cancer during their lifetime. Previvors hold the belief “it’s

not if I get cancer, it's when." Tara, a 28-year-old, Caucasian BRCA2 previvor explained this struggle:

You know the unknown is simply too much to handle...It is like, since I do have a strong family history [of cancer], and I do have the gene, to me it was like when is the cancer going to start. Is the cancer going to start? And the unknown of when it will start and if it will start...I mean it's not like I have a crystal ball to figure it out, you know. There's no way to know if I [will get] cancer or not, even though I have a strong family history, but it was just the unknown of not knowing, if I would get it or when I would get it. Will it be phase three [cancer] or phase one? I meant it was stuff like that. *The unknown of not knowing and not having a crystal ball to determine when it might be was just too much.*

Like Jacklynn, after testing positive for the BRCA gene, Tara struggled with when the cancer would manifest in her body like it did with her female family members. Thus, she constantly worried about if cancer was growing and how severe it would be when it was discovered.

Interestingly, it is not just previvors who hold this viewpoint about the unknown future. Savannah, a 31-year-old, Caucasian BRCA2 previvor reiterated a crucial interaction she had with a physician which increased her uncertainty about when she would develop cancer during her lifetime. She stated:

My biggest fear in life was always that I would get cancer...and my chances of getting cancer were just too high to deal with. I mean I was walking around with a 95% chance [of developing breast cancer], and after I tested positive for

BRCA2, I was talking to my gynecologist about options for dealing with this high risk such as increased surveillance versus a preventative double mastectomy, and *my doctor said that, 'It's not really a matter of if I would get cancer, but when,'* and when she said that, I said 'OK, what [breast] surgeon do I go see because it is time [to do a mastectomy].'

So for many other previvors as well as some clinicians uncertainty about the future can be too much to handle. As such, it is clear one overarching medical uncertainty source for previvors is the unknown future—not if they might get cancer but when.

“Peaks and Valleys”

The second source of medical uncertainty relates to medical consultations. Previvors explain they do not experience uncertainty all day, every day, but instead, such emotions and worries surface with their medical consultations. Previvors depict the “peaks and valleys” or “ups and downs” that occur every six months when they go in for their biyearly consultations. A biyearly consultation typically involves a mammogram and/or a MRI to check the breasts and a transvaginal ultrasound and a CA125 test to check the ovaries. Many previvors do not dwell on a possible suspicious spot or a lump for months at a time, but then the days leading up to their appointment they begin to experience significant, overwhelming fear and anxiety about what their physicians might be find.

Jennifer, a 30-year-old, Caucasian BRCA2 previvor, demonstrates this type of medical uncertainty as she depicted a recent medical consultation experience.

*It comes and goes in peaks and valleys. I will get these waves of emotions, and it is not related to my cycle, but it is every three to six months, and all of a sudden something will trigger...Because of [buying a new] house, we decided to wait on my surgery, and the part that I started to get anxious about was that I realized that because I was not having my surgeries, now it has been six months since my last round of surveillance, and so I have to go through another round of testing...Like I have to go through the blood test for the CA125. I haven't even gone into see my breast doctor for an office exam, but I have to get that taken care of, and I need to go see my gynecologist who is going to set up the ultrasound, and I have to follow-up on the mass in my breast, and so that gave me a whole new...I think it was just because it was so fresh; I realized that I was going to have to go through this all of again, and 'Oh my gosh,' what if they find something and it ends up being nothing, but I end up going through that fear again of what if. *It is almost like every six months or every year you are simply just waiting to find out if you have cancer. That in and of itself is very stressful, and it takes a major emotional toil...Every time I have to come back and do one more wave of surveillance and tests, it's just more emotions.**

Here, Jennifer provides a window into understanding uncertainty's emotional rollercoaster. Because she was not able to undergo the preventative surgeries due to her family's relocation, she experienced uncertainty and emotions again, feelings she thought she had left behind after deciding to have the preventative surgeries.

Samantha, a 35-year-old, Caucasian BRCA2 previvor, also understands this type of medical uncertainty. During a medical consultation after she turned 35, her breast surgeon informed her they now had to do surveillance every six months (e.g., rotating back and forth between mammograms and MRIs) to make sure cancer was not developing. Upon hearing this news, she shouted to her physician, “No! I don’t want to do that. I don’t want to go through those six months up and down.”

Likewise, Madison, a 32-year-old, Caucasian BRCA1 previvor, shared a similar perspective:

Getting mammograms and MRIs, I would just get stressed out before each one, so it was just a stress I didn’t want to deal with. I would wonder is this was the day that they would find the cancer. *I would just get really stressed out before each one, and I would wonder if this was my last day of ignorance, and I would just get really worried every six months.*

Bailey (33-year-old, Caucasian BRCA1 previvor) expanded on this concern, discussing how this medical uncertainty type relates to making health decisions. She said,

My fear with surveillance was that just because you are being screened every six months doesn’t mean that you aren’t going to get cancer, and I just, well you are hopeful that [the clinicians] pick it up earlier than they would have otherwise. And I am kind of a worrier, and *I think I would have been worried in the weeks leading up to the appointment*, and then once I had the appointment, it is a day off of work, or a half of a day, and then you have to drive back and forth to the

hospitals and the centers to have the screening done, and then it's another day or week before you get the results, and *so is that really worth dealing with every six months?* And at what point and at what age in my life am I going to get the phone call that I need to come back in for a biopsy, or they think that they see something? So I made my decision that I was not going to deal with that.

So not only is it being uncertain about one's future, but also a previvor's uncertainty is heightened at each medical consultation. As such, because of this medical uncertainty type, which occurs approximately every six months, many previvors, like Jennifer, Samantha, Madison, and Bailey, decide to undergo preventative surgeries. Previvors see surgery as a way to manage the uncertainty at each medical consultation, which is discussed in research question two.

“Cancer Scares”

The third source of medical uncertainty for previvors is personal scares of a possible cancer diagnosis. Many previvors described after they tested positive for the BRCA gene, they engaged in increased surveillance, but then during a mammogram or MRI screening test, a physician found a “suspicious lump” or “dark spot” in a breast. Identifying this possible cancerous lump or spot also heightened previvors' uncertainty about their unknown future.

Camille, a 47-year-old, Caucasian and Ashkenazi Jewish BRCA2 previvor, described a personal experience where she had to confront a possible cancer threat and how the experience increased her medical uncertainty.

In 2012, in early in May, [the doctors] saw something, and so I had to do the whole needle biopsy guided by an MRI, which is very painful and very, very stressful while you are waiting for those results. And so that was really the ‘icing on the cake’ for me...So I just decided that [the doctors] are always going to see something. Luckily, [the results] came back negative, but just with my dense breast tissue and with my heightened surveillance, you know, *how many biopsies can you have* [before they discover something cancerous]?

However, this medical uncertainty type is not only rooted in a possible cancerous spot found during clinical surveillance but also during personal surveillance. Nancy, a 40-year-old, Caucasian BRCA2 previvor, explained how she has always worried about missing something while performing her own self-breast exams. She said, “So basically, it was just, you know, a fear or worry in the back of my mind that I’m not catching something, or even if there’s something little that I can’t feel.” Now, much of this worry originated because Nancy’s sister’s cancerous lump grew rapidly, but the fear of missing a lump was constantly in Nancy’s mind.

Much like Nancy’s experience, for many previvors, finding a possible cancerous lump or spot solidified their high genetic cancer risk and made their unknown future finally feel “real.” Before, possibly being diagnosed with cancer seemed in the future, but when a physician identified something that could be cancerous, the women “freaked out.” For instance, during one clinical consultation, Madeline’s (a 38-year-old, Caucasian BRCA2) clinician found eight suspicious lumps! She exclaimed,

At the time that I tested positive, [the doctors] had also done breast MRIs on me, and they found eight [spots] that they thought were *very suspicious*. And so they wanted to test some of those spots, and I had two small children at home, and this diagnosis, and then I had all of these suspicious spots! So I felt a lot of anxiety, fear, really thinking about the journey that my mother took, and really just hoping that that didn't play out for my children to watch. It was a lot of stress at the time. But luckily, the spots came out clean, well three came out clean, but there were five more that they wanted to get a good look at, but it was at that point that I just decided, you know what, I know I have this gene, and I'm done having children, and I have all of these spots, so I decided to just go ahead and do a double mastectomy...*The spots that I was having, I just couldn't handle going through the testing for those spots and then waiting for the results and worrying about it.*

Similarly, Maria, a 30-year-old, Caucasian BRCA2 previvor, expressed the medical uncertainty she felt when her doctors found a lump in a breast after she gave birth to her second son. The breast surgeon recommended waiting six months to determine if the lump was indeed "something." But Maria emphasized she could not play the "waiting game" because she was going "crazy." She hated how she knew there was something "suspicious" in her body, but she could not see it or do anything about it. Thus, even though these lumps often turn out to be non-cancerous, the personal cancer scares influence previvors' health decisions such as deciding to undergo a preventative double mastectomy.

In sum, previvors first source of uncertainty is medical. Medical uncertainty includes the following types: the unknown future, peaks and valleys associated with medical consultations, and personal cancer scares. Yet as seen above in some previvors' responses, family is also a source of uncertainty. I now expound on this source.

Familial Uncertainty

“I Don't Want to Be My Mom.”

The second main source of uncertainty is familial uncertainty. Under familial uncertainty, the first type is previvors' traumatic family experiences with cancer. Previvors illustrated how cancer infiltrated their extensive family trees with diagnoses and deaths. The significant past experiences typically related to their mothers, but also sometimes, previvors would talk about other family members' experiences (e.g., sisters, aunts, grandmothers, and cousins).

Veronica, a 38-year-old, Caucasian BRCA2 previvor, described her family's past experience with cancer as a source of familial uncertainty.

Because my siblings and I were so young when my mother died, it was such a traumatic thing for our family, and you know, I had a stepmom that did her best, but it's not the same as having your own mother...Anyway, I've got 3 kids. At the time of my [preventative mastectomy] surgery, my eldest had just turned 7, and then I had a 1 and 3-year-old. *So it was very personal for me in that having many children. I didn't want them to go through what I went through.*

Veronica's past experience mirrors many previvors' experiences. Previvors discussed how they spent countless hours in hospitals and doctors' offices and watched their loved

ones undergo endless surgeries, radiation, chemotherapy, nausea, and vomiting. These past experiences forever imprinted their lives with cancer fears. As such, testing positive for the BRCA gene is extremely difficult since it triggers previvors' past memories with family members who fought cancer.

Moreover, previvors emphasized they do not want to be their mothers and go through what their mothers did. Savannah, a 31-year-old, Caucasian BRCA1 previvor, said,

I love my mom, but I don't want to end up like her...I don't know how my mom is alive; she's battled cancer six times, and it's amazing she is walking around today, but I've had to take care of her at a very early age for nearly 15 years, and I don't want my kids to have to do, even though I know they would, and do it proudly...

Likewise, Lacy, a 51-year-old, Caucasian BRCA2 previvor, discussed how her memories with her mother's cancer affected her experiences. Lacy's mother was diagnosed with breast cancer at 69-years-old and then was diagnosed with Stage IIIC ovarian cancer at 74-years-old. Lacy's experiences were difficult and emotional because not only was Lacy dealing with her own positive tests results, but also she put all of her time and energy into helping her mom fight her cancer. She explained, "Having watched my mom have ovarian cancer, you know, obviously I'm not looking forward to doing that [oophorectomy] surgery, but I am highly motivated to not get ovarian cancer." So in different ways and at different life stages, both Savannah and Lacy had to take care of their mothers, which left a lasting impact on their own health.

Lastly, other previvors noted their uncertainty and anxiety is related to attending medical consultations that trigger past memories such as being in hospitals and caring for loved ones. For instance, Addison, a 33-year-old, Caucasian BRCA1 previvor, described how traumatic her first surveillance appointment was after she tested positive for BRCA. While sitting in the waiting room for her appointment, Addison “busted into tears” because she was next to old cancer patients who reminded her of her mother. She exclaimed:

There you are sitting having known what your mother had gone through, and I mean I knew what cancer had done to her body and the damage. *I saw how strong she was, and I just, you know, I was in the waiting room with women who had Stage III cancer and next to older women, and here I was healthy and 25, and they were just looking at me weird...I just felt angry.*

Addison’s past memories with her mom overwhelmed her in that moment. She felt alone, scared, and like she did not belong. In the waiting room, Addison experienced intense feelings of fear and uncertainty, which solidified what it truly meant to test positive for the BRCA1 genetic mutation. Thus, traumatic family cancer experiences are a type of familial uncertainty for previvors.

“What About My Babies?!”

The second type of familial uncertainty, and the final uncertainty source for previvors, is the importance of motherhood and being present for children’s lives. For some previvors, the first type originated from the fear of being diagnosed with cancer, dying, and then leaving their children behind. In this way, it also relates to the previous

uncertainty source—traumatic family experiences with cancer—and not wanting their own children to grow up without a mother. Previvors shared the belief they did not want their children to ever see them sick or struggle with cancer and certainly did not want their children to see them die.

For example, Bailey (a 33-year-old, Caucasian BRCA1 previvor) described her concerns about her children:

My fear was that as my kids would get older, and they would remember more and more about my sickness or struggles or battles that I went through, and with being so young, this quick recovery hasn't been so bad [referring to the recovery after her preventative mastectomy], but what if I was sick for years and years? I don't want that to be burned into their memories—that for ten years Mom was sick. Or for ten years Mom couldn't make baseball games or go take me to school or do this or do that.

However, this worry of developing cancer and not being present for children's lives was also framed in positive ways. Camille, a 47-year-old, Caucasian and Ashkenazi Jewish BRCA2 explained, "I have an amazing child who is going to get married and have babies one day, and I have to be there for that." So this uncertainty type is connected to previvors' role as a mother.

Finally, because of familial uncertainties, previvors make particular health decisions. For instance, Savannah's (a 31-year-old, Caucasian BRCA1) decision represents many previvors' decisions. She chose a preventative double mastectomy, hysterectomy, and oophorectomy because she believed the surgeries would provide her

with the greatest chance to watch her kids grow up and take care of them. In short, not getting sick and being present in children's lives is essential for previvor mothers.

Summary

In sum, there are two main sources of uncertainty for previvors—medical and familial uncertainty. First, an unknown future is a medical uncertainty type because previvors never know when their high cancer risk might actually manifest in their bodies. Also, the time leading up to medical surveillance appointments invokes uncertainty about if a cancerous spot or lump will be found. Moreover, personal cancer scares create uncertainty as previvors anxiously wait for test results to determine if cancer is present or not. In fact, such personal scares often remind previvors of the traumatic family memories they experienced in the past, which only reinforces their uncertain future. Lastly, being a mother and being present in children's lives is a final uncertainty source because previvors do not want their children to experience what they went through with their own mothers and relatives.

Uncertainty Management Strategies

Because previvors experience uncertainty in clinical encounters, the second part of research question one asked what types of strategies do previvors employ to manage their uncertainty in clinical encounters. Analysis revealed the following four main strategies: 1) seeking clinicians as an informational source, 2) seeking clinicians as a partner for decision-making, 3) seeking clinicians as an emotional support, and 4) seeking referrals from clinicians for emotional support. I first discuss the most common uncertainty management strategy—seeking clinicians as an informational source.

Seeking Clinicians as an Informational Source

The first uncertainty management strategy previvors engage in is seeking clinicians as an informational source. Because previvors are uncertain about the unknown future, experience peaks and valleys, worry about personal cancer scares, reflect on past family experiences, and fear leaving their children behind, information and knowledge is seen as an effective way to manage those uncertainties.

First, previvors placed a significant emphasis on clinicians' expertise and knowledge regarding BRCA patients, research, treatments, and experiences. For example, Tara, a 28-year-old, Caucasian BRCA2 previvor, explained the extreme difference in knowledge between her clinicians in Los Angeles who specialize in BRCA and her clinicians in San Antonio who are general gynecologists.

My doctors in San Antonio don't know as much about the BRCA gene as my doctors in LA did. Like there aren't many people in my practice in San Antonio that have the gene, and so [the clinicians] don't really know how to properly communicate the steps of what you need to do next... When I lived in LA, I had a gyn-onco [gynecologist oncologist] as my OBGYN who specifically dealt with cancer. But when I moved back to Texas, and I went back to my old OBGYN, he who doesn't really deal with cancer a lot. I haven't found a gyn-onco that I like, and so it's like they don't really know how to deal with the whole BRCA gene, what the patients have to go through, and so I am teaching the doctors about it in a way... I am having to be my own self-advocate about my health. And it's

exhausting to have to keep teaching people that this is what the gene is and this is how you should be treating me.

Likewise, Jennifer (a 30-year-old, Caucasian previvor) portrayed her experience visiting her OBGYN after testing positive for BRCA2 and declared how frustrated she was about her gynecologist's lack of knowledge about BRCA. She said,

I went to my gynecologist, and when I told him that I had been positive for BRCA2, his response – not to the exact words – it was ‘Oh, so you have both BRCA’s?’ And I went ‘Ah, no!’ *You don’t know what you’re talking about. And that really made me immediately uncomfortable because I thought, am I in the wrong place?* He’s a great OB, but I could tell he was not the gynecological specialist in the office...I felt like I was educating my physicians.

In both Tara and Jennifer’s cases, their clinicians’ lack of BRCA knowledge and expertise produced immense frustration and caused them to have to educate their own physicians, which only increased their uncertainties.

So interacting with clinicians who are knowledgeable about BRCA related issues is important because otherwise previvors worry more about their unknown future. Lacy, a 51-year-old, Caucasian BRCA2 previvor, discussed how after testing positive, she wanted to get involved in a high risk center that specialized in BRCA patients because she did not want to have to worry about their expertise. As such, Lacy joined a high-risk surveillance program at Stanford. Since then she has greatly enjoyed not having to explain things about BRCA to her physicians because they know what is expected,

appropriate, and important. Because as Tiffany (a 38-year-old, Caucasian BRCA1 previvor) said, “It is doctor’s ignorance that is killing people.”

In addition then to being “well-versed in BRCA” as Rebecca (a 44-year-old, Caucasian BRCA2 previvor) pointed out, previvors are better able to manage their uncertainties if they are able to discuss all relevant information about what it means to be BRCA+ and the different health decisions. Hence, it is not enough to be knowledgeable about BRCA, previvors also seek clinicians who can provide and discuss BRCA information, ranging from topics such as receiving genetic test results to making decisions about preventative surgeries.

For example, Nancy, a 40-year-old, Caucasian BRCA2 previvor, emphasized what helped her feel better about her unknown future after she received her tests results was a detailed conversation with her genetic counselor. The counselor spent a long time talking about the results and what the results meant for her and her family’s lives. She explained:

Our genetic counselor, she was amazing. *I mean she was a wealth of information!* When we got our test results, my mom and my sisters and I all went together to get our results together, and she spent probably an hour with us afterwards talking about, you know, what our next steps were and things we needed to be doing, and what doctors we needed to be seeing. It was just so, so helpful.

Likewise, when shopping for a plastic surgeon, Jacklynn (a 34-year-old, Caucasian and Colombian BRCA1 previvor) stated the plastic surgeon she picked, “He

answered so many of my questions, and I felt like I was going to drive him crazy, and that he might refuse to treat me because I had so many questions.” But by answering her many questions, Jacklynn felt better about her decision.

Yet it was not just the provided information that allowed Jacklynn to manage her uncertainty but also the manner in which the information was provided. In addition to providing information, clinicians need to make sure their patients understand the information. For instance, Sophia, a 33-year-old, Chinese BRCA2 previvor highlighted how her genetic counselor not only provided her with information but also made sure she understood the information before leaving the consultation. Also, Sophia’s nurse practitioner in charge of her case was helpful because she talked about everything—from testing positive to increased surveillance to surgeries and made sure Sophia understood all the information.

Also, previvors stressed information must be provided in laymen’s terms in order to help them manage their worries and anxieties. Janet, a 51-year-old, Caucasian, BRCA1 previvor, explained her clinicians at MD Anderson were excellent communicators due to their ability to speak in terms she could understand. She asserted,

An excellent communicator is someone who can explain things in terms that I would understand. Medical person to medical person you can use all of the jargon that you want, but medical person to patient bring it down to my level.

And I think all of the doctors at MD Anderson have been able to bring it down to my level.

The final component then of information as an uncertainty management strategy is providing additional information to previvors upon leaving the clinical consultation. Previvors underscored the importance of providing “extra” information—handouts, brochures, websites, etc.—in order to help them manage their uncertainty after leaving the clinical encounter. Caitlyn (a 37-year-old, Caucasian BRCA2 previvor) stressed this point to “have resources ready.”

One thing [my genetic counselor] was decent but not great on was having resources lined up—like who can I go to for this and who can I go to for that...She just didn't have enough of that set up...*I would have loved some information about a gynecological-oncologist; I had to research that by myself online and find one on my own. Breast surgeons. She didn't give me anything. None. Counselors if necessary.* She said, ‘You may need all of these [resources], but I don't have anything to give you.’...So I am now stuck at this where do I go next step?

Because Caitlyn did not receive additional information upon leaving her genetic counseling appointment, she left feeling very scared and confused about what to do next and ultimately had to search online for the resources she needed, which in many ways made her even more uncertain about her future.

In sum, the first important strategy that assists previvors in managing their uncertainty about the future is interacting with and being cared for by clinicians who are knowledgeable about BRCA, provide information, answer questions, check understanding, and provide additional resources at the end of the consultation. Because,

as Sophia (a 33-year-old, Chinese BRCA2 previvor) concluded, “Information is an effective coping mechanism.”

Seeking Clinicians as a Partner in Decision-Making

The second uncertainty management strategy previvors engage in is seeking clinicians as a partner for decision-making. Since previvors experience uncertainties about when they might get cancer, how it might develop, and who they may leave behind, clinicians who encourage and engage in shared and informed decision-making assist previvors in managing their uncertainties.

To do this—and extending the previous uncertainty management strategy—clinicians should provide previvors with all the information surrounding their health risks, possible health decisions, and each decision’s benefits and consequences. Jenelle, a 41-year-old, Caucasian and Ashkenazi Jewish BRCA1 previvor, described how her clinicians engaged in informed decision-making by discussing surgical preventative options but then letting her make the decision.

I actually switched gynecologists because I needed someone who could discuss with me the pros and cons of making these different decisions...Because I needed someone who was going to be like, ‘Yes, we can get you looked at every six months. Yes, we can do the blood test for ovarian cancer, which is a CA125 test. And a lot of physicians will say, ‘Well, it’s very nonspecific, not even worth doing it,’ but for me I needed to have it done...So I ended up switching to a gynecological-oncologist who would be willing to do those procedures...*The oncologist was very open to that fact that it is my decision.* Because the data said

this [referring to a preventative mastectomy] isn't absolutely what has to be done, he was very careful with how he supported me if I wanted to do it, but was also saying at the same time, he was upfront with 'I don't know what this will mean or not mean, and it is a big procedure.'

So Jenelle effectively managed her uncertainties in that encounter because her clinician provided her with all the information about increased surveillance and preventative surgeries and then stated he would support her final decision.

Indeed, it is important for clinicians to maintain a balance between not pressuring previvors to choose a particular health option while also providing their own medical advice. Previvors want their clinicians to be honest and straightforward with them. For instance, Jennifer (a 30-year-old, Caucasian BRCA2) illustrated the frustration she experienced with her breast surgeon when he would not give her clear advice to help her make a decision.

I tried to talk to him about the preventative mastectomy and [get] his thoughts... I mean, as a patient, I personally, I look to my doctors for support and opinions and advice, and I know that generally speaking, they're not supposed to give you their personal opinion, *but it's so much more difficult when you're relying on the expertise, and they say, 'Well, I can't really tell you what you should do.'* I mean you just want someone to give you an honest response.

In contrast to Jennifer's experience, Maria (a 32-year-old, Caucasian BRCA2 previvor) praised her breast surgeon because she gave Maria "real answers" to her questions especially about decision-making. Maria loved how her clinician would give

her personal answers about what type of preventative health decision she would make. It made Maria feel like the clinician was a “real person” and understood her situation. And in the end, Maria and her breast surgeon made the decision together, which helped Maria manage her uncertainty.

Jennifer’s frustration and Maria’s satisfaction with clinicians’ decision-making approaches highlight how important patients’ preferences are in clinical consultations. When engaging in either shared or informed decision-making, it is essential for clinicians to ask previvors for their preferences as well as respect their preferences. For example, Kelly, a 44-year-old, Caucasian BRCA1 previvor, illustrated how her clinicians at MD Anderson never pressured her into making a decision about undergoing a preventative mastectomy or not. The clinicians simply provided all the information and made sure she understood the options so she could make her own decision. Similarly, Nancy (40-year-old, Caucasian BRCA2 previvor) explained,

So you know, [my clinicians] have been able to tell me their recommendations, but it’s never been a high-pressure thing. *It’s always, you know, here are the options, but you need to make the choice, and whatever decision you make, you know, we stand by you.*

Again, by not feeling pressured and feeling supportive by her clinicians, previvors like Nancy and Kelly are able to make a decision that works best for them.

Finally, as touched on above, once the previvor makes a decision, the clinician should offer support, affirmation, and reassurances regarding that decision. Also, the clinician should not judge the previvor’s final decision. Veronica (a 38-year-old,

Caucasian BRCA2 previvor) described her interaction with her breast surgeon after receiving her positive test results from the genetic counselor.

My husband and I had pretty much decided that was what we were going to do, and then I had those fears of ‘Oh no, what if they [referring to her clinicians] say I shouldn’t [do the mastectomy]’ or what if, you know, like I was having doubts [about the surgery], *but then talking with [the doctor] just sort of reaffirmed that that was the path I wanted to take.*

In brief, the second helpful uncertainty management strategy is seeking clinicians as a partner for shared and informed decision-making. Doing so includes seeking patients’ preferences about decision-making, respecting patients’ decisions, and providing reassurances once decisions are made, which ultimately assists previvors in managing their uncertainties in medical encounters.

Seeking Clinicians as an Emotional Support

The third uncertainty management strategy previvors engage in is seeking clinicians as an emotional support. Generally, physicians who acknowledge, validate, and discuss previvors’ feelings, are empathetic and compassionate, actively listen, seek to understand previvors’ situations, build trust, and are concerned about previvors’ well-being assist previvors in coping with an uncertain future and help previvors make the best decisions for themselves. In the present study, many previvors sought clinicians who would assist in the emotional side of testing positive for BRCA and making health decisions; the previvors who did not have clinicians who supported them emotionally emphasized the desire for clinicians to help them cope by providing emotional support.

For example, when discussing the role her clinicians played in helping her cope with her high cancer risk and the associated stress she experienced, Jamie (a 27-year-old, Caucasian BRCA2 previvor) talked about how her primary care physician would occasionally ask how she was doing emotionally.

She asked how I was doing with this, and we talked about everything. And now I am okay with it [referencing high cancer risk]. I am at a really good place now, and I have accepted it. It is what it is. I can't change it. I don't have control over it; I just have control over what I do and how I respond to it. And so I am not going to let it control and ruin my life...She was just supportive.

By asking about her feelings throughout the journey, Jamie was able to process her emotions, which helped her cope and manage her stress and uncertainty.

In addition to asking about emotions, another helpful thing clinicians can do is treat previvors' as patients who have emotions, which influence their experiences.

Camille, a 47-year-old, Caucasian and Ashkenazi Jewish BRCA2 previvor, described how her plastic surgeon helped her cope with the emotional, uncertain side of having a high cancer risk by being concerned for her “full well-being.”

I just felt like he wasn't the nose job plastic surgeon—Yeah we will fix that and then I am done with you. I definitely felt like he was concerned for my full well-being not just his little part of the job. That was helpful. *I mean you have your support from your family and friends, but on the medical side, it felt really good to be supportive on that end as well...*He showed an absolute sensitivity. First of all, as a man, there is just no reason for him to get it, and I felt like he did. When

he would talk about how I was doing in all of my follow-up appointment, well I had some issues when they cut my stomach hip to hip, and I had a lot of healing to go through and had a lot of issues that caused it to take longer, but I just felt like when I went in to meet with him, he wanted to know how I was doing emotionally with this, and the fact that I was having to deal with a wound weeks longer than I should have. And also, when my husband was with me, he wanted to know how he was doing with it, and then when he wasn't with me, he wanted to know how our relationship was doing...so totally above and beyond...He was just completely aware of how emotional this whole process is for a woman.

Camille effectively managed her uncertainty because her clinician focused on her as a whole person not just a body part to fix and constantly checked in to see how she and her husband were feeling emotionally.

Third, clinicians can provide emotional support through physical touch. Skylar, a 30-year-old, Caucasian and Hispanic BRCA1 previvor, asserted the most memorable moment during her health journey was when her clinician demonstrated care and concern for her through physical touch. Specifically, Skylar's plastic surgeon held her hand before she went under for her preventative mastectomy. Through this simple act of holding her hand as the drugs caused her to fall asleep, Skylar did not feel alone anymore and felt supportive emotionally.

Overall, clinicians should help previvors deal with the intense emotions associated with a high cancer risk and making preventative health decisions. Clinicians who are concerned about the whole person, acknowledge and support the emotional part

of testing positive for BRCA, and ask about emotions assist previvors in managing their uncertainties.

Seeking Referrals from Clinicians for Emotional Support

The last uncertainty management strategy, least performed by previvors' clinicians but highly desired, is seeking referrals from clinicians regarding emotional support. This strategy includes two types of emotional support referrals—social support/social network groups and therapists/counselors/psychologists. I first discuss social support and social network groups as a way to cope with uncertainty.

Sometimes clinicians' emotional support is not enough to help previvors cope with their uncertainties. Thus, previvors want their clinicians to provide referrals to local and online social support/social network groups and sites. Doing so connects previvors to people who are in similar situations—people who have a large family cancer tree, people who have had similar traumatic cancer experiences, and people who have similar questions and concerns about dealing with a high cancer risk. Ultimately, connecting previvors with individuals who have similar situations helps previvors because they hear about different experiences and decisions as well as feel like they are not alone in their health journey.

Previvors suggest two ways clinicians can provide this emotional support. First, clinicians such as genetic counselors, breast and plastic surgeons, gynecologists, and oncologists should provide information about social support groups. Clinicians can give brochures and handouts about groups focused on assisting previvors as well as a list of credible websites to visit.

For example, FORCE and Bright Pink, two popular organizations committed to previvors and their families, would be excellent resources to share with previvors.

Nancy (a 40-year-old, Caucasian BRCA2 previvor) explained how after receiving her positive test results the genetic counselor pointed her to FORCE and Bright Pink's websites. Once she visited the websites, Nancy realized even though she felt like she was in her "own little circle of the world," there were in fact other people out there "who are ten steps ahead of you," which assisted in managing her own uncertainties.

In fact, these groups, especially FORCE, were praised as wonderful social support networks. Jenelle, a 41-year-old, Caucasian and Ashkenazi Jewish BRCA1 previvor, proclaimed:

...It has been wonderful! The people in FORCE, for my sister and me, have just helped us so much through this. I mean I am so thankful for these women; I mean they have gone above and beyond support. Just amazing. Like as far as emails and calls; they made a meal when each of us came home from the hospital [from surgery]...To see real people in your community tell you they are so happy they did this, and they feel and look great just makes a huge difference.

Yet despite that benefits of organizations like FORCE, as Carly's (a 31-year-old, Caucasian and Ashkenazi Jewish BRCA1 previvor) comment reveals most of the time clinicians do not provide previvors with information about these organizations unless requested. Carly talked about how her breast surgeon gave her information about a local FORCE chapter when she was deciding whether or not to undergo a preventative mastectomy. She said, "And it wasn't until I asked her if she knew of anybody who

would had done [a mastectomy] preventatively that she told me about the local FORCE coordinator and gave me her card and information.” Providing such resources is essential for previvors to receive the emotional support they need.

Additionally, previvor Facebook groups are helpful resources for managing uncertainties. Example groups include the following: Previvors, Young Previvors, BRCA Sisterhood, BRCA Advanced 101 and 102, BRCA Commons, and groups designed for the different health decisions (e.g., Young Previvors’ Surveillance Sisters and Prophylactic Mastectomies). For instance, Sophia (a 33-year-old, Chinese BRCA2 previvor) emphasized how the Facebook groups she is a part of have been instrumental in providing emotional support especially as it relates to making health decisions.

The second suggestion previvors discussed is to have clinicians match their BRCA+ patients with other BRCA+ patients. Patients could be matched according to who has the same BRCA status, similar demographics, or most importantly, who has chosen similar health decisions. Matching previvors with similar others would help previvors provide support for each other and learn more about the possible health pathways.

For instance, Anna, a 44-year-old, Caucasian and Ashkenazi Jewish BRCA1 previvor, stated how nice it would be if clinicians would ask their current previvor patients if they would be willing to serve as a contact for other previvor patients. Simple questions like, “Can I use you as a contact? Would you be open to talking to other patients of mine about [your] experience?” would be extremely helpful. Also, Anna

suggested providing patient testimonials on clinicians' websites. That way, patients could learn more about BRCA+ patients' experiences and decisions.

Yet in addition to providing social support groups and building a previvor patients network, previvors also want their clinicians to provide referrals for therapists, counselors, and/or psychologists. Such referrals assist previvors in coping with intense emotions. Unfortunately, not many previvors received such referrals. In the present study, sometimes the clinician simply provided the therapist's name "just in case." Sometimes the clinician told the previvor his office employed a full-time psychologist but did not discuss or encourage seeing the psychologist. But on two occasions, previvors exemplified so much verbal, physical, and emotional concerns about testing positive, cancer fears, and making the right health decision, the clinician did expressly provide a referral.

However, more often than not, previvors did not receive referrals to therapists. Thus, the previvor had to take matters into her hands. This was the case for Addison (a 33-year-old, Caucasian BRCA1 previvor). Addison sought out a therapist to help her cope and "sort out [her] relationship with BRCA" because she did not feel enough emotional support from her clinicians. She described her experience in therapy:

We just talked about it a lot. I won't go into everything that we talked about in therapy, but she really helped me come to terms with feeling like I had something in my future, and she helped me face my fear. And she also helped me to recognize my emotions and be able to be more perceptive about them. Where I realized that I started investing so much feeling in the future and things...A lot of

what we did [revealed] that I was constantly talking about the future, maybe not really just cancer, but other things, and she really helped me to come back to the present and live in the present and be happy with the present. Knowing that there's nothing I can do about the future, no matter what happens. And there was a lot of relief and power in that. It is something I still work on today. I mean, I think we all do.

For Addison, seeing this therapist was the most helpful thing a clinician did for her to help her cope with her uncertainties. Thus, because of her experiences, she stressed clinicians need to provide referrals to previvors when needed.

In short, the final uncertainty management strategy previvors enact is seeking referrals from clinicians regarding emotional support. Previvors who are having a difficult time coping with their high cancer risk desire their clinicians to provide referrals to social support/social network groups as well as therapists, counselors, and/or psychologists. Doing so assists in managing emotional and medical uncertainties.

Summary

Overall, there are four strategies previvors engage in to manage their uncertainties. First, previvors seek clinicians as an informational source—wanting clinicians who are knowledgeable, easy to understand, and provide as much information as possible. Second, previvors seek clinicians as a partner for decision-making, desiring their clinicians to provide information about all possible health options while guiding and supporting their decisions. Third, previvors seek clinicians as an emotional support because their own emotions can be overwhelming and difficult. Finally, when

clinicians' emotional support is not sufficient, previvors seek referrals from clinicians for social support groups and therapists.

Research Question 2

Research question two asked how do previvors' uncertainties influence their health decisions in clinical encounters. Analysis revealed that the following contributed to previvors' decisions: 1) risk perception of developing cancer, 2) scares of identifying potential cancer, 3) traumatic family experiences with cancer, and 4) current life status. In the current study, such factors were not present in all previvors' stories, but a large majority of the previvors did discuss one or more of these factors and how the factors ultimately influenced their health decisions.

There are three main health decision pathways for previvors. First, after testing positive for the BRCA gene, previvors can engage in increased surveillance—attending medical consultations every six months to check for cancer through clinical breast exams, mammograms and MRIs, and transvaginal ultrasounds and CA125 blood tests. Second, previvors can undergo chemoprevention, which involves injecting chemotherapy medication into one's body to reduce the likelihood of developing cancer. Or third, previvors can undergo preventative surgeries such as a preventative bilateral mastectomy, oophorectomy, and hysterectomy.³

In the present study, previvors made a variety of decisions with preventative surgeries as the most common decision. Four previvors shared that they are engaging in

³ A preventative bilateral mastectomy is the surgical removal of one's natural breasts in order to prevent a cancer. An oophorectomy is the surgical removal of one's ovaries, and a hysterectomy is the surgical removal of one's uterus in order to prevent cancer.

increased surveillance. One previvor is currently trying chemoprevention, but the majority of previvors (e.g., 31) have undergone preventative surgeries (see Table 1). Specifically, 17 previvors have completed a preventative double mastectomy, also referred to as a prophylactic double mastectomy or preventative bilateral mastectomy.

Increased surveillance (4)	Chemoprevention (1)	Preventative surgeries (31)
Lacy (breasts) Jasmine Theresa (planned PBM) Alexa (all)	Lacy	Savannah Mary Elizabeth Carly Jenelle Madison Janet Jacklynn Madeline Kelly Sarah Jamie Camille Nancy Lacy (ovaries) Tara Anna Sue Jennifer Samantha Rebecca Maria Bailey Veronica Shauna Skylar Sophia Caitlyn Addison Tiffany Gabriella

Six previvors have undergone either an oophorectomy or hysterectomy. Lastly, eight previvors have done a preventative double mastectomy and either (or sometimes both) an oophorectomy or hysterectomy (see Table 2). Because the most common health decision for previvors was a preventative surgery, I first describe the reasons for this particular decision.

Table 2. List of Types of Preventative Surgeries		
Preventative Surgeries		
Mastectomy	Oophorectomy and/or Hysterectomy	Both
Mary	Jenelle (put has planned PBM)	Savannah
Elizabeth		Jacklynn
Carly	Kelly (put has planned PBM)	Sarah
Madison		Nancy
Janet	Lacy (minus PBM with no intention)	Samantha
Madeline		Rebecca
Jamie	Anna	Shauna
Camille	Sue	Tiffany
Tara	Caitlyn	
Jennifer		
Maria		
Bailey		
Veronica		
Skylar		
Sophia		
Addison		
Gabriella (maybe O/H)		

Surgical Health Decisions

The majority of the present study's previvors chose preventative surgeries to manage their high cancer risk. Generally, previvors who underwent preventative surgeries had the following beliefs, experiences, or circumstances: 1) believed they

would get cancer at some point in their lives, 2) experienced death (or severe cancer diagnoses) in their family, 3) had physicians identify suspicious lumps or spots during increased surveillance appointments, 4) were married, and 5) had finished bearing children. In other words, for many previvors, the medical and familial uncertainties are simply too much to handle, and so they choose the most drastic health option—surgery. In this section, I first describe the main reasons why previvors decided to undergo preventative surgeries, and then I discuss why certain previvors chose to undergo a preventative mastectomy versus an oophorectomy and/or hysterectomy.

Previvors choose to undergo preventative surgeries for several reasons. The most prominent reason for undergoing a preventative surgery was previvors did not want to live in an ongoing uncertain world. Previvors did not want to worry constantly about *when* they might get cancer during their lifetime. Previvors discussed by undergoing a preventative mastectomy, for instance, they could choose the day, the time, and the place, thus giving them some control over their own body.

Also, previvors do not ever want to get cancer. They do not want to go through the many surgeries, medical appointments, various treatments, and experience the numerous, unpleasant side effects. For example, Carly, a 31-year-old Caucasian and Ashkenazi Jewish BRCA1 previvor, stated,

I pretty much decided that I [had] a hundred percent guarantee that I was going to get breast cancer based on my family history, so I think once I decided that, it was a matter of time when I was going to have a double mastectomy, and I put the timeline that I needed to do it by age 40, but I ended up having it when I was

35. So I was turning 35, and it [was] hanging over my head, the surgery. I guess I was dreading it. *I knew I was going to have to have it. I thought, you know what, I should be able to move forward in my life. I needed to get it [referencing the surgery] behind me.*

So even though Carly was hesitant to do a preventative surgery, she did not want to worry about when she might develop cancer. Carly said she always knew getting the surgery was her best chance to reduce her high cancer risk, and she is very happy she made the decision. In short, previvors—who are certain they will get cancer at some point in their lives—often choose to undergo preventative surgeries because it manages the uncertainty.

The second reason previvors decided to undergo preventative surgeries was twofold. First, previvors did not want to experience uncertainty each time they attended a medical consultation. Camille (a 47-year-old, Caucasian and Ashkenazi Jewish BRCA1 previvor) explained it this way:

I mean, like I said, from a very young age, I always felt like I was predetermined to have breast cancer, and just from an emotional standpoint watching my mom go through that, and it's freaking me out and everything, but then to have those kind of numbers, to be faced with that I just... there's no way... *The heightened surveillance just wasn't feeling like enough for me.* And then, like I said, to have that biopsy, which was extremely uncomfortable, and I knew that this was going to become a sort of a repetitive thing.

Second, previvors did not want to worry if the clinician would find any suspicious lumps or spots during the consultation. For example, when Maria (a 30-year-old Caucasian BRCA2 previvor) attended a medical consultation, the clinicians found several possible lumps. She explained,

So after an ultrasound with biopsy was done, they're like let's do an MRI with a biopsy. So I scheduled that appointment, and while I was waiting for that one to happen, I just decided to schedule the surgeries for the preventative bilateral mastectomies because I was looking at six biopsies...*I was like going crazy by all of this, so I decided, you know, just go ahead with the surgery and be done with all of that.*

Like Carly and Maria, previvors do not want to wait every six months to hear if their clinicians found something suspicious in their breasts or ovaries. They do not want to worry if cancer is developing in their bodies. They do not want cancer to define their lives. Therefore, removing one's natural breast tissue, ovaries, and/or uterus is worth it because it reduces those uncertainties.

The last reason previvors decided to undergo preventative surgeries related to their role as a mother. Many previvors discussed a main reason for undergoing a preventative mastectomy, oophorectomy, and/or hysterectomy was their children. They did not want their children to grow up without their mothers. They do not want their children to ever see them sick. They did not want their children to ever worry about losing their mother to cancer.

Such feelings and worries relate back to previvors' family experiences with cancer, which left deep, unhealed scars, and previvors did not want their children to be scared about losing them when they knew they could do something about it. For instance, when discussing why she underwent a preventative mastectomy, Jennifer (a 30-year-old Caucasian BRCA2 previvor) talked about her children.

I have three boys actually. One of them is only 1½, and so, it was also really scary for me to think 'Oh my gosh,' you know, what if I don't have as great of an outcome, you know. *[I was] worrying about whether or not my children [were] going to know how much I love them. If they were going to remember me, if something terrible happened because they're young.*

So having preventative surgeries was worth it to Jennifer because the surgeries alleviated her uncertainty, fear, and worry about developing and dying from cancer, and thus she could focus on participating in her children's lives.

In addition to these main reasons, age was also an indicator for the specific type of preventative surgery previvors chose. Most previvors close to or over age 40 had or planned to undergo a preventative oophorectomy and/or hysterectomy. Such decisions are common because experts recommend previvors remove their ovaries between 35 and 40-years-old and after having children (Friedman, Sutphen, & Steligo, 2012). Moreover, ovarian cancer is harder to detect, and consequently, when this cancer is discovered, oftentimes it is extremely advanced and commonly results in death. Consequently, if the previvor is done having children, it is recommended to remove these body parts.

Ages for previvors who chose a preventative double mastectomy ranged from 27 to 51, but the majority of the previvors in the current study completed the surgery between ages 30 and 35 years old. This decision is often made by women who have the BRCA gene, have a large family history of cancer, and more importantly, have relatives who were diagnosed and/or died before their 40s (Friedman, Sutphen, & Steligo, 2012).

There are, however, several consequences to having preventative surgeries. For one, an oophorectomy and hysterectomy causes the previvor to go into early menopause, which is often unpleasant and distressing. Additionally, this surgery can have an impact on women's sexual enjoyment. Side effects include vaginal dryness and occasional pain during intercourse (Roth Port, 2010).

Like an oophorectomy and hysterectomy, there are consequences for undergoing a preventative mastectomy. On a personal level, many women have emotional attachments to their breasts, and many think their breasts make them a woman. Of course, breasts are sexualized body parts, but breasts are also functional, for example with breastfeeding. Also, undergoing a preventative mastectomy can impact women's body image. In fact, the main reason why women do not choose a preventative mastectomy is due to body image. Lastly, when removing breast tissue, there is often a lack of stimulation in the nipples thus affecting sexual enjoyment (Roth Port, 2010). Yet despite the side effects, the previvors in the present study expressed they were not as concerned about these issues because the surgeries helped them manage uncertainty surrounding their high cancer risk.

It is important to note after testing positive for the BRCA gene, many previvors engaged in increased surveillance first; however, they eventually decided to undergo preventative surgeries because increased surveillance is *not preventative*. In other words, uncertainty still exists. The fear of the unknown can keep growing and growing, and for many previvors, the fear and uncertainty is simply too much to handle.

Previvors feel something has to be done, and the ‘something’ is usually a preventative double mastectomy and sometimes a preventative oophorectomy and/or a hysterectomy and sometimes both.

Sarah’s (a 56-year-old, Ashkenazi Jewish BRCA1 previvor) health decisions illustrate this perspective that increased surveillance is not preventative. Initially, Sarah did not want to undergo a preventative mastectomy, yet she ended up doing it because people close to her were dying from cancer. One such woman was a therapist in her school who was diagnosed with non-smoking related lung cancer. Sarah described her as a really young health nut who “within a year [went] from being like this beautiful vibrant person to wearing a wig and having no eyebrows.” Knowing someone with cancer personally who was completely healthy was very difficult for Sarah. In one interaction Sarah will never forget, this therapist and colleague said to her, “You have to do whatever you can do to avoid having chemotherapy...Because it’s not the cancer. It’s the chemotherapy that’s killing us.” Because of this interaction, not long after, Sarah went to see an oncologist, a breast surgeon, and gynecologist. In short, Sarah’s perspective changed because she realized she had the opportunity to do something

preventative so she would never get cancer and never have to undergo chemotherapy like her friend.

So engaging in a preventative surgery helps manage uncertainty because it is the most effective medical way to reduce one's high cancer risk. In fact, removing one's natural breast tissue or ovaries or uterus reduces one's risk of developing cancer from the 60-80 percent to 5 percent (Roth Port, 2010)! In other words, these surgeries "defuses the time bomb," makes the previvor "feel healthy," and ultimately "feel like she is reducing her risk as much as she can." Thus, even though preventative surgeries mean giving up one's breasts, and sometimes ovaries and uterus, previvors think it is worth it.

Indeed, many participants talked about a "sense of relief" or a "peace of mind" or "mind resting" produced after undergoing a preventative surgery. For instance, when asked how she felt after completing her surgeries, Anna (a 44-year-old, Caucasian and Ashkenazi Jewish BRCA1 previvor) expressed, "The number one feeling I felt when I woke up [from surgery] was relief...Oh, huge weight. Huge weight lifted!" Furthermore, she said she always asks previvors how they feel after their surgeries, and they always say the same thing—Getting the surgeries provided an immense amount of relief because they no longer have to worry about their high cancer risk.

Summary

In brief, preventative surgeries help previvors manage their medical and familial uncertainties. By undergoing a preventative mastectomy, oophorectomy, and hysterectomy, previvors no longer have to worry about when they might get cancer, do not have to deal with the peaks and valleys or personal scares each time they attend a

medical consultation, are not reminded as much about past family experiences with cancer, and know they will have the best chance to watch their children grow up. Therefore, previvors view this health decision as getting rid of the death sentence mentally associated with a cancer diagnosis. As many previvors described, “it’s choosing life over your body parts.”

Nonsurgical Health Decisions

Yet as discussed earlier, surgical options are not the only way to deal with one’s high cancer risk. Despite the preference for preventative surgeries, previvors can also engage in nonsurgical options such as increased surveillance and chemoprevention. Increased surveillance typically encompasses rotating between MRIs and mammograms to check breasts and ultrasounds and CA125 tests to check ovaries every six months. The goal of increased surveillance is to catch the cancer early enough so there can be a favorable diagnosis, a minor surgery like a lumpectomy, and no radiation or chemotherapy. Chemoprevention includes using medication (e.g., Tamoxifen) to reduce one’s breast cancer risk. This health decision is debated in the medical field; there is some research which supports chemoprevention, while other research questions chemoprevention’s effectiveness for individuals with BRCA (“Chemoprevention and breast cancer,” 2014).

In the present study, nonsurgical health decisions were not common. Only four women opted for a nonsurgical pathway. One previvor is currently undergoing chemoprevention through a high-risk program at Stanford University as well as doing

increased surveillance for her breasts, and the three other women are engaging in surveillance for their breasts and ovaries.

There are several reasons why these women decided not to engage in preventative surgeries. First, Jasmine (a 32-years-old, Caucasian and a BRCA2 previvor) who chose increased surveillance talked about the desire to have children and thus is “not ready to give up any body part yet.” She said,

I’m just thinking, I mean even though I’m not yet 33, I keep thinking about some of these girls who talk about having their ovaries removed, and I’m freaking out like ‘Don’t jump the gun just yet!’ You know?! ‘You’re young.’ I know anything can happen doing... Anything can happen, but I just, I feel like maybe there’s not enough information out there to make us kind of choose. *I mean it is one thing not to breastfeed, but it’s another thing to not to have kids.* So even if you’re 25, you know. I mean when I was 25, I wanted kids one day and hated them the next. And now that I’m 32, I want kids so bad, and I don’t have anyone to do that with, and I don’t make enough money to be able to do it on my own.

So younger previvors may choose to undergo increased surveillance because they have not had children. In addition to wanting kids, Jasmine also emphasized it is important to “Keep your stuff!” She explained when a person is young, she should enjoy her breasts while she can and not be in a hurry to get rid of them.

Along the same lines, a second reason why previvors choose increased surveillance is their breasts’ importance. As mentioned earlier, many women are emotional attached to their breasts because breasts make them feel like beautiful, sexy

women. For example, when discussing why she is engaging in surveillance, Alexa (a 38-year-old, Caucasian BRCA1 previvor) stressed she is “not through with her sexuality.” Alexa explained she simply does not want to remove her natural breasts because her breasts represent her sexuality, and she is not ready to give that up yet.

The third previvor—Lacy (a 51-year-old, Caucasian BRCA2)—picked a variety of health decisions, which provide further insight into previvors’ health decisions. First, she decided to undergo a preventative oophorectomy and hysterectomy, but then opted for increased breast surveillance and chemoprevention. Lacy had three main reasons for why she decided not to undergo a preventative mastectomy but did the preventative surgeries for ovarian cancer. The first reason was her age. She stated,

I mean I think it more than has to do with the age you’re at. I was 48 when I was identified BRCA+, so I know I didn’t get cancer at 35, you know. I know I didn’t get breast cancer at 40 or whatever. So it’s not like I’m look at 60 years of screening, you know.

If Lacy had tested positive for BRCA earlier in her life, she acknowledged she might have considered a preventative mastectomy more, but given her current age, the most pressing issue was the possibility of developing ovarian cancer.

The second reason for her health decision was her clinicians’ recommendations. Lacy’s clinicians recommended she immediately remove her ovaries and tubes to prevent ovarian cancer. She explained her decision-making process:

Well, when I spoke with the genetic counselors, they said their recommendation for me was that I do have my ovaries and tubes⁴ removed...So [the clinicians] were pretty straightforward. *That was their recommendation because of the risk for the ovarian cancer is a lack of good screening for ovarian cancer, and you know, my age and stage of my life...*

Lacy also talked about how her clinicians discussed with her there is not a lot of information to date regarding breast cancer risk reduction and mastectomies.

For the breast cancer risk, [the clinicians] said, pretty much said, ‘There are two ways you could go,’ you know, and they did not say one or the other would be their recommendation...And there wasn’t much data on it, or the mastectomy, *and they did also say that actually the majority of folks [do] surveillance, not mastectomy, which, you know, I think if you read, if you just look in the media, you probably think the other way because it’s a lot more dramatic the things they say...*

Her clinicians explained further to Lacy each option’s risks and benefits. She reported, ... If you do surveillance, the risk is you could get cancer, you know. So you might have to have cancer and cancer treatment, but you also might never and might never have plastic surgery, and if you do preventive mastectomy, you won’t ever have to have cancer treatment, but you will by definition do the mastectomies...

⁴ Removing the ovaries and falopian tubes is commonly referred to as a bilateral salpingo-oophorectomy (BSO).

Clearly, Lacy's clinicians' recommendations significantly influenced her health decision. The risk of undergoing a preventative mastectomy surgery and possible surgical complications did not outweigh the benefits. Lacy also decided if it ever felt like surveillance was not enough, she could simply change her mind and do the surgery then.

The last issue, which influenced Lacy's health decision, was watching her mother suffer from ovarian cancer. Lacy's mom was diagnosed with ovarian cancer at a later stage in life and thus the cancer was advanced Stage IIIC. Furthermore, it was her mother's diagnosis that alerted Lacy to undergo BRCA testing in the first place, and as such, the ovarian cancer was something she was more concerned about at the time she received her positive test results. She explained,

*Having watched my mom have ovarian cancer, I was, you know, it wasn't that I was looking forward to doing that surgery, but I was highly motivated to not get ovarian cancer...*The ovarian surgery was certainly a first priority, you know.

That's what [the clinicians] presented to me, and as far as how I looked at it, and I knew that if I chose down the road, I probably would do the mastectomy later after, you know, screening for some period of time, so that was a good way to, you know, initially do the more sort of high priority surgery...

Finally, the last previvor is currently doing increased surveillance but is planning on undergoing a preventative mastectomy soon. Theresa, a 34-year-old, Caucasian previvor, learned her BRCA2 status in February 2014, and as such, she has not had enough time to process everything and decide what she wants to do. In addition, similar

to Alexa, Theresa disclosed she thinks her hesitation to do the mastectomy is due to the fact she does not want to part with her breasts. She explicated,

I want to say that it is not for superficial reasons, but I think it is for very superficial reasons. I'm still moving forward with the preventative mastectomy, because I think it will save my life; I don't want to waste anymore of my life...*I don't want to know I could have prevented my own death. So now I am trying to reconcile with myself that I am doing something traumatic to myself for a preventative reason, as good of a reason as it is*, and it is still kind of surreal... I know I will have all of the preventative surgeries, but it is really a question of when.

Thus, Theresa's struggle with increased surveillance and a preventative surgery reveals the tension between a preventative mastectomy's benefits—reducing one's cancer risk—and a preventative mastectomy's risks—what it does to the previvor's body and morale.

In fact, Lacy acknowledges this struggle too, despite her own health decisions.

She discussed,

Occasionally, I will think that I sort of re-talk all [referencing her decisions] of this through, but I haven't come to any different conclusion about it yet, and I guess, you know, just having that uncertainty and that risk, I know some people really hate it. They just want to know and be done, but I have seen a lot of people go through mastectomy, and it's a really big surgery, and it's very hard. People often have complications, and you know, if I can avoid that that would be great.

So even though Lacy admitted increased surveillance is not the best health decision to reduce her uncertainties, she still has chosen this health route because of the uncertainties associated with undergoing a preventative mastectomy. As a result, despite the fact that increased surveillance may invoke fear, anxiety, and worry, a surgical health option is not always previvors' choice for managing her uncertainties.

Summary

Overall, a few previvors chose increased surveillance and/or chemoprevention as a way to manage their high cancer risk. Reasons for choosing this particular health decision include the following: children, emotional attachments to breasts, body image, clinicians' recommendations, and past familial experiences with cancer. It is important to note, however, because the majority of previvors in the present study chose to undergo preventative surgeries, it is difficult to completely flesh out why previvors choose particular health decisions over others. Yet this study's findings do provide insights into why previvors, both young and old, might engage in preventative surgeries. In short, because preventative surgeries tend to be viewed as "extreme," choosing to have a preventative surgery demonstrates uncertainty's immense power on previvors' lives.

CHAPTER IV

DISCUSSION AND CONCLUSIONS

Because of previvors' high cancer risk, they live in a constant state of uncertainty—wondering not *if* they might get cancer but *when*. Such uncertainty cannot always be eliminated and therefore must be managed. Thus, the purpose of this dissertation study was to identify previvors' sources of uncertainty and the ways in which they manage such uncertainties in clinical encounters as well as understand how the uncertainties influence previvors' decision-making.

Analysis revealed previvors experience medical and familial uncertainty, which manifests in the following ways: an unknown future, peaks and valleys associated with medical consultations, personal cancer scares, traumatic family cancer experiences, and being a mother and being present in children's lives. To deal with such uncertainty, previvors engage in particular uncertainty management strategies including seeking clinicians as an informational source, seeking clinicians as a partner for decision-making, seeking clinicians as an emotional support, and seeking referrals from clinicians for emotional support. Overall, previvors' cancer risk perception, individual cancerous scares, traumatic family experiences, and current life status impact their health decisions. The findings are now discussed and then limitations and future directions are noted.

Theoretical Implications

Uncertainty Revisited

The present study reveals and supports previous research that uncertainty is inherent in health and illness experiences (Babrow & Kline, 2000) especially in clinician-patient communication about risk (Kasper, Geiger, Freiburger, & Schmidt, 2008). Broadly, previvors experience uncertainty because they are not able “to foresee the future and explain the past and through the experience of ambiguous or unpredictable events” (Berger & Bradac, 1982, as cited Miller, 2014, p. 234). More specifically, the findings illustrate uncertainty is a living, breathing thing previvors must deal with each day (Roth Port, 2010), yet particularly in clinical encounters. Previvors do not just worry about when they might get cancer, but also must cope with cancer worries every six-month during a medical consultation or when reflecting back to their loved ones’ battles with cancer.

Therefore, the findings also reveal uncertainty is a complex phenomenon and should be approached as something to be *managed* not reduced (Brashers, 2007; Bylund et al., 2012; Epstein & Street, 2007). As mentioned earlier, previvors undergo BRCA genetic testing to reduce their uncertainty about whether or not they have a high cancer risk, which initially may reduce that uncertainty, but if they test positive for the BRCA gene, different uncertainties may arise such as peaks and valleys, personal cancer scares, traumatic family experiences, and being a mother and being present for children’s lives. As such, previvors experience chronic uncertainty, and both clinicians and patients must learn how to manage such uncertainties.

Sources of Uncertainty

Because uncertainty often cannot be eliminated and thus must be managed (Epstein & Street, 2007), an essential first step for uncertainty management is to identify the sources of uncertainty for the population at hand; doing so assists in understanding how uncertainty influences communication (Babrow & Kline, 2000; Bylund et al., 2012). As such, I first discuss previvors' uncertainty sources and how such sources support and extend existent research.

First, the present study's uncertainty sources support past research's sources of illness uncertainty. When examining individuals living with HIV, Brashers et al. (2003) identified three sources of uncertainty in illness: medical, personal, and social. Medical uncertainty sources, the most prominent in health care, include "issues of diagnosis, symptom patterns, systems of treatment and care, and disease progression or prognosis" (p. 502). The current study's sources of uncertainty (e.g., the unknown, peaks and valleys, and personal cancer scares) loosely reflect medical uncertainty. For example, previvors' belief that the future is always uncertain coupled with the belief cancer will be discovered at some point during their lifetime reflects the medical uncertainty property diagnosis (Brashers et al., 2003) and, more specifically, the inevitability of diagnosis as explained by Middleton, LaVoie, and Brown (2012). Additionally, previvors' uncertainty about cancer scares is related to ambiguous symptom patterns and unpredictable disease prognosis (Brashers et al., 2003). When performing a self-breast exam or undergoing a mammogram or MRI, previvors worry about discovering a suspicious lump or change in their breasts. Even after making particular health decisions

(e.g., increased surveillance or preventative surgeries), previvors are uncertain about treatment failure (Brashers et al., 2003), which ultimately heightens uncertainty about the unknown future.

Second, previvors' medical uncertainty of the unknown future is also related to risk or uncertainty about future outcomes (Politi, Han, & Col, 2007). Politi and Street (2011) characterize being uncertain about future outcomes or events related to an illness or treatment as stochastic uncertainty (Politi, Lewis, & Frosch, 2013). On the other hand, Han (2013) terms such uncertainty as probability, referring to the fundamental principle that future outcomes are not determined or fixed but rather are random (Han, Klein, & Arora, 2011). An unknown future is a source of uncertainty for previvors because they do not know if/when their high cancer risk might manifest as actual cancer. In brief, the present study supports previous research that different health experiences and illnesses generate certain types of uncertainty (Brashers et al., 2003; Bylund et al., 2012; Middleton, LaVoie, & Brown, 2012).

Nevertheless, the current study's sources extend beyond previous research identifying a third, important source of uncertainty—familial uncertainty. Familial uncertainty includes traumatic, family experiences with cancer and being a mother and being present for children's lives. For some previvors, past experiences of watching loved ones battle cancer greatly enhances their fear and uncertainty of cancer and what cancer can do to the body. For others, losing their mothers during their childhood and not wanting their own children to experience such loss is a significant source of uncertainty.

Though past research has not explored familial sources of uncertainty for previvors, some research has examined family relationships and breast cancer (e.g., Bylund et al., 2012; Fisher, 2010). For instance, in genetic counseling, Bylund and her colleagues (2012) found mothers who were breast cancer survivors experienced uncertainty about their daughters' cancer risk, identifying three main sources including disease risk, future cancer screening, and communicating relevant information to daughters. Additionally, Fisher (2010) examined emotional support communication between mothers and daughters who were coping with breast cancer. She learned sometimes daughters avoid discussing issues surrounding breast cancer with their mothers as a way to cope with such distressing topics. In short, these sources of uncertainty speak to "the critical role family-related uncertainty plays in genetic testing decision making" (Bylund et al., 2012, p. 299) and reveal the emotional connection between mothers and daughters regarding breast cancer (Fisher, 2010).

Uncertainty Management Strategies

Since previvors experience various uncertainty sources, which can produce severe psychosocial side effects (Neville, 1998), it is essential to manage them (Epstein & Street, 2007). Yet as the present study indicates, "uncertainty is multilayered, interconnected, and temporal," and thus "the appropriateness and effectiveness of responses used to manage [uncertainty] are likely to vary across contexts and situations" (Brashers, 2001, p. 481).

The current study identified the following four uncertainty management strategies: (a) seeking clinicians as an informational source, (b) seeking clinicians as a

partner for decision-making, (c) seeking clinicians as an emotional support, and (d) seeking referrals from clinicians for emotional support. Overall, these strategies indicate communication plays an important role in managing uncertainty (Babrow & Kline, 2000), and particularly, communication between health care clinicians, patients, and families is essential to the uncertainty management (Bylund et al., 2012). I now discuss the identified uncertainty management strategies and how they support and extend past research.

Seeking Clinicians as an Informational Source

The first management strategy, and most commonly discussed by previvors, is seeking clinicians as an informational source. In order to manage medical and familial uncertainties, previvors want clinicians who are knowledgeable about BRCA, provide information about cancer risk and possible health decisions, answer questions, confirm understanding of provided information, and offer additional resources as needed or desired. Hence, it is first necessary for clinicians to assess previvors' preferences for "what information they desire and what role they wish their clinicians to play" because doing so assists in managing uncertainty (McCormack et al., 2011, p. 1091).

Prior research indicates information and thus knowledge are the main mechanisms for managing uncertainty (Brashers et al., 2003; Miller, 2014; Mishel et al., 2005; Mishel, 1988). Information enables individuals to interpret their situation, which can then provide closure for the uncertainty (Mishel, 1990). For example, Miller (2014) found cancer survivors use information as a means to cope with illness-related uncertainty. She reported cancer survivors seek information from their clinicians in

order to manage their uncertainty about their illness as well as their care. Also, in a different study about cancer survivors, Mishel and her colleagues (2005) conducted an uncertainty management intervention for breast cancer survivors and found it improved knowledge about cancer and clinician-patient communication. Clearly, receiving information is a helpful way to manage uncertainty.

Seeking Clinicians as a Partner for Decision-making

In addition to information, the second uncertainty management strategy is seeking clinicians as a partner for decision-making. Previvors emphasize when their clinicians engage in shared or informed decision-making (e.g., *shared*: the clinician and patient decide together and *informed*: the patient decides given provided information from the clinician and other sources; Charles, Gafni, & Whelan, 1999), it helps them manage their uncertainties. Additionally, respecting decisions and providing reassurances once decisions are made also assists previvors in managing their uncertainties in medical encounters.

Past research supports this connection between uncertainty and decision-making (Epstein & Street, 2007; Kasper, Geiger, Freiburger, & Schmidt, 2008), yet also notes a significant knowledge gap about decision-making and risk communication (Bottorff et al., 1998). In one study, Kasper and his colleagues (2008) examined decision-related uncertainty qualities for cancer patients in order to develop “a theory about people’s perception of decisional uncertainty and about the way it changes when they elaborate information relevant [to] decision[s]” (p. 43). Interviews with cancer patients revealed uncertainty management as a pivotal challenge to coping with decisions about cancer,

thus demonstrating “uncertainty as the core content of the decisional communication” (p. 43), thus similar to previvors’ experiences.

Also, Bottorff and her colleagues (1998) conducted an extensive literature review on communicating cancer risk information. The authors found cancer patients want clinicians to respect their preferences for decision-making (Vogel, Yeomans, & Higginbotham, 1993) and crave ample amounts of information in order to make informed decisions (Kelly, 1992). Therefore, an effective approach to decision-making is a mutual-participation model where the patient and provider participate equally when making decisions regarding cancer risk (Kenen & Smith, 1994).

Seeking Clinicians as an Emotional Support

A third uncertainty management strategy is seeking clinicians as an emotional support. Because previvors often express negative emotions such as worry, anxiety, and fear, they state when their clinicians acknowledge and validate their emotions, are empathetic, and are concerned about their well-being, previvors are able to manage their uncertainties. Moreover, previvors are better able to cope with their uncertainties when physicians actively listen to previvors’ emotions and seek to understand their specific situations.

The connection between emotions, uncertainty, and cancer has long been supported. Previous research acknowledges the importance of addressing uncertainty’s emotional side (Bradac, 2001; McCormack et al., 2011). Dean and Street’s (2014) three stage model of patient-centered communication for addressing cancer patients’ emotional distress notes two affective strategies—acknowledgement and validation of

emotions and empathy—which are helpful in managing uncertainty. By acknowledging and validating emotions, clinicians can address patients’ emotional concerns, which may contribute to patients’ sense of feeling known by their clinicians (Anderson et al., 2008; Politi, Han, & Col, 2007; Street et al., 2009). Furthermore, being empathetic, respecting patients, and communicating support makes patients feel their clinicians understand their emotions and experiences (Arborelius & Österberg, 1995; Eide et al., 2011).

For example, one study examined uncertainty management and communication preferences for families coping with severe genetic diseases. Through survey methods, Parrott, Peters, and Traender (2012) learned patients and their families’ negative feelings about a genetic condition directly related to the uncertainty management as well as the desire to communicate about the condition. In other words, negative feelings were a mediating factor between illness uncertainty and uncertainty management. Hence, an effective way to manage uncertainty is to communicate about negative emotions.

Seeking Referrals from Clinicians for Emotional Support

The final strategy previvors engage in to manage uncertainty is seeking referrals from clinicians for emotional support. Sometimes receiving emotional support from clinicians is not enough to manage uncertainty and the associated negative emotions, and thus previvors seek out clinicians to provide referrals to social support and social networking groups as well as therapists, counselors, and/or psychologists.

This last uncertainty management strategy is also supported by prior research. Coping resources like counseling services and social support groups have been found to be effective in managing patients’ emotional states (McCormack et al., 2011; Mishel et

al., 2005). First, social support has been found to be a resource for alleviating uncertainty because it provides a solution to the problem at hand and can change the interpretation of the problem (Cohen, 2004; Michael et al., 2002). What is more, social support assists in reducing the unpredictability of the illness experience (Mishel, 1997). In short, being a part of a satisfying social support network is associated with better coping skills and less uncertainty (Mishel & Braden, 1987).

Second, sometimes a patient experiences psychological morbidity, which is beyond the clinician's ability to help, thus requiring the clinician to provide a referral to a therapist to help the previvor cope with her negative emotions (Dean & Street, 2014). To provide a referral, the clinician should express his or her willingness to help and support the patient, review next steps with the patient, invite questions, build a partnership, offer to delay any decision-making, and summarize important content (Brown et al., 2002). Following such communicative steps is essential because many individuals coping with cancer are not referred to counseling services when needed the most (Hardman, Maguire, & Crowther, 1989; Keller et al., 2004; Maguire, Tait, & Brooke, 1980). Overall, the present study demonstrates when addressing previvors' uncertainties, "health care professionals and supportive others cannot apply a one-size-fits-all solution when aiding in uncertainty management (Brashers et al., 2003, p. 194).

Uncertainty Theories

Uncertainty in Illness Theory

The findings of this dissertation have implications for three theories related to health and illness uncertainty. First, Mishel's (1988, 1990) theory of uncertainty in

illness helps explain this dissertation's findings. This theory argues patients facing long-term health illnesses must learn how to manage chronic uncertainty. According to the theory, a previvor is uncertain when she cannot form cognitive representations of her high cancer risk. This lack of cognitive capacity is caused by previvors' uncertainty sources such as lack of information about the unknown future, lack of awareness about cancer risk, lack of experience with possible cancer scares, and a lack of understanding in how to manage the uncertainties (Mishel, 1988; Mishel & Braden, 1988).

In other words, previvors experience chronic uncertainty about developing breast and ovarian cancer because there is always a threat. As the findings indicate, a previvor might undergo BRCA genetic testing to reduce her uncertainty about whether or not she has a high cancer risk, but if she tests positive for the BRCA1/2 gene, new uncertainties arise. She now must deal with uncertainties like visiting clinicians every six months, waiting for test results at least twice a year, reliving loved ones' traumatic battles with cancer, and/or worrying about whether she will be around to watch her children grow up.

Further, in Mishel's terms, previvors tend to appraise uncertainty as a threat and thus often adopt uncertainty reduction strategies. To reduce uncertainty, structure providers like educational level, social support, and credible authority can be employed (Mishel, 1988); however, social support and credible authority are most relevant for previvors' experiences.

First, the uncertainty management strategy of seeking referrals from clinicians for emotional support is supported by this theory as a support network helps prevent life crises by providing information on what illness events mean. More specifically, social

support opens opportunities for communication between individuals with similar experiences as well as reveals how such individuals handle threatening illness events (Mishel, 1988). Thus, the ability to communicate about one's high cancer risk through open discussion in supportive networks aid previvors in forming cognitive schema about illnesses (Wortman, 1984).

Also, the uncertainty management strategy of seeking clinicians as an informational source reflects Mishel's (1988) credible authority component. Credible authority refers to previvors' trust and confidence in their clinicians. Having and interacting with credible clinicians strengthens stimuli frame by providing information about physical symptoms to look for, environmental situations to be aware of, and discrepancies between expectations and possible experiences and outcomes. Hence, credible authority is important because the clinician-patient relationship is a vital means to prevent uncertainty (Mishel & Braden, 1988; Mishel et al., 2005). In brief, Mishel's theory of uncertainty in illness assists in explaining why previvors see uncertainty as a threat and thus implement coping strategies.

Uncertainty Management Theory

Second, because previvors' uncertainty cannot always be reduced, this study has important implications for uncertainty management theory (Brashers, 2001).

Uncertainty management theory is "a theory of the process of communication and uncertainty *management* in which the desire to reduce uncertainty is assumed to be only one of several possible responses to events and circumstances marked by

unpredictability, ambiguity, or insufficient information” (Brashers et al., 2000, p. 64, emphasis in original).

For one, the findings reveal previvors’ uncertainty sources are intrinsically connected, and when attempting to manage such sources through particular strategies, sometimes the uncertainties can be reduced, while others may be heightened. For example, previvors’ medical uncertainty sources (e.g., the unknown future, peaks and valleys, and personal cancer scares) are related to each other. Leading up to a medical consultation, a previvor begins to experience anxiety about what the clinician may find in her breasts or ovaries. Then during a mammogram or ultrasound, a clinician might find something suspicious, and she must wait for test results. Both of these sources of medical uncertainty only reinforce previvors’ fears about the unknown future. This connection supports uncertainty management theory’s key principle that uncertainty cannot always be eliminated and thus must be managed (Brashers et al., 2001).

Along this line, the findings support information seeking and information avoidance as types of uncertainty management strategies. According to Brashers et al. (2003), information seeking can assist in reducing uncertainty, while information avoidance helps evade distressing or overwhelming information. Information seeking has been found to be an important way to manage uncertainty (Pomerantz, 1988). Previvors heavily emphasized the importance of seeking clinicians as an informational source in order to manage their medical and familial uncertainties. By interacting with clinicians who are knowledgeable about BRCA, provide information, answer questions, check understanding, and provide additional resources, previvors’ uncertainties are

reduced and managed because information distinguishes options and fosters meaning (Brashers, 2001; Brashers et al., 2000).

It is important to note though that while the majority of previvors expressed seeking clinicians as an information source as a way to manage their uncertainties, a few participants did not. It might be argued previvors who did not choose preventative surgeries as a way to manage their high cancer risk and instead opted for increased surveillance are avoiding information and thus maintaining their uncertainties. More research needs to explore this possibility.

Finally, the findings of this dissertation also validate this theory's emphasis on social support as an uncertainty management strategy. Previvors' uncertainty management strategy of seeking referrals from clinicians for emotional support again stresses the importance of having a social support system. As stated previously, inadequately managed uncertainty produces harmful psychosocial effects (Neville, 1998), but social support improves individuals' psychological and physical health (Brashers, 2001). For previvors, supportive others assist in the uncertainty management process because they provide a relationship with someone who understands their experience, serves as an information source for coping and making health decisions, offers opportunities for venting, and validates each other's negative emotions and feelings (Brashers, 2001). In sum, Brasher's uncertainty management theory helps explain previvors' uncertainty sources and uncertainty management strategies.

Problematic Integration Theory

Third, the dissertation's findings speak to problematic integration theory (PI). PI theory seeks to address an individual's expectations, desires, and uncertainty management (Ford, Babrow, & Stohl, 1996). PI theory acknowledges individuals assess life based on probabilities through two ways—an individual's ideas regarding the likelihood an event or issue will happen during her lifetime (termed probabilistic orientations) and the individual's ideas about the goodness or badness or the desirability or undesirability of an event or issue (termed evaluative orientations; Babrow, 1995; Babrow, 2001; Sparks & Villagran, 2010).

PI theory helps explain previvors' experiences with uncertainty. According to the theory, uncertainty arises when previvors' judgments about the likelihood of the unwanted outcome (read: not developing cancer) and the desired outcome (read: health decisions preventing cancer) conflict (Babrow, 2001; Sparks & Villagran, 2010). For example, all previvors do not want cancer, but they are often uncertain about what preventative health decision to make (e.g., increased detection, chemoprevention, or prophylactic surgeries). This uncertainty may exist because, on one level, the previvor is overwhelmed with the information provided for each health option; while at the same time, she may be uncertain about whether the chosen option will reduce her cancer risk. Consequently, problematic integration occurs when the expectations previvors hold and the evaluations previvors think will occur are at odds.

PI theory also helps explain situations where probabilistic and evaluative orientations are in conflict, or problematic, and explicates previvors' uncertain

experiences. PI tries to shed light on what individuals “ought to believe and whether what they believe is good or bad” (Matthias & Babrow, 2007, p. 788). Moreover, probabilistic orientations are rooted in cognition, while evaluative orientations are rooted in emotions, and though these two orientations are interdependent, sometimes one orientation receives more attention (Babrow, 1995, 2001; Bradac, 2001).

Using Babrow’s terms, for many previvors, their probabilistic orientation tells them they will get cancer during their lifetime because of their high genetic risk, while their evaluative orientation tells them engaging in certain health decisions such as increased detection, chemoprevention, or preventative surgeries may reduce their risk. In other words, though previvors are aware of their cancer probability and all the possible health options, previvors’ medical and familial uncertainties and the intense desire to never get cancer profoundly influences their health decisions (read: undergoing preventative surgeries)—thus emphasizing evaluative orientations over probabilistic ones.

Lastly, a crucial component of PI theory is that communication is essential to problematic dilemmas because it serves as a “source, medium, and resource” (Babrow, 1995, p. 286), meaning PI is constructed, maintained, and altered through communication (Babrow, 1992, 2001, 2007). For instance, communication serves as a coping mechanism for individuals experiencing PI (Matthias & Babrow, 2007). Previvors engage in communication with their clinicians as a way to manage their uncertainty and make health decisions in clinical encounters. Whether they seek clinicians as an informational, decision-making, or emotional source, communication

between previvors and clinicians assists in addressing expectations and desires as well as the management of uncertainty (Ford, Babrow, & Stohl, 1996). Overall, communication enables a previvor “to reappraise the value she or he places on a particular event or object” (Matthias & Babrow, 2007, p. 789).

Practical Implications

In addition to theoretical implications, several practical implications can be derived from this study. Based on the findings of this dissertation, I now discuss important take-away points for managing chronic uncertainty and patient-clinician communication.

Managing Chronic Uncertainty

First and foremost, this dissertation’s findings stress the complex nature of managing chronic uncertainty. Uncertainty becomes chronic when an individual must constantly and consistently manage inconsistency, ambiguity, and unpredictability about health and illness over a long period of time (Brashers, 2001). Though previvors do experience uncertainty in clinical encounters, which leads them to make particular health decisions, sometimes, even after undergoing the most extreme and risk-reducing preventative surgeries, previvors are still uncertain. Said differently, a preventative surgery may be seen as the best way to reduce uncertainty, but there is always a small chance of developing cancer, and thus uncertainty must be managed continually. So it is simply not enough for clinicians to help previvors when they are determining to undergo genetic testing. It is not enough for clinicians to assist previvors after they make their

preventative health decision. It has to be a continued conversation. Clinicians need to help their previvors manage their uncertainty throughout their health journey.

Moreover, though this dissertation focused on managing uncertainty within the clinical encounter, previvors' uncertainty sources in clinical encounters may reveal a need to explore and manage uncertainties outside medical consultations. One way to help previvors manage their chronic uncertainty is by teaching previvors self-management skills for when they leave clinical consultations (Epstein & Street, 2007). For instance, clinicians can teach previvors how to create action plans and lay out contingencies if cancer is discovered at some point. Additionally, clinicians should discuss the benefits of journaling, meditation, positive thinking, and calming self-talk as well as teach such skills to help manage uncertainty (Mishel et al., 2005; Fatter & Hayes, 2013; Ullrich & Lutgendorf, 2002; Utley & Garza, 2011; Wagner et al., 2001). That way, when previvors leave the clinical encounter, the uncertainty “does not swallow [them] whole like a black hole.”

Recommendations for Clinician-patient Communication

Given the above point about chronic uncertainty, the dissertation also necessitates vital recommendations for patient-clinician communication. When asked about recommendations for improving communication between patients and clinicians, previvors advocated for the following five recommendations: (1) be knowledgeable about BRCA; (2) provide more information; (3) encourage previvors to be active patients; (4) use patient advocates; and (5) stress being a part of social support system.

First, paralleling the uncertainty management strategy of seeking clinicians as an informational source, previvors need clinicians who are knowledgeable about BRCA related issues. Previvors state genetic counselors, gynecologists, breast surgeons, plastic surgeons, and oncologists need to be experts in BRCA. In fact, previvors' medical and familial uncertainties are often increased when their clinicians do not know what they are talking about and thus previvors cannot trust their clinicians to provide accurate and up-to-date information about risk and prevention. Though it is a good start if clinicians are familiar with cancer patients and survivors, previvors' experiences are different and need to be respected.

Second, related to the same uncertainty management strategy, previvors emphasized the desire to receive more information from their clinicians. Previvors view information as empowering. Information and statistics about cancer risk, details about available health options for preventing cancer, and side effects, risks, and benefits for the different health decisions help previvors manage their uncertainties and feel in control of their lives. Also, information on social support groups is important because previvors feel like their clinicians care about their well-being.

Third, because clinicians are often not knowledgeable about BRCA or do not provide enough information, previvors need to actively participate in their own care. Previvors suggest clinicians should encourage and support patient participation. Actively participating means being knowledgeable, understanding one's body, doing research, asking good questions, and being honest and direct with clinicians about

preferences. Because in the end, as a Maria (30-year old, Caucasian BRCA2) stated, “You are your own best advocate.”

Fourth, previvors promoted the use of patient advocates in the BRCA medical community. According to the National Patient Safety Foundation, a patient advocate is “a supporter, believer, sponsor, promoter, campaigner, backer, or spokesperson” who acts on the patient’s behalf (p. 1). Patient advocates would be helpful because previvors are not cancer patients or survivors, and so clinicians often do not know how to treat previvors. Hence, a BRCA patient advocate could focus on educating previvors on self-management as well as determining what care is needed based on their preferences.

Finally, mirroring the uncertainty management strategy of seeking clinicians for emotional support referrals, previvors stress the importance of being a part of social support system. Whether such support comes from previvors’ families, friends, or online communities, having a support system is essential for attempting to manage chronic uncertainty (McCormack et al., 2011). So in clinical encounters, clinicians should check and make sure previvors have a network, and if they do not, then clinicians should provide a list of former previvor patients who are willing to talk about their experiences. This way no previvors ever feels alone in the journey through hereditary cancer.

In sum, clinicians need to engage in patient-centered communication in order to help previvors manage their health journey. Clinicians must engage in effective information exchange, foster healing relationships, respond appropriately and effectively to emotions, assist in making quality decisions, enable patient self-management, and

manage uncertainty (Epstein & Street, 2007). Doing so will assist previvors in managing their medical and familial uncertainties and make the best health decisions for their lives.

Conclusions

Limitations

There are two main limitations of the present study. The first limitation is the sample. The study's population was not very diverse. The lack of diversity was partly due to sampling. Because I wanted to interview female previvors who strongly identified as a previvor (or a BRCA+ individual), I targeted particular groups. Furthermore, because I used online methods (e.g., social media pages) to recruit my participants, it is likely I am missing parts of the previvor population. For example, the digital divide might play into the lack of diverse participants, yet at the same time, more individuals now have access to the Internet (Hong, 2008) and are using the Internet for social support (Wald, Dube, & Anthony, 2007).

Additionally, the majority of the participants were Caucasian and between the ages of 30 and 40 years old. However, these demographics might also be explained by cancer recommendations. For example, it is recommended previvors consider removing their ovaries and uterus between ages 35 and 40 as well as to consider undergoing a preventative double mastectomy around age 35 (Friedman, Sutphen, & Steligo, 2012). Thus, it is possible such demographic factors skewed the decisions the previvors made and shared.

Second, the findings are limited to previvors' uncertainty experiences. Because managing uncertainty is a communicative process especially within clinical encounters (Epstein & Street, 2007), clinicians' perspectives of previvors' sources and strategies for managing uncertainty are missing. Therefore, future research should explore how clinicians, who interact with previvors, help manage previvors' uncertainties. Exploring such perspectives will hopefully shed light on how clinicians can further assist previvors in managing their uncertainties.

Future Research

Although the present study's findings speak to uncertainty in cancer care, additional exploration is warranted. Generally, future research should test how clinician-patient communication about uncertainty sources and uncertainty management strategies impact health outcomes. Hypotheses could test how the patient-centered communication function managing uncertainty leads to intermediate and long-term health outcomes (Epstein & Street, 2007; Street et al., 2009). By testing proposed pathway models based on qualitative research like the current dissertation, scholars can further understand how communication impacts health outcomes. Also, because previvors experience chronic uncertainty, previvor-focused uncertainty management interventions should also be developed and tested. Finally, clinicians especially gynecologists, oncologists, and breast and plastic surgeons, need to be trained to frame and provide information to previvors in ways that manage anxiety and achieve understanding; clinicians also need to learn how to offer quality emotional support and know how to provide a referral to appropriate specialists.

Summary

This dissertation explores sources of uncertainty and strategies for uncertainty management in cancer care yet extends such understandings to a new population—previvors. Data were collected through semi-structured interviews. Previvors’ sources of uncertainty, uncertainty management strategies, and health decisions are identified in the interview transcriptions. Analysis revealed medical and familial uncertainty, four uncertainty management strategies—seeking clinicians as an informational source, seeking clinicians as a partner for decision-making, seeking clinicians as an emotional support, and seeking referrals from clinicians for emotional support—and found previvors’ uncertainty sources and uncertainty management strategies impact their preventative health decisions.

Overall, the purpose of this research is to gain insight into previvors’ uncertain health experiences in order to improve patient-centered communication between previvors and clinicians and ultimately previvors’ health and well-being. This research contributes to the literature by extending the exploration of uncertainty management to a new population, reinforcing the belief that chronic uncertainty should be managed not reduced, supporting health and illness uncertainty theories, and providing practical recommendations for clinician-patient communication.

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APPENDIX A

INTERVIEW GUIDE

Demographic Questions

1. Do you identify as male or female?
2. What is your age?
3. What race/ethnicity do you identify as?
4. Have you tested positive for either BRCA1 or BRCA2 gene mutation?
5. How long have you know your genetic test results?

Interview Questions

1. Opening Question: How do you feel about your family's cancer history? What emotions do you experience?
2. What do you believe your risk or likelihood is for developing breast or ovarian cancer in your lifetime?
3. How did you learn about your high genetic risk? Where do you get your information about the BRCA mutation and its associated health risks?
4. What causes you to be uncertain or anxious about your future risk for breast or ovarian cancer?
5. How do you cope with the possibility of developing cancer in the future? Can you give me a specific example of how you use that strategy to cope?
6. What is the clinician's role in helping you manage your uncertainty (and anxiety) about the possibility of developing cancer in the future and ultimately make health decisions?
7. Do your encounters with clinicians increase or decrease your uncertainty (or anxiety) about your future risk? How so? Can you give me an example of when your uncertainty was increased or decreased after talking to a clinician about your genetic risk?
8. *Tell me what it means to you to be a "previvor." (Only ask this question once the interview participant mentions this term).
9. Closing Question: Is there anything else you would like to tell me? Perhaps something I did not address that you think is really important given our conversation and your experiences?

APPENDIX'D

LIST OF PARTICIPANTS' DEMOGRAPHICS

Name	Race/Ethnicity	Age	BRCA Gene	Health Decision
Savannah	Caucasian	31	BRCA1	Preventative mastectomy, oophorectomy, and hysterectomy
Mary	Caucasian	30	BRCA2	Preventative mastectomy
Elizabeth	Caucasian	32	BRCA1	Increased surveillance and then preventative mastectomy
Carly	Caucasian and Ashkenazi Jewish	31	BRCA1	Increased surveillance and then prophylactic mastectomy
Jenelle	Caucasian and Ashkenazi Jewish	41	BRCA1	Preventative oophorectomy and plans on getting mastectomy
Madison	Caucasian	32	BRCA1	Preventative mastectomy
Janet	Caucasian	51	BRCA1	Increased surveillance and then prophylactic mastectomy
Jacklynn	Caucasian and Colombian	34	BRCA1	Preventative mastectomy and oophorectomy
Madeline	Caucasian	38	BRCA2	Preventative mastectomy
Kelly	Caucasian	44	BRCA1	Preventative oophorectomy but scheduled mastectomy
Sarah	Ashkenazi Jewish	56	BRCA1	Preventative oophorectomy and mastectomy
Jamie	Caucasian	27	BRCA2	Increased surveillance and then prophylactic mastectomy
Camille	Caucasian and Ashkenazi Jewish	47	BRCA2	Increased surveillance and then prophylactic mastectomy
Nancy	Caucasian	40	BRCA2	Preventative oophorectomy and hysterectomy and then preventative mastectomy
Lacy	Caucasian	51	BRCA2	Preventative oophorectomy and hysterectomy, chemoprevention, and increased surveillance
Tara	Caucasian	28	BRCA2	Preventative mastectomy
Anna	Caucasian and Ashkenazi Jewish	44	BRCA1	Preventative mastectomy and hysterectomy
Sue	Caucasian	60	BRCA1	Preventative mastectomy and then hysterectomy

Jennifer	Caucasian	30	BRCA2	Preventative mastectomy
Jasmine	Caucasian	32	BRCA2	Increased surveillance
Samantha	Caucasian	35	BRCA2	Preventative mastectomy and then oophorectomy
Rebecca	Caucasian	44	BRCA2	Preventative mastectomy and then oophorectomy
Theresa	Caucasian	34	BRCA2	Increased surveillance and planning mastectomy soon
Maria	Caucasian	30	BRCA2	Increased surveillance and then preventative mastectomy
Bailey	Caucasian	33	BRCA1	Increased surveillance and then preventative mastectomy
Veronica	Caucasian	38	BRCA2	Preventative mastectomy
Shauna	Caucasian	67	BRCA2	Preventative mastectomy and then hysterectomy
Skylar	Caucasian and Hispanic	30	BRCA1	Preventative mastectomy
Sophia	Chinese	33	BRCA2	Preventative mastectomy
Caitlyn	Caucasian	37	BRCA2	Preventative hysterectomy and considering mastectomy
Addison	Caucasian	33	BRCA1	Preventative mastectomy
Tiffany	Caucasian	38	BRCA1	Preventative mastectomy and then oophorectomy
Alexa	Caucasian	38	BRCA1	Increased surveillance
Gabriella	Caucasian	39	BRCA1	Preventative mastectomy and considering oophorectomy

APPENDIX'E

LIST OF TECHNICAL TERMS

- Preventative mastectomy = The surgical removal of one's breasts in order to prevent breast cancer.
- Preventative oophorectomy = The surgical removal of one's ovaries in order to prevent ovarian cancer.
- Preventative hysterectomy = The surgical removal of one's uterus in order to prevent ovarian cancer.