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The Narratives of Young Women with BRCA 1/2 Gene Mutation: A Qualitative Analysis

A Dissertation

Submitted to the Graduate Faculty of the
University of New Orleans
in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy
in
Counselor Education

by

Drew David Reilly

B.S. Vanderbilt University, 2008
M.Ed. Vanderbilt University, 2010

December 2014

Copyright page

Dedication

I would like to dedicate this dissertation to the strong and brave women that shared their stories with me. Their openness and vulnerability was inspiring. I feel honored to be the vehicle to share their powerful and moving narratives. To my four previvors, thank you.

Acknowledgement

I would like to acknowledge my dissertation committee, Dr. Barbara Herlihy (Chair), Dr. Ann Ohanlon (methodologist) and Dr. Zarus Watson. Dr. Herlihy, honestly, you were the driving force that helped me begin, muddle through, and, eventually, complete this dissertation. Thank you for your unwavering support, thoughtful feedback, and encouragement. You have served as an inspiration, both professionally and personally, throughout my doctoral journey. Dr. Ohanlon, thank you for your support where qualitative research was concerned. I am grateful for your vested interest in my topic and dissertation. Dr. Watson, thank you for being the lone brave man on my committee in a study about women and feminist voice. I always appreciate your perspective and guidance.

To my family: Ross Reilly, Suzanne David, Clint David, Elliott David, Barton David, Chuck Reilly, and the little Reilly yet to be born. Ross, thank you for reminding me why I wanted to get my doctorate when I questioned myself several times throughout this whole process. Your support and love helped me continue to sit at our kitchen table and type away at this dissertation. Thank you for your support in my own BRCA struggle. I love you. Mom, we share this BRCA “thing” and I know you get it. Watching you go through your surgeries and observing your story through my own lens has pushed me to complete this dissertation. Your strength blows me away and I truly believe that your narrative is the inspiration for all of this. Dad, thank you for being my biggest cheerleader. You always tell me how proud you are of me and it really means the world. Chuck, my puppy angel, thank you for sitting on my lap all those hours that I worked away. You heard me reading aloud, cursing under my breath, and rejoicing when I finished a chapter. I really think you are well versed in Feminist Theory and the smartest

Multipoo to ever walk this earth. To the little Reilly that is not yet here: thank you for being my biggest motivator. Your impending arrival has forced me to set a deadline to defend my dissertation. I loved feeling your little kicks throughout this process and it felt like you were cheering mommy on! I cannot wait to meet you (after I finish my defense, of course!)

To all of my BRCA ladies out there: you are all so strong and powerful. Thank you for serving as the basis for this study. I am honored to call myself a previvor and be in the company of such resilient and tough women.

While I know I have only mentioned a few people, there are so many others that deserve acknowledgement for their support. You all know who you are and thank you. This has been a crazy ride, one I am glad to have taken, but also, one that I am glad to get off. On to the next chapter!

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Abstract

A narrative qualitative research design was used to understand the stories of young women diagnosed with BRCA1 and BRCA 2 genetic mutation. Four participants were selected who met the following criteria: (a) the participant is diagnosed with BRCA1 or BRCA2 genetic mutation, b) is within the age range of 18 to 35, (c) is without a cancer diagnosis, and is (d) not currently pregnant and does not have children. The four participants were interviewed through open-ended inquiry. The participants' narratives proved both similar and dissimilar. The themes were organized into within-case narratives and across-case narratives. The narratives revealed that young BRCA previvors face unique challenges and experiences, and many can be viewed from an underlying feminist lens. In response to the research questions, BRCA previvors revealed detailed narratives, explored issues of family planning, and explained the ways in which BRCA has changed their worldviews.

Keywords: BRCA1 and BRCA2, feminist, family planning, narratives, previvors

CHAPTER ONE

INTRODUCTION

In this chapter, an overview of the proposed study is presented. The breast cancer and ovarian cancer gene (BRCA 1/2 mutation) are explained, and narratives with BRCA previvors are discussed. The purpose and significance of the study are discussed, the conceptual framework is presented, and the researcher's personal experience is discussed. This chapter also contains an overview of the method, grand tour research questions, limitations and delimitations, assumptions of the study, and definitions of terms.

Background

Genetically inheriting a BRCA1 or BRCA2 deleterious gene mutation substantially increases a woman's lifetime risk of developing hereditary breast and ovarian cancer (HBOC). Women identified with the BRCA1/2 gene mutation have a risk of 50-85% for developing breast cancer and a risk of 15-60% for developing ovarian cancer in their lifetimes (Oostrom et al., 2007). The lifetime risks for both breast and ovarian cancer for *BRCA1/2* positive women far exceed the general population risk of 13% for breast cancer and 1.4% for ovarian cancer (Vadarparampil, Miree, & Wilson, 2007).

Women with BRCA are at risk for developing HBOC at a younger age than women in the general population. By the age of 50, 50% of women with BRCA will develop breast cancer; only 2% within the general non-BRCA population will develop breast cancer. By the age of 70, an estimated 87% of mutation carriers will develop breast cancer and 44% will develop ovarian cancer; the percentages for the general population are 7% and 2%, respectively (Easton, Bishop & Ford, 1995). BRCA 1 and BRCA 2 are passed through a pattern of autosomal dominant inheritance, meaning that each child of a BRCA1/2 parent has 50% chance of inheriting the

mutation. Therefore, this is a generational predisposition passed down, often several times, affecting many families for generations.

Women who learn that they are BRCA mutation carriers are offered risk management options, which consist of surveillance (e.g., regular mammograms and MRI mammograms, CA-125 blood test, and trans-vaginal ultrasound), chemoprevention (e.g., oral contraceptives or other risk-reducing and hormone-altering drugs), or risk-reducing surgery (e.g., risk-reducing bilateral mastectomy and oophorectomy) (Hoskins & Greene, 2012). The least invasive of the three options is increased surveillance, according to current standards of care. This can include the use of mammograms, MRI mammograms, breast self-exams, breast exams by doctors, pelvic and transvaginal exams, and blood tests. Although increased surveillance is the least invasive option, the repetitive and continual testing can take a physical, emotional, and spiritual toll on BRCA women. Chemoprevention may include medications like Tamoxifen that are used as preventative measures to reduce the risks of breast and ovarian cancer. The most permanent option is risk-reducing surgery, in which breast tissue and/or ovaries are removed in the absence of a cancer diagnosis. Often these measures are combined throughout the lives of BRCA previvors to protect against breast and ovarian cancer. No option provides complete protection against cancer, however.

Although the preventative measures greatly reduce risk, up to 95% in the case of the prophylactic mastectomy, the effects on a woman's spirit and physical appearance are life altering. Many women become tired of the constant surveillance and feel overwhelmed by continuous anxiety, and resort to more permanent options for risk reduction. The chemoprevention medication, Tamoxifen, has many effects on the body; most significantly, it prevents women from reproducing and causes early menopause. As women are being diagnosed

at a younger age, many women who have received the diagnosis do not yet have children and many are also unpartnered. Risk reducing bilateral oophorectomy (i.e. preventative removal of both ovaries and fallopian tubes) impacts self-esteem, family planning, and estrogen levels, all of which can affect sexual aspects of a woman's life. Some previvors may feel that they have to choose between their physical health and their dreams for life that might include a partnership with another person, pregnancy, or a child.

BRCA 1/2 females have owned the title "previvor," which denotes that they are pre-survivors of cancer, but that they are also survivors of surveillance, chemoprevention, and prophylactic surgeries. Although the term "previvor" is widely used among those in the BRCA community to refer to peers, it is not as present in the literature. BRCA previvors survive the many struggles and hardships that come along with a BRCA diagnosis. When choosing among the risk reducing options, women may seek guidance and support from mental health professionals. If mental health professionals are to provide effective services, they need education regarding what it means to be a BRCA previvor, and a greater understanding of how to empower and support women diagnosed with the BRCA gene mutation.

Purpose of the Study

The purpose of this study was to honor the voices of women with BRCA1 and BRCA2 gene mutation through a qualitative narrative study and to provide useful information to mental health and medical professionals working with BRCA previvors. The preponderance of existing research focuses on medical data, rather than on the emotional and psychological effects that accompany a lifetime BRCA diagnosis. BRCA women must make difficult choices regarding their physical and emotional health, family planning, and course of treatment. Medical

professionals and mental health professionals need to understand what women experience when trying to make these life-altering choices.

Trends in informed consent in medical practice and the philosophy that underlies counseling both support the stance that previvors have the right to make their own choices about risk management options, to information about their diagnosis and support systems, and to make choices about family planning. When assessing formal and informal support needs of BRCA previvors, Werner-Lin (2009) discovered that genetic counselors and physicians often did not provide long-term emotional support following a diagnosis. Further, other support networks were not offered. One participant in Werner-Lin's (2009) study stated, "I had asked my genetic counselor to give me the names of some young women who had gone through this and he couldn't seem to come up with any. There was no support group, there was nothing. I wanted to talk to somebody who had gone through it, but they couldn't seem to find me anybody" (p.123). Werner-Lin (2009) found that, although previvors were often offered short-term support, they were not given adequate resources to learn how to adapt to their diagnosis in the long term. It is my hope that results of this study may serve as a resource for medical and mental health professionals who work with BRCA previvors. Further, I hope this research study will serve as a referral source for BRCA previvors and help BRCA women share their own narratives.

Significance

BRCA previvors could find a sense of control and empowerment over their choices, bodies, and meaning making around their BRCA diagnosis through advocacy on the part of medical support personnel, mental health professionals, and fellow BRCA previvors and those touched by BRCA. Harley (2009) described empowerment as "a process in which individuals take an active and meaningful approach to making decisions that affect their lives" (p. 127). The

empowerment process begins with those who are marginalized becoming aware through power analysis of the power dynamics at play. Within the therapeutic process, individuals can develop the skills to gain control over their lives and to advocate for others on a greater scale.

BRCA previvors face many challenges in trying to advocate for themselves and the BRCA community. BRCA previvors are working against a patriarchal society and a society in which medical professionals are in control of presenting the information previvors need to make decisions about their family planning, treatment, surgeries, and options for risk management. In many cases, genetic counselors and physicians are not offering resources for emotional support (Werner-Lin, 2009). Werner-Lin (2009) found that “what health care professionals provided was contained to the time immediately surrounding testing, and no other support services were integrated into counseling to facilitate long-term adaptation” (p. 123). BRCA previvors struggle to advocate for their rights to resources and proper support following a diagnosis. Previvors often are left to find their own resources in a time of complete distress after learning of a positive BRCA diagnosis.

BRCA previvors may work against those in the medical community and even those in their immediate environment, as they struggle to make choices about family planning based on personal preference rather than make a decision based solely on their genetic predisposition. BRCA women, armed with new and informative research, may be able to educate and shape the future treatment of BRCA previvors.

Role of the Researcher

The conceptual framework for my study was born out of my personal experiences with BRCA; therefore, it is important to discuss my personal journey with BRCA and my connectedness to this topic. Two years ago, I was diagnosed with the BRCA 1 genetic mutation.

A diagnosis, by itself, would not have led me to explore this topic further; however, my experiences in diagnosis and subsequent surveillance triggered me to look further into the existing research. It was after my exploration into the literature, prompted by my own personal story, that I discovered that there were gaps in the literature and came to believe that I could add meaningful data. I further present my researcher positionality statement in chapter 3.

Building on my research of the literature, I completed a small-scale project for my qualitative research class. As part of the project, I completed an observation exercise, a focus group, and individual interviews with my population of interest. I used the research questions and interview style that I intended to propose for my dissertation and found participants through the F.O.R.C.E network. After coding and restorying the data, I felt encouraged to continue in completing my dissertation. I was mindful of these preliminary interviews as I conducted my study, although I knew that different women would yield different narratives and themes. Many of the women in my pilot study revealed that they felt judged for getting the prophylactic surgeries “too young” or without a cancer diagnosis, yet there was also judgment if they got cancer and were aware of their genetic status. Women expressed feeling that they could not win in the eyes of society with either choice. They struggled to advocate for choices that are best for themselves as individuals, without judgment from society. Several women also felt pressure from the medical community to have children soon after a diagnosis. Many of these women were unpartnered and expressed that they were not ready for a family. These interviews suggested that many women are forced to advocate for their right to choose when they are ready to begin a family, even with a BRCA diagnosis.

Conceptual Framework

The conceptual framework for this study is feminist theory. Feminist therapy, born out of the feminist movement in the 1960s, reflects the voices of women who expressed concern regarding their unfair treatment in a patriarchal social system (Herlihy & McCollum, 2011). Feminists have asserted that established theories of development and human nature created by Western males cannot be generalized to the diverse population of both men and women (Herlihy & McCollum, 2011). Since the emergence of the feminist perspective, feminist therapy has evolved into a postmodern theory that analyzes social constructs, gender, and power to understand human struggles (Brown, 2010). Feminist theory honors the voices and lived experiences of individuals who have been relegated to the margins and who have been given the term “other” by those in power (Brown, 2010). BRCA-positive women have been defined as an “other” based on the gendered nature of the gene mutation. Additionally, carriers of the BRCA1 or BRCA 2 gene account for less than 1% of the population, making them a minority and, in many cases, a novelty in the medical community (Kluger et al., 2013). BRCA women may feel powerless, especially when it comes to choices about their own bodies. However, when a shift in perspective is made towards feminist ideals, BRCA women may become empowered and take charge of their bodies and choices.

Reflective and empathic mental health professionals work to understand the many layers and identities that make up the client’s whole self. BRCA positive women have been defined as “other” and marginalized based on a number of factors that extend beyond their BRCA diagnosis. Many of the women who have been diagnosed recently are young in age, leading some to believe that are not yet developmentally capable of making sound choices about their own bodies (Werner-Lin, Hoskins, Doyle & Greene, 2012). As this is a gendered issue, women must fight for rights and equality while living in a patriarchal society (Brown, 2010). Multiple

aspects of identity may play a role in the oppression of women diagnosed with BRCA. While gender and BRCA diagnoses are the constant sources of what may make previvors feel disenfranchised, a number of other factors like age, religion, ethnicity, and sexual orientation add complex layers and dimensions to their feelings of isolation and disempowerment. The literature shows that BRCA women have experienced layers of oppression that extend beyond their BRCA diagnosis. BRCA previvors may also be oppressed because of their age, religion, sexual orientation, and gender (Evans, Kincaid & Seem, 2011; Strueiwing et al., 1997; Werner-Lin, Hoskins, Doyle & Greene, 2012).

The feminist framework reflects the goal of this narrative study, which is to empower disenfranchised women and, hopefully, contribute to social change. As I analyzed the data through feminist lens, I anticipated that themes of oppression and gender would emerge, due to the gendered nature of the BRCA mutation. A feminist perspective, with support from the literature and from my anecdotal experience, is an appropriate framework to support the themes of this dissertation and facilitate the overall goals of the study.

Overview of Method

A qualitative approach was used to conduct this study, specifically a narrative method. A narrative approach is best when “capturing the detailed stories and lived experiences of a single life or the lives of a small number of individuals” (Creswell, 2007, p. 55). Data are gathered through collecting participants’ stories, reporting individual experiences, and then chronologically ordering or “restorying” the stories to make meaning of the experiences (Creswell, 2007).

A narrative study was best to capture the stories of previvors with the BRCA gene, especially at a young age. I conducted extensive interviews with four women who are BRCA

previvors and who were involved in active surveillance, chemoprevention, or had received prophylactic surgeries. I was interested in young BRCA previvors, aged 18 to 35 years old, who have not yet received a cancer diagnosis, who do not have children or are not currently pregnant, and may have varied marital statuses. I conducted in-depth interviews to get an understanding of each BRCA previvor's story. I asked questions with the intent of expanding on current literature regarding this young population with respect to family planning, beating the biological BRCA clock, disclosing diagnoses to partners and family, anticipatory loss, and decision-making about risk management (Hoskins et al., 2008; Hoskins & Greene, 2012; Werner-Lin, 2008; Werner-Lin, 2009). However, I asked broad and general research questions, as to not lead the participants, and different and additional issues emerged. Through a narrative lens, I delved beneath the surface to capture a true picture of the experience of everyday living with BRCA1/2 gene mutation.

A narrative study provided a narrowly focused and in-depth look at the intricate experiences of BRCA. There were common themes and threads amongst the women, but it was their individual stories that were unique and meaningful. I believe that this research study gave voice to four women with BRCA and that their stories inform professionals working with BRCA previvors and, hopefully, will encourage advocacy for previvors on a greater scale.

Research Questions

Three primary research questions guided this study:

1. What are the narratives of women ages 18 to 35 whom have been diagnosed with BRCA 1/2 genetic mutation?
2. How do issues of family planning present themselves in BRCA previvors' narratives?
3. How (if) has their knowledge of BRCA changed their worldview or life course/plan?

Limitations and Delimitations

The delimitations of the study were the narrow age range of the participants (18-35), their parental status (no children), and the number of women I interviewed.

The aim of this study was to explore the narratives of women with BRCA gene mutation. Because my population is a sub-set within the BRCA population, a limitation is that the results may not be a true representation of the entire BRCA community and their struggles. Further, as I interviewed only four women, the study may not be generalizable to the BRCA population; rather, it served as a platform for a small number of women to share their specific narratives. All of these factors may have affected the generalizability of the data. However, generalizability is not the goal of qualitative research (Creswell, 2007).

Another possible limitation of the study was related to my close tie with the research topic. I worked to bracket my own experiences through peer debriefing, member checking, and journaling. While my personal experience served as a strength throughout the interview process and study, it also opened up potential pitfalls.

Assumptions of the Study

As I am a BRCA previvor and this study was born out of my own experiences, I hold certain assumptions. First, I assumed that feminist themes would emerge from the data. More specifically, I assumed that themes surrounding gender, oppression, family planning, and stories of empowerment would emerge from the data. I realized that not all of these themes would emerge and that additional, unforeseen themes might arise. I tried to make my questions as general as possible, as to not lead my participants in this direction. Second, I assumed that my

participants would be honest in relaying their BRCA narratives. Lastly, I assumed that a feminist conceptual framework was an appropriate perspective for this study.

Definition of Terms

BRCA Mutation: Mutations of either the BRCA1 or BRCA 2 gene. BRCA1 and BRCA2 are considered tumor suppressor genes, and therefore a mutation in the BRCA1 or BRCA2 gene lessens the gene's ability to suppress tumors. BRCA1 and BRCA2 are human genes that produce tumor-suppressing proteins.

Chemoprevention Medication: Chemoprevention is an option offered to BRCA positive women when discussing choices for risk prevention. Medications like Tamoxifen may be taken to help prevent breast and ovarian cancer.

Empowerment: Empowerment involves challenging the forms of oppression, which compel millions of people to play a part in their society on terms that are inequitable, or in ways that deny their human rights (Oxfam, 1995).

Family Planning: The decisions women make about partnership, having children, and general life planning that involves relationships and potential parenthood.

Feminist Theory: The framework that will underlie this study, including exploration of gender analysis, power analysis, oppression, empowerment, honoring women's voices, and enacting greater social change.

Hereditary Breast and Ovarian Cancer (HBOC): A term that is often used to describe BRCA previvors' situation, but that can also refer to non-BRCA women who are at a high risk for HBOC due to family history.

Previvor: A term that identifies BRCA women as pre-survivors of cancer. The term is also used to empower BRCA women in their journey of living with a BRCA diagnosis.

Prophylactic Surgery: A proactive choice that women make to remove breast tissue or ovaries in the absence of a cancer diagnosis.

Surveillance: A choice that BRCA women make to closely monitor their BRCA diagnosis through all or some of these treatments: mammogram, MRI mammogram, self-monitored breast exams, transvaginal ultrasound, and CA-125 blood tests.

CHAPTER TWO

LITERATURE REVIEW

In this chapter, research related to the BRCA1 and BRCA2 gene mutation and BRCA previvors is reviewed. A brief description of the BRCA gene is provided before exploring the larger context in which BRCA women exist. An explanation of feminist therapy and feminist theory is provided to set the foundation for understanding BRCA previvors and their experiences. An exploration of the key issues that BRCA women face and the layered oppression that BRCA women may experience is also presented. Finally, implications for counseling and support are explored.

BRCA 1/2 Gene Mutation

Genetically inheriting a BRCA1 or BRCA2 deleterious gene mutation substantially increases a woman's lifetime risk of developing hereditary breast and ovarian cancer. Women identified with the BRCA1/2 gene mutation have a risk of 50 to 85 % for developing breast cancer and a risk of 15 to 60% for developing ovarian cancer in a lifetime (Oostrom et al., 2007). The lifetime risks for both breast and ovarian cancer for *BRCA1/2* positive women far exceed the general population risk of 13 % for breast cancer and 1.4% for ovarian cancer (Vadarparampil, Miree, & Wilson, 2007). Women who learn that they are BRCA mutation carriers are offered limited risk management options (Hoskins & Greene, 2012). No option provides complete protection against cancer.

Research related to the BRCA gene is rapidly increasing, with new discoveries surfacing weekly. However, the majority of research is dedicated to medical discoveries rather than the exploration of the psychosocial effects of a BRCA diagnosis. Although the biomedical research on BRCA is helpful in understanding how to manage and better understand the genetic mutation,

it offers little understanding of what it means to live with this diagnosis. The language of this literature lacks sensitivity, often labeling BRCA as a “defect,” and the medical jargon is often difficult to understand without extensive medical training. In the following section, the larger context, or population of which BRCA previvors are members, is described.

Context of BRCA Diagnosis

Young BRCA previvors are a subset of a larger population of child-bearing-age women diagnosed with potentially life-altering diagnoses. Young women diagnosed with life altering diseases or genetic predispositions often have to think about family planning in a different light than their peers who have not received such diagnoses. Examples of the larger population of women of which BRCA women fit include young women diagnosed with multiple sclerosis, lupus, HIV/AIDS, and gendered forms of cancer.

Multiple Sclerosis (MS) is more prevalent in women of childbearing age than in any other group (National MS Society, 2013). Before 1950, most women with MS were told to avoid pregnancy because it was thought to exacerbate MS symptoms (National MS Society, 2013). Although more recent research no longer supports these earlier recommendations, healthcare systems often fail to provide women with information and support they need to make informed decisions about their health and pregnancy management (Anderson & Wallace, 2013). Anderson and Wallace (2013) interviewed women of childbearing age with MS and conducted a thematic analysis. Three themes emerged from the interviews. First, women were concerned both medically and practically about the idea of having children. Second, women stated that they had limited access to information about the relationships between MS and childbearing. Women recounted receiving conflicting and incorrect information from medical professionals. Lastly, opinions of medical professionals and family members regarding having children, in the context

of MS, affected women's decisions about family planning. Receiving a MS diagnosis at a young age affects women's decision making around family planning (Anderson & Wallace, 2013).

However, without proper resources and support, women may struggle to make informed decisions about childbearing in consideration of their diagnosis.

Systemic lupus erythematosus is a systemic autoimmune illness that affects women more frequently than men and little is known about living with lupus (Mendelson, 2006). Moreover, lupus is an autoimmune disease that predominantly affects young women of childbearing age (Mok & Wong, 2001). Issues that may arise during a pregnancy with lupus concerning flare-ups for the pregnant woman, risk of fetal loss, and the safety of various drugs to manage the disease (Mok & Wong, 2001). Thomas (1997) found that women with health concerns like lupus had difficulty getting their needs met with respect to receiving information about their diagnosis and childbearing. Further, women stated that they received inadequate help from health care professionals and mental health support. There is little research that explores the experiences of women with lupus and their reproductive journeys; however, both Thomas (1997) and Mendelson (2006) found that little support from the medical community exists for women with lupus who are of childbearing age.

Women diagnosed with HIV and AIDS may be concerned about childbearing because of the risk of HIV transmission to children and sexual partners (Sofolahan & Airhihenbuwa, 2012). Now, in the third decade of HIV and AIDS, women's choices surrounding childbearing and family planning have evolved. The ability of women who are HIV-positive to make childbearing decisions depends on the information available to them and their degree of independence and autonomy (Sofolahan & Airhihenbuwa, 2012). Sofolahan and Airhihenbuwa (2012) asserted that women's power in their own decision-making process surrounding family planning depends on

their resources and support. Without such resources and support, women with HIV and AIDS who wish to have biological children may feel powerless (Sofolahan & Airhihenbuwa, 2012).

Certain types of cancers that are unique to the female gender such as breast cancer, cervical cancer, and ovarian cancer, affect both BRCA and non-BRCA women alike. Breast cancer is the most dominant cancer in women and all women are at risk for breast cancer (Keitel & Kopala, 2000). Del Mastro et al. (2002) found that women with breast cancer report feeling distressed and anxious for as long as three years after the last treatment. Further, women with breast cancer may experience major depression, post-traumatic stress disorder, and generalized anxiety disorder (American Cancer Society, 2011). Dow (1994), in a qualitative study, found that women of childbearing age with breast cancer felt that conceiving after breast cancer would help them feel whole and well again. Dow (1994) found that being able to fulfill family planning desires was important in women's emotional recovery from breast cancer. Little literature seems to exist that explores the experiences of young women with breast cancer, ovarian cancer, or cervical cancer in the context of family planning.

Before the recent advances in mapping the human genome, BRCA women and non-BRCA women alike experienced female types of cancer. As technology has progressed, deleterious gene mutations have distinguished these populations. However, female survivors of cancer, women at risk of hereditary cancers, and women with BRCA all co-exist within the greater population of young, childbearing-age women with potentially life threatening illnesses. There seems to be a common thread in the literature regarding lack of support and resources for young women with life threatening illnesses and genetic predispositions, with respect to making choices about family planning. A BRCA diagnosis can be distinguished from the other diagnoses by a combination of several factors. First, a BRCA diagnosis is unique due to the startling

percentages, with respect to risk of developing a cancer diagnosis that accompanies a BRCA previvor title. These percentages of cancer risk do not increase with age, as they do in other forms of gendered cancer; rather, they act as a ticking time bomb that can explode at any moment. Second, the genetic component of this diagnosis makes it unique in that it creates a multigenerational issue, both medically and psychologically. The psychological effects of potentially passing on this gene create a unique dynamic among family members. Third, feelings of womanhood and womanly abilities are bound up with a BRCA diagnosis, in a way that might not be true compared to a multiple sclerosis or lupus diagnosis. These factors, when considered in combination, provide a rationale for studying BRCA women specifically, as their needs and experiences may be unique.

BRCA women's medical diagnoses force them to make difficult life choices. Many of these choices revolve around their identities as women. Therefore, the conceptual framework that undergirds this study, feminist theory, will be discussed next. Then, a review is presented of research with BRCA previvors that is not limited to a medical focus and has been conducted from a qualitative perspective. In the final sections of this chapter, the conceptual framework and the research literature are integrated in discussions of layered oppression and issues confronted by BRCA previvors.

Feminist Theory

As a self-identified feminist therapist, I see parallels between feminist themes and my BRCA experiences. After researching the literature, I believe that feminist constructs provide the best fit for my proposed qualitative research study. In the following sections, the origins of feminist theory and the basic tenets and goals of feminist therapy are reviewed and are related to BRCA previvors. My goal as a qualitative researcher is that the relationship between the

researcher and participants will mirror that of a feminist therapist and client. I assumed that feminist themes would emerge from the interview data and, therefore, a review of feminist therapy provides a conceptual framework for better understanding some of the issues that BRCA women may face.

Overview

Feminist theory, born out of the feminist movement in the 1960s, reflects the voices of women who expressed concern about their unfair treatment in a patriarchal social system (Herlihy & McCollum, 2011). Feminists recognize that established theories of development and human nature created by Western males cannot be generalized to the diverse population of both men and women (Herlihy & McCollum, 2011). Since the emergence of the feminist perspective, feminist therapy has evolved into a postmodern theory that analyzes social constructs, gender, and power when understanding human struggles (Brown, 2010). Feminist theory honors the voices and lived experiences of individuals who have been relegated to the margins, who have been given the term “other” by those in power (Brown, 2010). This phenomenon is relevant to my proposed study because BRCA positive women have been defined as an “other” based not only on the gendered nature of the gene mutation, but also based on the fact that carriers of BRCA1 or BRCA 2 gene account for less than 1% of the population, making them a minority and, in many cases, a novelty in the medical community (Kluger et al., 2013).

Basic Tenets

A belief inherent in feminist theory is that “the personal is political,” meaning that individual issues are reflective of a greater social disenfranchisement, oppression, and typecasting (Herlihy & McCollum, 2011). Feminist therapists make a commitment not only to help individual clients, but also to enact greater social change (Herlihy & McCollum, 2011).

Feminist counselors and clients create an egalitarian partnership to safely explore power dynamics and the client's oppressed role in a patriarchal society. The egalitarian relationship is the foundation of feminist therapy, as it models what an equal partnership may look like in the larger lives of clients. Further, within an egalitarian relationship clients may feel safer and more apt to share their true selves and unique perspectives.

In feminist theory, women's voices, experiences, and perspectives are valued and inform theory. The theory revolves around women's lived experiences and feminist counseling gives power to those experiences as sources of knowledge for future practice (Herlihy & McCollum, 2011). While gender may be a focus of feminist therapy, clients may also explore other aspects of their complex and marginalized identities.

The basic tenets of feminist theory would be an ideal match for a BRCA previvor client. The egalitarian partnership could allow BRCA women to safely explore their risk management options and family planning decisions in a way that empowers them to make choices that align with their own personal goals. As BRCA is a newer diagnosis, women's experiences, if documented, can inform best practice and facilitate changes in treatment for their medical and psychological/emotional health.

Goals

Feminist therapy differs from more traditional theories of counseling in that, although individual change is a primary goal of feminist theory, it is not the only goal. Social transformation is a crucial aspect of individual change as many of the client's problems are rooted in the oppressive world (Herlihy & McCollum, 2011). The counselor and client take on roles of advocate and activist to enact social change. Feminist therapists work to identify the intrapsychic symbols of the patriarchal system in consciousness and work to challenge those

symbols (Brown, 2010). In challenging socialized worldviews, clients may feel empowered as they create a feminist consciousness. One of the most important goals of feminist therapy is to help clients regain control throughout the therapeutic process (Brown, 2010). Through empowerment, clients learn how to define themselves, rather than allowing others to define them. Women are urged to trust themselves and their intuitive instincts. In helping women honor their inner voices, feminist therapists implore clients to set their own treatment goals and communicate their needs in an assertive manner.

A goal of feminist therapy is to create equality, not only within the therapeutic relationship, but also within the client's personal and professional life (Herlihy & McCollum, 2011). Within personal relationships, clients strive to find their own identity within each partnership or group. Throughout the therapeutic journey, it is important for clients to learn self-care. When clients begin to care for and nurture themselves, they may send a message to themselves that they are worthy of care and are valued.

Gender does not exist in a vacuum. Therefore, another goal of counseling is to recognize the many multicultural factors that encompass a whole individual. Treatment is holistic in that the counselor takes into account all the different parts of the client and how they intersect to make a whole self.

BRCA women may feel out of control in regards to decision making surrounding risk management and family planning. However, a feminist counselor may help BRCA women regain control of these choices and advocate for themselves in various medical and personal situations. Further, BRCA women may experience layered oppression, which is discussed in a later section. BRCA women may experience several layers of disenfranchisement and feminist

therapy is appropriate for helping BRCA women become aware of these different layers and other components of identity that make up BRCA previvor's holistic self.

Techniques

The main goal of interventions and techniques of feminist counseling is to empower clients to take action in their own lives and to advocate for others through promoting societal change. The egalitarian relationship sets a foundation from which other strategies and interventions can be safely explored. The therapist must make a concerted effort to work from an egalitarian perspective and act as a resource, rather than as an expert (Herlihy & McCollum, 2011). To facilitate change, different techniques can be used and adapted to fit the individual client's needs. Feminist therapists work against norms and implied treatment for women due to socialized gender roles through facilitating self-analysis, education on feminist ideals, or active participation in groups that promote social change (Herlihy & McCollum, 2011).

Feminist therapists set an intention of equality through the egalitarian relationship. Whereas many other theories focus on the importance of the relationship, the emphasis for feminist therapist is on the parity of the relationship, with the client in charge of the "direction, length, and choices of techniques to be implemented" (Herlihy & McCollum, 2011, p. 322). Feminist counselors disclose their feminist ideals and theoretical orientation in the beginning of treatment to fully inform clients of the services they will receive. Self-disclosure is also helpful to demystify the counseling process and help clients better relate to therapists. In moderation and when appropriate, feminist therapists share some of their own experiences of oppression in order to keep the power dynamics equal and model proper communication and ways of coping with oppression (Herlihy & McCollum, 2011). Feminist therapists also use assertiveness training as a technique in counseling. Assertiveness training helps clients communicate wants and needs in a

firm and explicit manner. This can be accomplished through bibliotherapy, role-play, and direct modeling (Herlihy & McCollum, 2011).

Gender role analysis and power analysis are key interventions in feminist therapy. In gender role analysis the therapist helps clients identify certain messages that they internalized at a young age about gender and their subsequent worth (Evans, Kincaid & Seem, 2011). In doing so, clients may realize the unrealistic nature of some of the gender expectations that have been placed upon them. Clients have power to decide how they define self and gender, so that the definitions are meaningful and important to them.

Power analysis allows clients to examine how power influences their relationships and many other aspects of their lives. Women have limited access to power and may need guidance on how to assert power because of their limited exposure (Herlihy & McCollum, 2011). Within the context of therapy, women can define how they would like power to exist in their lives and work with a feminist therapist to navigate how to exert this power.

As the main goal of interventions and techniques of feminist counseling is to empower clients to take action in their own lives and to advocate for others through promoting societal change, BRCA women could benefit from feminist counseling on both the individual and societal levels. Through power analysis, BRCA women could realize both their own individual power and their greater ability to change the structure in which BRCA women are treated and viewed.

Feminist Conceptualization of BRCA Positive “Previvors”

BRCA 1/2 females have owned the title “previvor,” which denotes that they are pre-survivors not only of cancer, but survivors of surveillance, chemoprevention, and prophylactic surgeries. When choosing among the three options, women seek guidance and support from

mental health professionals, friends and family, and medical professionals. Aside from education about the statistics of what it means to be a BRCA previvor, individuals who support BRCA women need a greater understanding of how to empower and support women diagnosed with the BRCA gene mutation (Hoskins, Roy, & Greene, 2012).

The principles and techniques of feminist theory can be generalized to qualitative research. The goal is that researcher and participants will have an egalitarian relationship, where the primary goal of the research is to honor women's voices. The narrative approach and feminist concepts work together to obtain an accurate unfiltered account of women's lived experiences. From a feminist view, the gendered nature of the BRCA gene mutation is a focus of the research. A feminist researcher works to understand a woman's meaning making around her gender as a woman and her diagnosis of BRCA and how the two intersect. A feminist researcher, much like a feminist therapist, attempts to learn about the previvor's sociocultural context and honor the other components of her identity that might contribute to her feeling marginalized or oppressed.

Consistent with feminist therapy, a main goal of this research study is to provide information that may later encourage social change and promote advocacy for BRCA previvors. It is my hope that this study will serve as resource for understanding the lived experiences of BRCA previvors.

Qualitative Research and BRCA Women

A limited number of qualitative studies serve as the base of knowledge about young BRCA previvors and how they make meaning of their diagnosis. Only a few researchers, including Hoskins, Greene, Roy, Werner-Lin, have studied BRCA previvors through a qualitative lens.

Hoskins, Roy, Peters, Loud and Greene (2008) explored the dynamics between young BRCA positive women and their partners. The researchers, using a grounded theory method, completed in-depth interviews with 11 BRCA previvors, aged 26 to 35, who learned of their positive mutation status before marriage. The researchers were particularly interested in how BRCA women disclosed their mutation status and their feelings surrounding the disclosure process. They elucidated themes surrounding disclosure and perceived risk. Many women felt that a cancer diagnosis was “inevitable” (p. 303) and therefore felt the need to share their diagnosis with partners and friends. There was a consensus among women that they felt fearful or anxiety-ridden before disclosing their BRCA status. Many of the women feared that it might complicate their relationships or make them seem “less viable” as a partner (p. 304). The women felt the need to time their disclosure, rather than alerting their significant others at the time of testing. Most women wanted their disclosure to emerge in the natural context of a conversation. When women described the disclosure experience, most had experienced at least one disclosure to a partner. They viewed it more as a process than as a moment in time because BRCA is a lifetime diagnosis that will continually affect the women individually and their partners. The women acknowledged that the diagnosis will continue to affect their relationships at various stages in their lives (Hoskins et. al, 2008).

Hoskins and Greene (2012) continued their interest in young previvors through the exploration of anticipatory loss and early mastectomies in women with BRCA mutation. They were interested in discovering the reasons that young previvors chose risk-reducing bilateral mastectomy (RRBM) instead of monitoring BRCA through surveillance methods or other alternative risk-reducing options. The participants were identified through F.O.R.C.E, an online support group for women with BRCA, and through snowball sampling. The researchers

conducted open-ended interviews over time with women aged 21 to 36 years, the large majority of whom had been diagnosed with BRCA 1 and a smaller percentage with BRCA 2. The goal of the study was to gather more information about how young women make choices about risk prevention to help inform those in the medical and mental health fields. Hoskins and Greene (2012) found these themes: view of risk reducing bilateral mastectomy as an alternative to cancer, an urgency to complete surgery, surveillance fatigue, and timing of surgery relative to family formation. Many women decided, most at a young age, that the best way to manage their cancer risk was through RRBM and other surgeries. For many, the decision was a response to early life experiences that influenced their perception of risk, or experiences of themselves as BRCA positive. The timing of the surgeries often depended on family formation. However, the researchers found that young BRCA women experience many different intense emotions and often struggle for extended periods of time to arrive at a decision with regard to risk management.

Hoskins, Roy, and Greene (2012) studied risk perception among young BRCA previvors. The data emerged from the larger Clinical Genetics Branch qualitative study of the impact of positive BRCA1/2 mutation status on the lives of young women (Hoskins, 2010). The interviewers conducted telephone interviews with 60 women with BRCA who ranged in from age 21 to 36. Through grounded theory analysis, the authors found that young women's risk perceptions and choices are different from those of their older BRCA mutation counterparts in the ways in which they understood risk and made decisions about risk management. Young previvors based decisions about risk management on ideas about what cancer would be like, family formation, and risk-management as a care-taking dynamic. Many of the young previvors in this study had an understanding of a cancer diagnosis experience because they had watched a

close female family member experience it. Many of these young women made choices about their risk management because of what they had seen their grandmothers, mothers, aunts, sisters, and cousins experience. Because younger previvors are in the stage of life at which family formation occurs, previvors cited childbearing as a consideration in terms of risk management options. Some of the risk management choices delay childbearing or render it impossible. Finally, young previvors made their risk management decisions based on loved ones in their lives and how their risk management decisions might affect those around them (Hoskins, Roy, & Greene, 2012).

Werner-Lin, Hoskins, Doyle and Greene (2012) used grounded theory to analyze interviews conducted with 32 women aged 18 to 24 years with BRCA mutation. Many of the women expressed that inconsistent recommendations from doctors and surveillance fatigue had led them to explore the option of RRBM before the age of 25. Werner-Lin et al. (2012) stressed the importance of understanding this unique population of young previvors through future research.

Lastly, Werner-Lin (2009) explored the compressed family life cycle of young women with BRCA and the pressure to beat the biological clock after learning of a BRCA diagnosis. In this narrative study, Werner-Lin (2009) interviewed 23 participants aged 21 to 35. Many of the women explained that coming from a “cancer family” (p. 427) pushed them to think about their own family development in ways that their peers were not required to think. All of the women stated that their current partner status had implications for the meaning of genetic testing and risk management options. The large majority of the women without children felt an urgency to have children to make biological parenthood possible. Younger participants without children faced different struggles in their risk management when compared to older women who had made

family planning decisions before learning of their BRCA status. Werner-Lin (2009) concluded that further investigation is needed to better understand the importance of timing of genetic testing in the life cycle.

There is a gap in the literature concerning the gendered nature of this diagnosis. The articles discussed above focused primarily on the risk management choices of BRCA women and how previvors make risk management choices. Family planning seems to come into play purely in regards to risk management decisions, rather than focusing on what it means to be a woman of childbearing age who receives a BRCA diagnosis. Issues of gender can exist in many different forms when exploring BRCA women's experiences. For example, what does it mean to be a young woman navigating life-changing decisions with the guidance of a male doctor? I hoped to further explore a specific population of young previvors who are of childbearing age but without children, from a feminist perspective.

Feminist Themes in BRCA Literature

Many feminist themes are present in the qualitative literature on BRCA previvors. Hoskins, Roy, Peters, Loud and Greene (2008) explored the disclosure process that occurred when BRCA previvors shared their diagnoses with their partners. Hoskins et al. (2008) likened the experience to the shame and distress of disclosing a sexually transmitted infection. Hoskins et. al (2008) found that when women disclose their BRCA status to male partners (the study did not include same sex partners), they fear rejection because they may not be able to offer the things that a woman should. Issues of diminished sense of womanhood and feeling like less of a woman arose frequently.

After learning of a BRCA diagnosis, women are offered options for preventative health. Werner-Lin, Hoskins, Doyle, and Greene (2012) found in their qualitative analysis that women

were not given proper resources following a diagnosis and often felt confused about their options. Women then sought information from medical journals but believed that they could not understand the terminology and how the risk statistics related to their own lives. Participants in this study felt powerless about something that was happening within their own bodies, yet they were expected to make decisions regarding surveillance, chemoprevention, or prophylactic surgery (Werner-Lin et al., 2012).

Hoskins, Roy and Greene (2012) explored the decision-making processes and risk prevention strategies of young BRCA previvors in a qualitative narrative study. Hoskins, Roy and Greene (2012) found that young BRCA previvors make unique and multifaceted risk prevention choices when compared to their healthy peers and to older mutation carriers. Young BRCA previvors made these choices based on information that they received from various sources, their assumptions about cancer and a life with cancer, family planning, and what might be in the best interests of their loved ones (Hoskins, Roy & Greene, 2012). Hoskins, Roy and Greene (2012) discovered that many of the women made choices about risk prevention that were non-oncologic. Rather, women made choices about perceived risk based on other factors, like the potential loss of ability to bear children, the potential to leave children without a mother, and the potential trauma and grief that it could cause their families. Hoskins, Roy and Greene (2012) concluded their discussion by urging practitioners working with young BRCA previvors to listen to their individual concerns and narratives and to disseminate information in a way that fits their personal needs. Many of the women in this study felt overwhelmed upon learning the different ways they can manage their risks during the same appointment in which they received a positive mutation status diagnosis. Hoskins, Roy and Greene (2012) learned that young BRCA previvors

experience BRCA in different ways than older mutation carriers, and they recommended that additional research may be beneficial to understanding this population.

Much of the research surrounding BRCA that is not related to medical significance focuses on psychological distress related to testing and the decision-making process and access to genetic testing (Keohly et. al, 2008). However, the literature seems to be more weighted towards the effects of genetic counseling and learning of a BRCA diagnosis, rather than living with the diagnosis. In one exception, Ostrom et. al (2003) found in a long-term study that the psychological impacts of a BRCA1/2 diagnosis are long lasting and evolve as women make decisions about how to decrease their cancer risk.

In summary, the feminist themes present in the existing literature, although not identified as such, are issues of women feeling that they have lost their “womanhood,” risk management choices in regards to family planning, and feelings of powerlessness.

Layered Oppression

BRCA women may experience various layers of oppression throughout their BRCA journey, from diagnosis to surveillance to preventative surgeries. As a researcher, it is important to be aware of how BRCA previvors may feel disenfranchised, in order to better understand their experiences. In the following section, literature related to oppression based on several demographic criteria will be reviewed. BRCA women may experience layers of oppression based on these demographic criteria that may be related to or independent from their BRCA status. Although the criteria are discussed individually, they may intersect to affect an individual with BRCA.

Age

Much of the cancer risk for BRCA previvors occurs before the age of 50 (Werner-Lin, Hoskins, Doyle, & Greene, 2012). Further, recent results suggest that by the age of 30, 3.4 percent of BRCA 1 mutation carriers and 1.5 percent of BRCA2 mutation carriers will develop breast cancer and 1-2 percent of BRCA1/2 mutation carriers will develop ovarian cancer (Werner-Lin, Hoskins, Doyle, & Greene, 2012). Most of the informed protocols for medically and emotionally treating BRCA positive women are indicated for an older population, rather than this younger population of high-risk carriers (Werner-Lin, Hoskins, Doyle, & Greene, 2012).

Younger BRCA positive previvors face unique struggles that differ from those of their older counterparts. Werner-Lin, Hoskins, Doyle and Greene (2012) found that younger women felt pressured from health providers to become pregnant or to raise a child, even when they expressed feeling inadequately prepared to do so. Women who were diagnosed after their childbearing years did not face the same pressure from the medical community. Young BRCA previvors have years or even decades of screening ahead of them, which can take a substantial toll emotionally. In the Werner-Lin et al. (2012) study, some women chose risk-reducing bilateral mastectomy (RRBM) due to the stress of constant surveillance testing. Hoskins and Greene (2012) found that women made choices about preventative surgery at younger ages to reduce cancer risk and the stress related with surveillance testing. Young women making proactive choices about their health (i.e., electing to have prophylactic surgeries) may be questioned about their abilities to make such a serious decision at a young age (Werner-Lin, Hoskins, Doyle, & Greene, 2012).

Religion

One of forty individuals of Ashkenazi Jewish heritage tests positive for the BRCA gene mutation (Strueiwing et al., 1997). This is at least ten times higher than the frequency of BRCA mutations in the general population. Seifert (2007) argued that there is a spiritual privilege in identifying with Christianity, as many of the holidays acknowledged and celebrated in United States society revolve around Christian ideals. Maglio (2009) argued that the inclusion of religion or spirituality as diversity issues in counseling is not only ethically appropriate, but also facilitates a greater understanding of the client's worldview and experience. Langman (1995) questioned why the Jewish culture is not usually included in the study of multicultural understanding in counseling and development. Langman (1995) argued that Jews may feel oppressed on many levels; however, this is often not acknowledged by non-Jews or taken into consideration when exploring multicultural concerns in counseling. Langman (1995) explored the reasons why Jews may not be included in discussions of multiculturalism, including assumptions that Jews are economically privileged, that Jews can blend with the White majority, and lack of knowledge about Jewish oppression. However, Langman (1995) stated that anti-Semitism should be addressed to the same extent as racism, sexism, homophobia, and other forms of oppression. Due to the lack of acknowledgment of Jews as a minority group, Jewish individuals, including women diagnosed with BRCA, may be reluctant to advocate for themselves due to fear of further oppression.

Gender

Living in a patriarchal society, women's voices are devalued and obscured (Brown, 1994). In our society, women are expected to be selfless, maternal, physically attractive, desirable to men, emotionally expressive, and caring (Evans, Kincaid & Seem, 2011). It is

apparent from watching television or looking in magazines that society grounds the value of women in their appearance and the body parts that make them “feminine.” BRCA previvors may make choices to remove these very parts that society deems their greatest asset. Also, in society women are expected to be maternal and bear children (Evans, Kincaid & Seem, 2011). BRCA previvors may not be able to biologically conceive children due to chemoprevention medications or prophylactic surgeries. BRCA previvors, living in a society that values women through sex appeal and ability to reproduce, may feel less worthy or womanly without breasts or ovaries (Hoskins, Roy, Peters, Loud & Greene, 2008).

Sexual Orientation

In general, lesbian women face certain challenges with seeking out healthcare resources (Hayman, Wilkes, Halcomb, & Jackson, 2013). Hayman, Wilkes, Halcomb and Jackson (2013) found that lesbian women faced homophobia when interfacing with “heteronormative healthcare services and providers” (p. 120), especially when dealing with issues related to conceiving and birthing their children. More specifically, the women in the study faced four different types of homophobia during their interface with healthcare services: exclusion, heterosexual assumption, inappropriate questioning, and refusal of services (p. 122).

No research studies were found that addressed sexual orientation and BRCA. However, my preliminary qualitative interviews suggested that women who identify as lesbian may feel further oppressed in their options for reproduction due to the perceived need to beat the BRCA reproductive clock. As reproductive options are not as readily available to lesbians in comparison to their heterosexual counterparts, lesbian BRCA previvors may feel added pressure to think about conception sooner than heterosexual, partnered BRCA previvors.

Issues Confronted by BRCA Preivors

According to the literature, motivations to seek out genetic testing for BRCA include a desire to learn about increased risk for family members, especially daughters (Jacobsen, Valdimarsdottier, & Brown, 1997; Lynch, et al, 1997), to plan for risk-prevention strategies and surveillance options (Evers-Kebooms, et al., 1999) and to inform family planning decisions (Werner-Lin, Hoskins, Doyle, & Greene, 2012), including beating the biological clock.

Beating the Biological Clock

Women with a BRCA diagnosis think about their family development and family planning in a different way than their non-BRCA peers (Werner-Lin, 2008). Werner-Lin (2008) explained that “the experience of creating a life plan that integrates the possibility of early illness and death is out of synch with normative developmental tasks of establishing intimate relationships and the start of family planning” (p. 427). Werner-Lin (2008) labeled BRCA women’s experience as a “compressed life cycle” (p.428), in which women without partners began searching for a partner who could withstand a life with the possibility of cancer and women without children began to feel a great sense of urgency to have children before becoming a biological parent became impossible. Prophylactic oophorectomy (removal of the ovaries) is recommended as early as the age of 35, leaving women feeling like they are racing against time to have children (Werner-Lin, 2008). In some cases, women in Werner-Lin’s (2008) study decided not to have children because of fear of leaving them motherless. Issues around family planning, love, partnership, and parenthood are emotionally charged topics and concerns for BRCA previvors. A recent trend in young adulthood is toward postponing marriage and children until careers have been established. By contrast, women with BRCA are experiencing the

opposite, feeling the extreme urgency to find a partner who is willing to go on the BRCA journey with them and is comfortable with the compressed life cycle (Werner-Lin, 2009).

Navigating BRCA Choices

After a positive diagnosis, BRCA previvors make decisions about how to manage risks through surveillance, chemoprevention medications, or proactive surgeries. Hoskins, Roy and Greene (2012) found that many young BRCA mutation carriers chose to manage their cancer risk through surveillance, especially directly following a positive diagnosis. The surveillance period lasted for the amount of time BRCA previvors could tolerate the cycle of stress that accompanies frequent screenings, suspicious findings, and repeat imaging. Some women may feel that surveillance is a passive option, and they would prefer to be more proactive in taking control of their lives through choosing the prophylactic surgeries. Hoskins, Roy and Greene (2012) explored decision making with younger BRCA previvors and found that they make their unique and individual decisions based on both personal and interpersonal factors in their lives. BRCA previvors often made decisions about risk management with family members in mind, putting others' needs first.

Lack of Power

Hoskins, Roy and Greene (2012) found that many women expressed feeling a lack of power or control following a BRCA diagnosis, and that communication with health professionals was an intense experience for them. Even with choices about preventative health, women expressed feeling powerless rather than empowered by the new information. Werner-Lin, Hoskins, Doyle and Greene (2012) found in their qualitative analysis that women were given limited information and often left the doctor's office confused about what to expect after a positive diagnosis. These women then sought information from medical journals and believed

that they could not understand the terminology and how the risk statistics related to their own personal lives. Women explained feeling powerless and uninformed about something that was happening within their own bodies, but were then pushed to make decisions regarding surveillance, chemoprevention, or prophylactic surgeries.

As access to genetic testing becomes more available and affordable, women are learning they are BRCA positive at a younger age and are also making decisions at a younger age about their preventative health (Hoskins, Roy & Greene, 2012). Young women have expressed that, after choosing a prophylactic mastectomy, they are often questioned about their abilities to make such a serious decision at a young age. Women, especially in the younger age bracket, are given positive test results, yet are not given the proper information and trusted to make the best decisions for themselves (Werner-Lin, Hoskins, Doyle & Greene, 2012). Werner-Lin, Hoskins, Doyle and Greene (2012) discussed several instances when genetic counselors, doctors, or other providers shared the women's positive genetic mutation status with parents *before* sharing it with the adult child. The women, all older than the age of 18, were not the first person to know about the positive mutation, which set a tone that they were passive participants in their own BRCA journey. Therefore, women may feel out of control or fearful after being diagnosed with BRCA, and compounding that loss of control is a lack of support and lack of power within the current system, leaving BRCA previvors feeling powerless and oppressed (Hoskins, Roy, Peters, Loud & Greene, 2008).

Anticipatory Loss

Risk-reducing bilateral mastectomy (RRBM) has become a more frequently utilized choice of BRCA previvors, with rates exceeding 40 percent of BRCA1 and 30 percent of BRCA2 carriers choosing RRBM within 5 years of diagnosis (Hoskins & Greene, 2012). Hoskins and

Greene (2012) characterized “anticipatory loss” as feelings of uncertainty and fear about the future (p.1633). Although BRCA previvors do not have cancer, living with a BRCA mutation is an illness experience. Hoskins and Greene (2012) explained, “although young breast and ovarian cancer previvors generally do not face an immediate health threat, they must cope with the likelihood of severe future illness (perhaps tomorrow, perhaps in one or several decades), which of necessity forces contemplation of the psychosocial and relationship implications of illness” (p. 1634). BRCA women are living with a sense of impending loss and need to grieve the loss of how they previously envisioned their lives (Werner-Lin, 2009).

In addition to loss of body parts and potential loss of life, BRCA women anticipate loss that is not cancer-related, such as “the potential loss of ability to bear children, of dying and leaving children motherless, and of inflicting a traumatic experience on loved ones” (Hoskins, Roy & Greene, 2012, p. 44). The anticipatory losses inform BRCA women’s decision about treatment and how to best manage their BRCA risk.

BRCA women face other important issues such as body image, relations with others, self-concept following a diagnosis, and grieving the loss of a life that they had imagined pre-BRCA. These issues are complex and multifaceted and would be best explored in therapy and through support groups with fellow BRCA previvors (Werner-Lin, 2009).

Implications for Counseling and Support

Hoskins, Roy and Greene (2012) discovered through qualitative analysis that young women with BRCA 1 and BRCA 2 genetic mutation may feel unsupported by professionals in the community when it comes to living with their diagnosis. Women in this study frequently identified the need for psychosocial support, suggesting that this is an unmet need within the BRCA population. Hoskins, Roy and Greene (2012) expressed “comprehensive and specific

psychosocial support from a professional who understands these complicated dynamics and decisions should be available to women in this population, not only during active decision-making, but also in an ongoing fashion as they continue to face challenges (both expected and unanticipated) brought on by their mutation status and decisions they have made in the past” (p.45). Those women who were provided support and had positive experiences were more at ease with their decision-making (Hoskins, Roy and Greene, 2012).

Werner-Lin (2009) found that “what health care professionals provided was contained to the time immediately surrounding testing, and no other support services were integrated into counseling to facilitate long-term adaptation” (p. 123). Women were provided with life-altering, potential traumatic information, apparently without the proper safety net and support to make meaning of their diagnosis.

Counseling can be used as a means of support and empowerment when working with individuals who may feel marginalized or oppressed (Harley, 2009). Harley (2009) described empowerment as “a process in which individuals take an active and meaningful approach to making decisions that affect their lives” (p. 127). More specifically, the main goal of feminist therapy is to empower clients to make individual choices that are right for them and to advocate for self and others (Brown, 2010).

CHAPTER THREE

METHODOLOGY

In this chapter, the methodology that was used in this study is discussed. The purpose of the study, an explanation of both qualitative inquiry and narrative analysis, research questions, participants, data collection procedures, data analysis plan, and the researcher's personal experience are presented.

Purpose of the Study

The purpose of this study was to honor the voices of women diagnosed with the BRCA1/2 gene mutation, through a qualitative research study with a narrative design. Most research surrounding BRCA has been quantitative in nature, without attention to individual women's experience with surveillance, chemoprevention medications, prophylactic surgery, and living with a BRCA diagnosis. This study explored in depth, through a narrative lens, the lived experiences of women with BRCA.

Qualitative Methodology

Glesne (2011) defined qualitative research as "a type of research that focuses on qualities such as words or observations that are difficult to quantify and that lend themselves to interpretation or deconstruction" (p. 283). Integral to qualitative research is the ability to listen and learn from other's stories and to later interpret and retell the account of the narrative (Glesne, 2011). Qualitative research explores individuals' lived experiences in a number of different ways (Creswell, 2007). Creswell (2007) explained that qualitative research is focused on the process rather than the outcome, and the procedures of qualitative research are inductive, derived from the researcher's experience in collecting and analyzing data.

Until recently, the primary means of understanding BRCA genetic mutation was through quantitative measures, and most studies focused on medically significant data. Recently, there has been a shift in the literature towards understanding BRCA through a qualitative lens with a focus on psychosocial understanding of the lived experience of BRCA previvors (Hoskins & Greene, 2012; Hoskins, Roy, & Greene, 2012; Hoskins et al., 2008; Werner-Lin, 2008; Werner-Lin et al., 2012). A qualitative method was best for exploring my topic because I wanted to better understand the lived experiences of BRCA women and honor their voices. Further, this study focused on words and observations, and the process of gathering and retelling women's narratives was key in my purpose of honoring and exposing BRCA previvors' narratives. I hoped that my findings would help medical professionals and friends and families of BRCA women to better understand previvors' unique experiences. The best way to accomplish the purpose of this study was through a narrative qualitative analysis.

Narrative Lens

Narrative research, or what Glesne (2011) refers to as life history research, "illustrates the uniqueness, dilemmas, and complexities of a person in such a way that it causes readers to reflect upon themselves and to bring their own situations and questions to the story" (p.20). Narrative inquiry employs participant observation in a way that the other qualitative inquiries do not; the participant interaction sets a context to the interviewees' words to help better interpret the interviews (Glesne, 2011). Narrative analysis is an examination of how the stories are told, and what the stories say about the social life and culture of which the narrator is a member (Glesne, 2011).

Chase (2005) distinguished narrative inquiry from other forms of qualitative design through the explanation of five analytic lenses. First, narrative discourse is unique and distinctive

in the way past experiences are retrospectively shaped and ordered (Chase, 2005). It is more than chronologically ordering events because narrative discourse communicates the narrator's specific and unique point of view, which is why the story is worth telling (Chase, 2005).

Second, narratives are viewed as "verbal actions," meaning that what the narrator says shapes reality in some way. When researchers honor the narrator's voice as a creative action, they emphasize the individuality of that voice (Chase, 2005, p. 657). The focus becomes less about the facts that the narrator shares and more about the "versions of self, reality, and experience that the storyteller produces through telling" (Chase, 2005, p. 657).

Third, narrative researchers are aware of what allows and constrains narratives. The narrator's communities, social situations, local settings, and cultural memberships are all examples of what can enable or constrain a narrative (Chase, 2005). This lens may be helpful when comparing similarities and difference among narratives.

Fourth, narrative researchers acknowledge that every narrative is situated in a social setting (Chase, 2005). More specifically, the setting in which a narrator shares his or her story may shape the story. My narrators shared their stories via Skype and, because the interviewees were asked to Skype from a place that they felt comfortable, all interviews were completed in a relaxed environment. All of the participants chose to Skype from their homes, as did I. The online nature of our communication invariably affected the narrators' stories in some way. For example, during my second interview with one of the participants, an Internet connection issue occurred and we had to restart the interview.

Fifth, narrative researchers view themselves as narrators as they share their narrator's stories (Chase, 2005). I developed my own voice as I described the voices of my participants. With awareness of these five analytic lenses, I designed my open-ended interviews and

conversations with the BRCA previvors to encourage them to be the narrators of their stories. Chase (2005) explained that the way to do this is to know what is “story worthy” in the narrator’s social setting and try to get an understanding of that (p. 661). I also reviewed other successful narrative inquiries within the BRCA literature to get a greater understanding of the narrative lens. For example, Werner-Lin (2008) successfully explored the compressed life cycle of BRCA women through narrative analysis. Werner-Lin (2008) was able to capture the words and lived experiences of women who were making decisions about family planning while concurrently dealing with their BRCA diagnosis. This study serves as a model for narrative exploration when working with BRCA previvors.

Because the purpose of the study was to honor women’s voices, a narrative frame was the best means of inquiry to truly honor BRCA women’s narratives. According to Creswell (2007) narrative research is best used to capture the detailed stories and life experiences of one life or several lives.

Research Questions

The main research questions that guided the overall research and interviews were:

1. What are the life stories of women, ages 18 to 35, who have been diagnosed with BRCA 1/2 genetic mutation?
2. How do issues of family planning present themselves in BRCA previvors’ narratives?
3. Has their knowledge of BRCA changed their worldview or life course/plan, and if so, in what ways?

Participants

I interviewed four BRCA positive previvors, using open-ended narrative- interviewing. I had planned to recruit participants from the Breast Surgical Center and the F.O.R.C.E network;

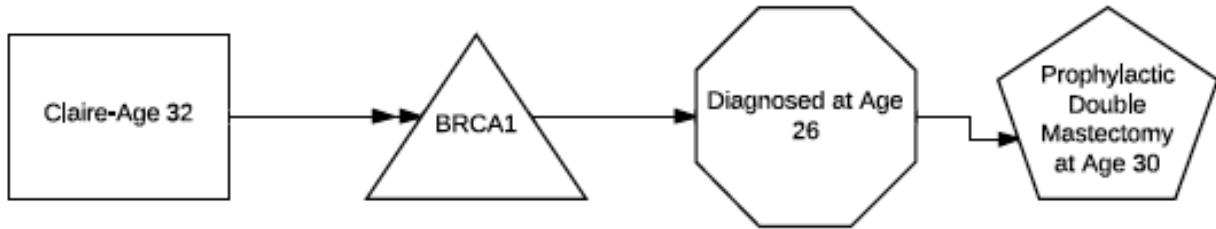
however, I was not successful in locating viable participants after reaching out to these resources. I recruited three women from BRCA Sisterhood, an online support group for BRCA women. I posted the information about my study and interested women who fit the criteria contacted me. I recruited the fourth woman from an ovarian cancer fund raising event, where I had asked some of the volunteers from an organization to reach out to BRCA women interested in participating. The fourth participant gave her email address and said she would be interested and I contacted her shortly thereafter. These four participants lived in different parts of the country. After conferring with my methodologist and dissertation chair, and more importantly the participants, we all agreed that interviewing by Skype would be the best course of action.

I used purposeful sampling, a type of sampling commonly used in qualitative research, in which the researcher intentionally selects individuals and sites for examination because they can purposefully inform the phenomenon that is central to the research (Creswell, 2007). Specifically for narrative research, the participants selected to interview “need to have a story to tell” (Creswell, 2007, p. 128). Although all BRCA positive previvors have a story to tell, individuals met certain criteria to participate in this study. Criteria for recruiting and selecting participants were that participants must be (1) women, (2) BRCA1/2 genetic mutation carriers, (3) aged 18 to 35 years, (4) have learned of their BRCA diagnosis no less than 6 months ago, (5) do not have children and are not currently pregnant, and (6) have an absence of a cancer diagnosis. The four women who met these guidelines were eager to share their narratives and had unique and powerful stories to share.

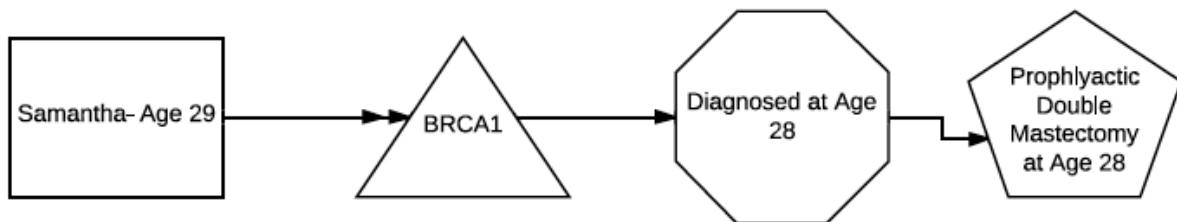
Participant Profiles

Claire. Claire is a 32-year-old BRCA1 previvor. Claire was diagnosed with BRCA 1 genetic mutation when she was 26 years old. She inherited BRCA 1 from her father. Her younger

sister has tested negative, while her older brother has yet to test for the genetic mutation. She is employed and is of Ashkenazi Jewish heritage. When she was 12 years old, her father's mother passed away at the age of 40 after being diagnosed with breast cancer. Claire completed a prophylactic bilateral mastectomy when she was 30 years of age. Claire is single. I recruited Claire from a cycle for life ovarian cancer event.

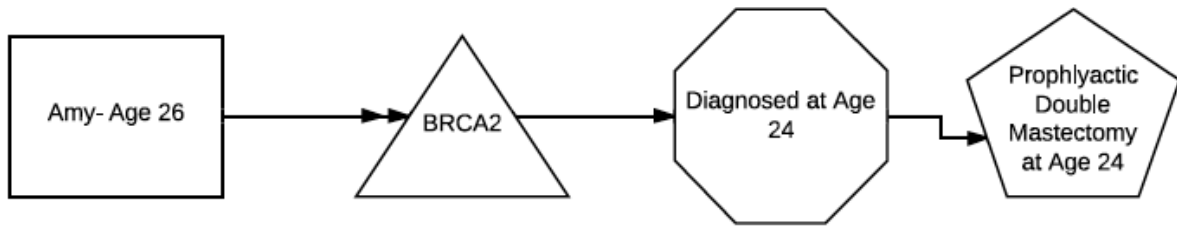


Samantha. Samantha is a 29-year-old BRCA 1 previvor. She was diagnosed with BRCA 1 genetic mutation when she was 28 years old. She inherited BRCA 1 presumably from her mother, who died from breast and ovarian cancer. She has no siblings or other known relatives with BRCA. She is an attorney. Samantha completed a prophylactic bilateral mastectomy when she was 29 years of age. Samantha is single, but is in a committed relationship. I recruited Samantha from an online support group for BRCA women.

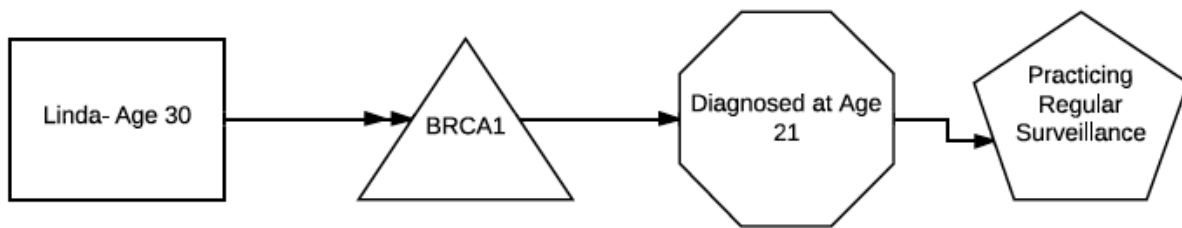


Amy. Amy is a 26-year-old BRCA 2 previvor. She was diagnosed with BRCA 2 when she was 24 years old. She inherited BRCA 2 from her mother. Although her sister tested negative, her mother, aunt, and two female cousins also had BRCA 2 genetic mutation. Amy is employed. Amy completed the prophylactic bilateral mastectomy when she was 24 years of age.

Amy is single, but is in a committed relationship. I recruited Amy from an online support group for BRCA women.



Linda. Linda is a 30-year-old BRCA 1 previvor. Linda was diagnosed with BRCA 1 at age 21, though she has known about the gene and her family’s predisposition since she was 14 years old. Linda inherited BRCA 1 from her mother. Linda’s sister, mother, and two aunts all were diagnosed with BRCA and both her sister and her mother had breast cancer. Linda is employed and works as a Yoga instructor and circus performer. Linda chose surveillance for risk prevention, but is contemplating getting a double mastectomy preventatively in the near future. Linda is single, but is in a committed relationship. I recruited Linda from an online support group for BRCA women.



Three of the four participants were in committed relationships with men, yet none were married. All were between the ages of 24 and 31, without children. All but one of the women had already completed the prophylactic double mastectomy, though Samantha was still in the process of completing the second phase of her mastectomy. One woman had no other known relatives with BRCA, while others had several known relatives with BRCA. The women all had unique stories to tell despite their many similarities.

Gergen (1994) made meaning of data collection in narrative design through the idea that narratives come into existence as a part of culture, reflected in social roles. An implication is that everyone has a story to tell. While all BRCA women have stories to tell, I wanted to focus on the stories of women who have not yet had children or are unpartnered, but may have had visions of children or marriage, or both, for their lives.

Data Collection

All procedures and protocol related to data collection were reviewed and approved by the University of New Orleans Committee for the Protection of Human Subjects in Research (IRB). Data collection took place in the form of open-ended interviews. I recorded the Skype interviews on three different devices. I conducted a pre-interview with each participant and interviewed each woman twice. Informed consent was explained and gained during the pre-interview. The women scanned and emailed me copies of their signed informed consent statements and also sent a copy of the questionnaire that they completed prior to the pre-interview. I explained that two 60-minute Skype interviews would be conducted. The interviews were in depth, yet informal, to help the women feel comfortable and to build researcher-participant rapport. I developed several grand-tour interview questions, which can be found in Appendix C, to ask all participants in the first round of interviewing with the aim of letting the natural themes emerge without leading the participants. From the data that participants provided in the first round, I developed relevant follow-up questions for the second interview that were meaningful to each participant's BRCA journey. I interviewed all women via Skype and each woman communicated that she felt comfortable with online interviewing, despite the sensitive nature of the topic. Cater (2011) found that online interviewing is a suitable alternative to face-to-face interviewing and found it to be more cost effective and convenient. Cater (2011) explained that online interviewing allows

for participants share their narratives in a time and place that is convenient for them. All of my participants completed the interviews in the convenience of their own homes, which I believe helped them feel more comfortable and safe sharing their stories. Cater (2011) discussed means to record the interviews by other devices, and I recorded the interviews using a program called Call Recorder. I alerted the women that I would be recording them and Call Recorder allowed me to play back our entire Skype interview, including the video portion. This allowed me to examine the women's facial expressions and non-verbal cues, along with their verbal dialogue.

Interview Process

Due to the sensitive nature of this topic and the semi-structured format of the interview process, attention to potential risks and benefits was crucial prior to conducting interviews with BRCA previvors. Corbin and Morse (2003) explored the potential vulnerabilities and power differentials that exist between a researcher and a participant when conducting interviews for qualitative research in which participants shared intimate and traumatizing information. They noted that the interview process, if not handled appropriately, could re-traumatize the research participant. On the other hand, when the interviews were conducted ethically and with care and understanding, research participants reported that the interviews served as a catharsis, provided self-acknowledgement and validation, contributed to a sense of purpose, increased self-awareness, granted a sense of empowerment, promoted healing, and gave a voice to the voiceless and disenfranchised (p. 346). Three of the participants shared at the end of our interviews that the process was helpful and that it was wonderful to be able to share their stories. I used my counseling skills to my benefit in the interviews. I reflected feeling and meaning after the women shared experiences, which seemed to encourage continued sharing and reflections. My energy in

the interview was one of camaraderie and empathy, but it was clear that the participants were the focus and the narrators.

Data Analysis

Data analysis in a narrative study focuses on the stories told, the chronology of unfolding events, and turning points or epiphanies in the story (Creswell, 2007). I interviewed each participant two times, not including the initial pre-interview. The first interview included most of the questioning and narrative, and the second interview was used to ask any clarifying questions. Both interviews lasted 60 minutes and were conducted in my home office and the participants' homes. I listened to the first interview before conducting my second interview with each woman so that I could reflect and tailor the second interview to ask clarifying and relevant questions. The interviews were spaced a week apart to give the women time to reflect between interviews. I analyzed data as I collected, which helped focus the shape the research was taking as I explored the previvors' narratives. After the first interview, I reflected and analyzed the data to tailor questions for the second interview. I also member-checked at the beginning of the second interview to ensure the data I gathered were accurate in the eyes of the participants. I consistently reflected and worked to organize my data through memo writing. Memo writing is a reflective log that serves as a container to hold thoughts, even preliminary ones, to free up space for new thoughts and perspectives. I kept a memo log by hand and also kept a recorder handy to record thoughts when writing was not possible. I used analytic files to keep information organized and certain themes emerged. These beginning steps to analysis occurred simultaneously with data collection and were helpful in the second phase of analysis, coding.

Coding was the main technique through which I analyzed the data. Glesne (2011) defined coding as a "progressive process of sorting and defining and defining and sorting those scraps of

collected data (i.e., observation notes, interview transcripts, memos, documents, and notes from relevant literature) that are applicable to your research purpose” (p. 194). Clumping the data allows researchers to make meaning and thematically organize participants’ narratives. In coding the data, I created relationships among the women’s narratives, and I highlighted some of the unique pieces of each woman’s story. The codes were organized into themes within the individual women’s stories and themes across stories. Coding also helped illuminate what was not said in the narratives or what was missing. Codes were the starting point from which I moved forward to look for further patterns and seek further understanding from the data. My codes evolved and grew, just as the study evolved and grew as I gathered information.

Data displays can take the form of matrices, graphs, flowcharts or other visual aids to help make sense of the data, as well as expose potential gaps where more data might be needed. I hand-wrote several data displays as helpful tools to get a “big picture” understanding. The displays helped me view all my data in one place at one time, illuminating where the women’s narratives converged and diverged. While coding and data displays helped organize and classify the data, I still had to make connections that were meaningful to the research. I transformed the data through description, analysis, and interpretation. Description refers to the process of staying close to the data and allowing the stories to speak for themselves. The most challenging aspect of the data analysis, which will be further discussed in Chapter 4, was understanding the narrative voice of each woman. I learned that simply ordering the stories into chronological events does not give each narrator her voice. I needed a greater understanding of each participant in order to understand her narrative perspective.

Trustworthiness

Trustworthiness is a term used to describe whether certain criteria are met in qualitative research to establish reliability. Lincoln and Guba (1985) operationalized trustworthiness into several criteria: credibility, transferability, and confirmability. I ensured trustworthiness through ensuring that these criteria were met throughout data collection and analysis.

Credibility can be achieved through prolonged engagement, triangulation, and persistent observation (Lincoln & Guba, 1985). Prolonged engagement occurs when a researcher spends sufficient time to achieve certain criteria in learning the culture and building trust among participants. As a researcher, I worked to be engaged in the BRCA community for a long period of time in order to build rapport with participants and truly get an understanding of the culture. In a sense, I am already a part of this culture; however, I was aware of my role as a researcher versus my role as a fellow member of this culture. Whereas prolonged engagement provides scope and a view of the big picture, persistent observation provides depth and a narrow look into the culture in which the researcher is immersed. Lastly, triangulation, the third way of improving credibility, is a way of confirming the credibility of the data through multiple sources and methods. I triangulated the data through member checking, peer debriefing, and through a reflexive journal and an audit trail. At the beginning of the second interview, I member checked with each participant to make sure that what I gathered from the first interview was accurate.

Transferability is the ability to generalize the data to other situations or populations. This can be accomplished through thick description. Lincoln and Guba (1985) describe the researcher's role in creating transferability as "the responsibility to provide the data base that makes transferability judgments possible on the part of the potential appliers" (p. 17).

The major techniques for establishing confirmability in a qualitative design are through triangulation, keeping a reflexive journal, and an audit trail. I kept a reflexive journal and triangulated my data through clarification with the BRCA women, checking with current literature, and peer debriefing.

The reflexive process was present throughout data collection and data analysis and saturated every stage of the research. Mason (1996) defined this intangible process as “means that the researcher should constantly take stock of their actions and their role in the research process and subject to the same critical scrutiny as the rest of their data (p.6).” This process urges the researcher to ask the questions “what do I know” and “how do I know what I know?” Being a reflexive researcher, I was aware of potential ethical issues that might arise and I prepared for how to proceed when they did arise. I prepared by regularly checking in with myself, and had regular peer debriefing and member checks. I checked in regularly with my dissertation chair and methodologist and consulted when potential ethical issues arose.

Researcher Positionality Statement

My personal experience with BRCA was relevant in how I managed my own subjectivities and personal experiences throughout this process. Two years ago, I was diagnosed with the BRCA 1 genetic mutation. My experiences thereafter prompted me to look further into research about the psychosocial effects of a BRCA1/2 diagnosis, especially in young women. I discerned that the majority of the research about BRCA focused on the medical aspects of BRCA rather than the lived experiences of women who were diagnosed. It was the pairing of my own personal experience and the lack of existing research that led me to pursue my dissertation topic, and to aim to explore the narratives of BRCA women. By placing myself in the context of this

research and owning my subjectivities, I minimized and remained aware of potential biases that arose throughout the research process.

Peshkin (1988) described subjectivity as a “garment” that we always wear and cannot take off (p.17). The garment is present in the research and non-research aspects of our lives. It is the awareness of our subjectivities that is important. Peshkin (1988) urged researchers to enter into projects with awareness of these subjectivities, rather than happen upon them when collecting or analyzing data. My personal journey with BRCA was my subjectivity and it shaped every aspect of my dissertation. Therefore, it was important to put a brief narrative of my journey on display before collecting data.

My maternal grandmother died at the age of 24 of ovarian cancer, just months after giving birth to my mother. Other than my mother, there are very few living female relatives on my maternal side. After I learned about the BRCA gene from my gynecologist at the age of 18, I urged my mother for almost seven years to get the BRCA genetic testing. She resisted because my grandmother was the only evidence of a possible genetic mutation. Two years ago, she finally agreed and was shocked to find that she tested positive. After learning that my mother was BRCA 1 positive, I knew that I would have a 50 percent chance of having a positive result as well. After testing and a grueling two week wait, I, sadly, found out that I also had the gene. My doctor called with the results and I could tell by the tone of his “hello” that I would be getting bad news. I went the following week for my appointment with the doctor to discuss my options.

Because I had done my own research in the interim, I decided that I could handle this appointment and it was better to have the information than to be blindsided by a breast cancer or ovarian cancer diagnosis. While I was deeply saddened by the diagnosis, I felt hopeful and

almost empowered to be armed with a warning, something most people do not get. My husband and I went to my first appointment feeling lucky to be meeting with this particular doctor, an older male who was renowned for completing prophylactic double mastectomies. He gave me my options, performed a breast exam, and asked if I had any questions. I came prepared with written questions, all of which he answered. I began to ask about family planning, in regards to having children and potential prophylactic surgeries. “Do I need to rush into having children?” I asked. In response, he made a statement that has changed the course of my life: “Well, Drew, you have to decide how you feel about having children now that you know you have this gene. You will need to ask yourself if it is responsible to have children knowing that you have a chance of passing this onto them.” Silence fell over the room and I felt my husband’s eyes on me. Immediately, tears began to well up as I thought about the prospect of not being a mother, as the role of “mom” is something I have dreamed of since I was little. While I am aware of the risks to my future children, I would never let that stop me from having my own biological children. If my mother had let that stop her, my brothers and I would not exist. I do not think he knew the scope of his words and how deeply they affected me then and still affect me today.

Although I have been resilient enough to disregard the doctor’s words and continue on my path towards motherhood, I realize that other women may rely more heavily on doctors’ opinions. It was after the doctor’s statement that I realized I wanted to look further into this topic as a potential dissertation subject. The feminist inside me wondered how gender came into play and how this doctor could possibly fail to understand what it would mean to take away my right to be a mother. As I came into contact with more and more doctors throughout my BRCA journey, almost all of who were male, I began to wonder how the differences between men and

women come into play, as BRCA is a gendered diagnosis. Thus, from these considerations, my conceptual framework was born.

I made assumptions that feminist ideals would be present in the results based on my own experiences. I have worked to bracket these assumptions through broad interview questions that would not lead the participants. I assumed that feminist themes of gender, power, oppression, disenfranchisement, and empowerment would arise in my data.

I was proud to wear my BRCA 1 diagnosis as a garment throughout my dissertation journey. While I realized my own experiences created a potential for bias, I also saw my own experiences as serving me greatly throughout this process. My own connection to BRCA helped me gather participants, connect with the BRCA survivors, and understand the language of the interviews. I believe the participants were more comfortable sharing their experiences with someone who might be able to relate or understand their unique experiences and feelings related to BRCA. Also, the language in our interviews often included acronyms, names of organizations, and abbreviations for surgical procedures and surveillance techniques that are second nature for me. Another interviewer may not have understood these same terms and I think understanding this language and being a part of his culture helped me establish rapport with the participants. On the other hand, my membership in the BRCA culture made it more difficult for me to separate myself in the researcher role. The participants wanted to know more about my story and I worked to create boundaries, but without making them feel that their curiosity was inappropriate. I reminded them that this was their time to share their story.

CHAPTER FOUR

RESULTS

In this chapter, the results of this narrative study of four previvors are presented through within-case analysis themes and across-case analysis themes. To gather the data, I conducted 60-minute interviews with four previvors. I completed a 60-minute follow-up interview with each participant about a week after the original interview. I analyzed and coded the data and through that process the themes both within and across stories began to emerge. I developed themes within each individual previvor's narrative and also developed overarching themes across the narratives.

As I gathered the narratives of the four previvors and coded the data, it became apparent that the women's stories were both similar and dissimilar in many ways. When coding the data, several themes emerged within each previvor's narrative. Throughout the coding process, overarching themes emerged across the women's narratives. In this chapter, results are presented beginning with the within-case analysis, through which the individual participants' stories are told. Then the across-case analysis is presented, detailing the ways in which the stories converge. In the first section, I present the stories of Claire, Samantha, Amy, and Linda, highlighting their uniqueness and distinct narrative voices through displaying their individual themes.

Within-Case Analysis

Claire

Claire is a 32-year-old BRCA1 previvor. She is employed and is of Ashkenazi Jewish heritage. Claire was diagnosed with BRCA 1 genetic mutation when she was 26 years old. She inherited BRCA 1 from her father. Her younger sister has tested negative, while her older brother

has yet to test for the genetic mutation. When Claire was 12 years old, her father's mother passed away from breast cancer at the age of 40. The themes that emerged during the analysis of Claire's story were diagnosis, preventative choices, prophylactic double mastectomy, family relations and family planning, experiences with doctors, and challenges and changes in worldview. See Figure 1 below.

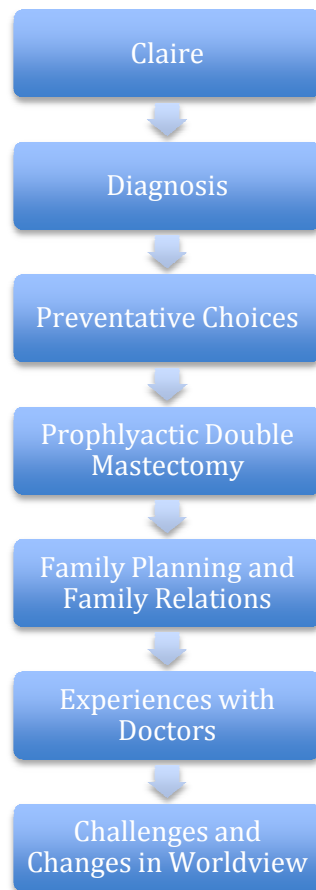


Figure 1. Within-case themes for Claire

Diagnosis

The theme that appeared first chronologically in Claire's narrative was diagnosis. Claire began our first interview by describing how she first came to understand what BRCA is and how she came to be tested. Claire heard about the BRCA gene through her sister, whose previous job

had been at a non-profit organization for women with cancer and hereditary predispositions to cancer. After hearing about the gene, Claire's parents decided to get tested for the gene due to their Ashkenazi Jewish heritage and family history of breast cancer. Claire related her family's testing process.

They didn't even tell us that they were getting tested and they went to our doctor in (city) and they had the full panel run on my dad... then when they found out that he was positive, they met with the genetic counselor to find out what it meant, what exactly the mutation was and what the risk was for their children.

Claire's family was significant within this specific theme of diagnosis and in her overall narrative. Claire explained that her personality and personal characteristics affected how she processed the information that BRCA was within her family.

When I heard my dad had BRCA 1, I just don't think I knew what it meant...At that point, I still was not into doing research myself. And I think that I don't really remember feeling strong one way or the other about it. I went into it without information about what it would mean to test positive, because that is my personality. I am not one to really dig deep into things. I really listen to the doctors more so than researching a lot. Which is good in the sense that I don't over-research...But it is bad in the sense that I went into a lot of these experiences without knowing a lot on the front end, but figuring it all out on the back end. That is just my personality to dig deeper once I get involved. So, I went to the same genetic counselor my parents went to.

Claire met with the genetic counselor, and the moment she learned of her positive mutation status seems to be one that she remembers well.

So, I was the first of my siblings to get tested...The geneticist had called to give me my mutation status. And when she called me, I knew before she even said anything. I remember I was sitting on my couch and it must have been, I don't know what day it was, it was dark outside and I remember she told me, and I was okay on the phone and I called my mom and started crying. My mom came over and we talked about how it was better to know, I can be proactive with my health. It's just knowing what's in your body and having that ability to be screened and looked at and monitored much more closely than other people...

It took Claire a long time to digest the information that she would be a BRCA 1 previvor for the rest of her life. She felt isolated, especially in the beginning of her BRCA journey as her sister tested negative and her father was the only known relative with BRCA. She stated, *"I think ... everyone has a different way of reacting to it, digesting it and comprehending what exactly it means for them. For me, it took a year, or maybe a year and a half, to fully digest it and really think what I was going to do. And I didn't know anybody either at the time that had BRCA, so I felt kind of alone."*

Preventative Choices

The second theme that emerged in Claire's narrative was preventative choices as she discussed the choices she made to manage her BRCA risk. After meeting with a breast surgeon, she *"went and scheduled my mammogram...the first mammogram was terrifying. It is like I am 26 years old, why do I need to get a mammogram? Just like what am I doing here at this point my life, with my breasts getting smushed? The first MRI mammogram I had was 45 minutes long and miserable."*

Claire questioned why she needed to be taking these steps at this point in her life, though she knew rationally that they were part of her surveillance. As she explained, *“I did surveillance for 5 years, getting mammograms, MRI mammograms and ultrasounds at my OB’s office. I am an anxious person to begin with.”*

For Claire, the surveillance process was scary and anxiety provoking. She found it frustrating to feel in the dark during her surveillance scare. She stated that she had intimate knowledge of her own body and wished she would have been included in the conversation with the nurses and the radiologist because she could have helped the doctors understand more about her specific body. It was after a surveillance scare that Claire decided that she could no longer take the anxiety that comes with surveillance, and she chose to get a prophylactic double mastectomy. She described this decision-making process:

And I had gone in in January, it was 5pm on a Friday. They had noticed a spot that they wanted to re-look at, so they took more pictures and at this point I couldn’t call my mom and ask her to come meet me...so I am sitting in the waiting room by myself and they took me in in the sonogram room. The second they put the machine on the one spot they thought they saw something, I knew exactly what it was at that point. I had this one area depending on the time of the month that would flare up a little bit. And I was like, ‘if you would have asked me about it I could have told you what it was.’ I could have told them because I know my body. I understand they are trying not to scare me, but at the same time had they told me I could have told them what it was. And, so after that appointment, I decided it was time for me to just do it. I don’t want to have to deal with this and... I didn’t want to live in the anxious place anymore of going through surveillance.

Prophylactic Double Mastectomy

The next theme in Claire's journey relates to her preventative prophylactic double mastectomy. Claire described what it was like to inform her family members that she had decided to go ahead with the preventative surgery. Claire never wavered in her decision, although her father was hesitant initially.

When I first told my parents about the surgery, I think my dad was in a bit of shell shock. Even when he got on board after we had talked about it and digested it, even after I had scheduled the surgery, he said 'look I am on board, but I think it is a major surgery to have.' He was suggesting that I should get re-tested again for the BRCA gene. So, I asked my doctor that the chances were that the test was wrong and she said slim to none... I did not get re-tested. And I told my dad, 'look, I am doing this.' He came around eventually.

Claire explained her decision-making process regarding nipple sparing and having a one-step versus two-step with expanders procedure.

I ended up doing nipple sparing and my mom was really hesitant at first because she said 'you are going to go through all of this and get your breast tissue taken away, why would you keep your nipples and still have a risk?' It was important for me to keep my nipples because I am single... I don't want to have to deal with dating and tattooed nipples. It was important for me to keep a normal appearance of my breast. So, I ended up doing the expanders. I could have done the one-step, but it made more sense to do the expanders because you get to play around with the size. I felt like I had more control with the expanders.

For Claire, the choice to keep her nipples was tied to her relationship status and the desire to keep her breasts looking "normal." She shared that the surgery has prevented her from

becoming intimate with a partner due to fears of having a conversation about her surgery. As she discussed how BRCA and her surgical procedure keep her “guarded” in some ways, this led into a discussion of family planning and family relations.

Family Planning and Family Relations

Family planning and family relations was a constant theme throughout Claire’s narrative. She is just beginning to mentally tackle the idea of family planning now that her surgery is behind her. Claire’s family planning timetable has changed throughout her BRCA journey. She thinks that she might have to get pregnant immediately after getting married, which is a shift from what she previously wanted for her life. She stated:

I was so focused on the surgery, I did so much research on that. By the end of the year, I have to think about egg freezing. Or if I started dating someone, then I would think about it too. With BRCA, I think it is about tackling one thing at a time. Well, it’s scary. I think about being 32 and technically they want me to get my ovaries out at 35, which isn’t realistic any more, but I do think about I am going to end up having to get pregnant right away. I used to always think I would be able to be married for a while and then get pregnant, and that can’t happen anymore.

Partnership and dating were topics present throughout Claire’s narrative. Her surgery affected her feelings about self in relation to dating. Claire described herself as the “new me” post- surgery and worried about what it will be like to open up to someone as her new self.

After surgery, I am a little more nervous to open up to guys that I am dating. It is a scary Band-Aid to take off. I feel like when I look in the mirror, I look normal, there is nothing alarming, but you know, when I do certain movements, I can make my boobs dance, it’s

weird... I worry about little things like that. Like when I start dating someone, are they going to be disgusted by it or are they going to be turned off by it? That is I think for me what is affecting my womanhood. It is like dealing with the new me and going about it dating and trying to feel comfortable opening up to someone. I am nervous about exposing myself.

Claire returned to the subject of her “timetable” and wondered how to talk to a partner about her accelerated timetable.

I think too much about that all of my friends are married with kids, but I am the one that has a timetable. I am scared to put myself out there to be vulnerable to something. A part of it too is that I don't want to freak them out by having this time frame and having the conversation too early. I don't want them to think that we have to get married and have kids right away. I don't want there to be a ticking time bomb in their head too where the relationship is concerned, but I am on a time line.

Experiences with Doctors

Claire spoke about her experiences with doctors throughout her narrative. This theme arose throughout her diagnosis, surveillance, and preventative surgery. She began by discussing the first doctor with whom she met after her diagnosis.

My first experience with doctors was the breast surgeon that was originally connected through my genetic counselor. I went to him and was really big into research... So, he was doing a study that was injecting HCG into women's breast to make their breasts think they were pregnant. Let me remind you that this is my first appointment and he is asking me about this trial and if I want to take part in it...I was just so, I didn't even know what it meant, I was still trying to comprehend what it meant to be BRCA positive. And I

didn't know what I was going to do with the information. So for me, I was the wrong personality to have that conversation with. I felt like he jumped in right away before talking about what it meant for me to be BRCA positive and my surveillance strategy of what we think would be best for me and if I had any questions about what I should be doing. He was not like that. He was more of a research guy, so he said 'there are these studies that we are doing, I would love for you to participate if you want to.' He scared me. I was like, ummm, I don't think I can even attempt to think about this right now.

Claire relayed that this was a negative experience and that she felt it was inappropriate for the doctor to discuss the study with her, knowing it was her first appointment with a doctor post-diagnosis. Although she had a negative experience with this doctor, she had positive experiences with other doctors. She wanted to feel “cared” for and that her doctors “backed” her decisions. As she explained,

I doctor shopped after I didn't like the research guy. I started looking for a breast surgeon. I knew I had a year before I needed to see another breast surgeon. I was at my parents' house and there was a whole article [in a newspaper] about the BRCA gene and ... a breast surgeon. I really liked the fact that she had done a question and answer because it made me feel like she cared about the BRCA gene and she had a vested interest in it. That was important to me. So, I ended up seeing her a year after I had seen the other guy. She didn't make me feel like I was crazy or making this radical decision when I decided to get the double mastectomy. She thought that it was a good decision to make. That was probably the biggest part for me, she was really backing me on it and she was there to answer any and every question I could have asked.

Claire expressed that it was important for her to feel that her doctor backed her decisions and had a vested interest in BRCA. She felt supported by doctors when they answered her questions and supported her choices about risk prevention. She also expressed a preference for female doctors, stating that *“I generally prefer female doctors. I feel that they have better bedside manner. Maybe I just feel that they are a little bit more comforting, where the male doctors are more straightforward.”*

Challenges and Changes in Worldview

The last theme that I identified in Claire’s story was challenges that she faced and changes in her worldview. Claire reflected on what it means to her to be a previvor.

I am not trying to get through cancer, it is different. It is more about being a previvor. It is just different. It is just remembering that you have information to prevent things, but you still have the thought in the back of your mind that it could happen, but it hasn’t happened. But it is always there and affects so much. A lot of times I probably focus too much on the ‘why me’ instead of going ‘it is going to be okay and I can work through it’.

Claire perceives the experience of a BRCA previvor as being different from that of a cancer survivor. Her identity as a previvor is always present and affects many aspects of her life. When asked about how BRCA has changed her or her worldview, Claire discussed how BRCA has affected her in her relationships with others. She is cautious since her diagnosis when opening up to potential romantic partners.

Well, I think that, for me... it has brought out more of my middle child syndrome.

Because I was positive and my sister was negative, you know? It has put more a strain on my mental state and in turn a strain on dating. I have a hard time opening up to people. I am a very outgoing person, I can easily talk to people, but I feel likes sometimes I do not

want to get too emotionally connected or involved with someone early on because I put a wall up. This has been happening more so since I have been diagnosed.

Claire related that she sees family planning and dating as the most challenging aspects of her narrative. Even after all she has been through with the testing, she believes the most difficult time is “right now.”

Honestly, I feel like right now is the most difficult. The age I am and the situation that I am in, and the fact that I am not dating. This has been the most challenging. Going through the testing was scary and finding out that I was positive was scary and it took a little while to come to terms with everything and actually realize what it meant for me and how to live with it. But, right now is the hardest time. The ticking time bomb. I just turned 32 and I am supposed to get my ovaries out at 35 or shortly after, so I just feel like you know each year that goes by is getting closer and closer to that. That is going to lead to more serious choices about my life.

Claire became emotional at this point in the interview. She referred to the “ticking time bomb;” as the years pass, she feels more pressure to make decisions regarding family planning. Through the themes of diagnosis, preventative choices, prophylactic mastectomy, family planning, experiences with doctors, and challenges and changes in worldview, Claire unfolded her unique narrative.

Samantha

Samantha is a 29 year-old BRCA 1 previvor. She is an attorney. She was diagnosed with BRCA 1 genetic mutation when she was 28 years old. She inherited BRCA 1 presumably from her mother, who died from breast and ovarian cancer, though her mother was never tested. She has no siblings or other known relatives with BRCA. Samantha completed a prophylactic

bilateral mastectomy when she was 29 years of age. Samantha is single, but is in a committed relationship. I recruited Samantha from an online support group for BRCA women. The themes that arose during the analysis of Samantha's story were diagnosis, preventative choices, prophylactic double mastectomy, family planning, experiences with doctors, identity as a woman, and challenges and changes in worldview (see Figure 2 below).

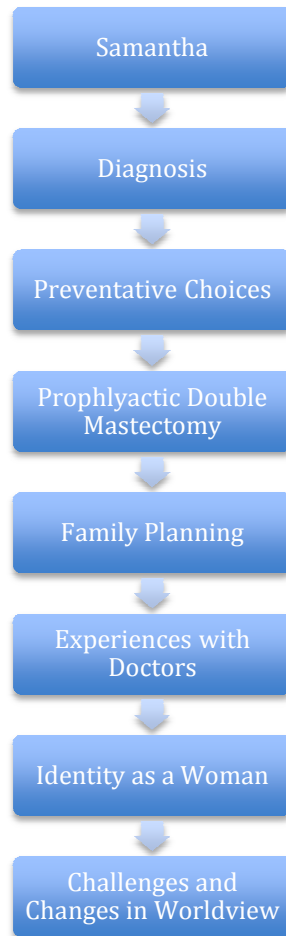


Figure 2. Within-case analysis themes for Samantha

Diagnosis

The first theme that emerged in Samantha's narrative was diagnosis. Samantha's story is different than the stories of the other three previvors because she has no known relatives with the BRCA mutation. Samantha's story began with discussing her mother, who had both breast and

ovarian cancer. After Samantha's mother died, Samantha knew of her positive results within weeks. Her mother's life and death surfaced several times throughout her narrative, both in the diagnosis theme and other themes in her narrative.

My mom had breast and ovarian cancer. I am an only child and my parents are only children and I don't know much about my family tree beyond that... I had heard about the gene, but just in passing...for whatever reason she [her mother] didn't push me to get the test... It's hard from my lens to tell, but a couple of years ago, right after she got ovarian cancer, she said, 'this might be an issue for you.' So, I think she was always concerned about my predisposition for breast cancer... Then two days after she passed, I was asking her doctors to put me in touch with a geneticist to get the testing done immediately. She passed October 17th and I had my positive results by Thanksgiving.

Samantha explained her choice to get tested after her mother's death. She revealed that her decision to wait to get the test until after her mother died was predicated on a desire to protect her mother from dying with the knowledge that Samantha might be BRCA positive.

It was the trauma of seeing her in her last days and it was time. It wasn't time when she was going through her thing. It wasn't a time or place for me to take the energy away from her when she was dying. It would have killed her to die knowing I had the gene...I already worry about my unborn children having BRCA, so, I didn't want to do that to her...I am an only child, so it would have killed her to know that.

Samantha's story is unique in that a positive diagnosis was almost a relief to her. Due to her mother's cancer diagnosis, she acknowledged that she was at high risk with or without a genetic mutation. Therefore, a BRCA diagnosis gave her structure and control with her elevated risk.

You know, it was a rough time anyway... I secretly, well not really secretly, openly wished I would have the gene. I knew if I had it that I wouldn't have to worry about the unknown, I would know that I was high risk either way, but with the positive result, the insurance company would cover everything. It is almost like it gave me more control. I cried a little bit because I was like 'God, this is going to suck,' but I had the steering wheel. I was in control.

Samantha discussed the feelings of isolation that came with a BRCA diagnosis, especially when she had few resources to turn to for information about BRCA 1 mutation.

I felt so rare, like a rare mutant at first. I couldn't find anything about it. I found some really weird websites and some astounding numbers of how few people actually had BRCA 1. I thought, I am alone and I will never find anyone that is going through the same thing.

Later in our interview, Samantha opened up about her feelings related to her BRCA diagnosis and her relationship with her mother. Much of Samantha's narrative related to her diagnosis was tied in with the death of her mother. She stated,

Thinking about when I found out, I think maybe I thought that I deserved it. Because I wasn't there for her [her mother] enough or in the right way. And in the tiniest way I felt like I deserved to get the gene because I didn't do enough for her. Maybe I wasn't the best daughter, so I deserved to understand her experience a little bit.

Preventative Choices

Samantha discussed her decision making process regarding risk prevention throughout the interview. This theme served as an important thread through Samantha's narrative, as some people in her life did not agree with her quick decisions about surgery. Samantha explained

throughout her story that many people felt that her decision to get the surgery was in direct response to her mother's recent death. Samantha agreed that, while her mother's death influenced her choice, other factors also played into her decision.

I knew the same day I found out about my results that I wanted to meet with a surgeon. They said 'don't you want to wait?' and I said 'no, I want to do this as soon as possible.' I got a lot of kick-back from a lot of people that thought that my decision was very reactionary and I was reeling from my mother's death. My dad especially...I was just like 'look' and I rattled off all of the statistics and told him it is not your decision and that this is very important to me.

Samantha explained that her emotional connection to her breast did not outweigh her past experiences with watching her mother experience cancer, when she was making preventative choices. As a child of a mother with both breast and ovarian cancer, Samantha decided that this was a cycle that she did not want to repeat in her own life for her future children:

The choice for the surgery wasn't as hard for me...I haven't fed babies with my breasts, I don't really have an emotional attachment to them. I knew because of my experience that I needed to be there for my future children. The first time my mom got cancer [Samantha] was in 4th grade. It darkened our household and I just think it is such a fucked up thing for children to have to go through. I don't want to do that to my kids, not that anybody does that, but if I can prevent it, I will.

Prophylactic Double Mastectomy

Samantha's double mastectomy was a theme that surfaced throughout her story. Samantha's experience was unique in that she faced major complications due to skin necrosis and had her expanders in for over a year, compared to the typical length of three months.

Expanders are used to stretch the skin, so that during the exchange surgery, breast implants can be inserted without the breast tissue present. Samantha had one expander filled, while the other was flat due to complications. Samantha explained how that experience affected her self-esteem and even recognition of self.

It has been a crazy year. I have had my expanders in for a year. One came out and then they had to put another back in. I had necrosis all over my chest after surgery. So, that was like a pretty big complication that set time back. I am getting my final exchange surgery for implants on Thursday. I am so excited, I can't even tell you. I am over the moon...There has been a lot of tears and sometimes, you just don't recognize yourself. For a long time, I had a right one in and nothing on the other one...I gained weight, my clothes didn't fit, I just didn't feel like myself. I didn't feel like a girl. I get now why girls get boob jobs and say 'it was for me, I didn't feel like a woman.' I get that now...

Samantha talked about the first time her expanders were filled and how she felt. She laughed at the ways she loved her breasts after getting the expanders filled for the first time, although most people would not even classify expanders with air as breasts.

The first time I got both of my expanders pumped up, I felt like a million bucks. I felt like I had just gotten my first training bra. And it's so funny because they were funny shaped and there were scars all over them, they weren't boobs by any stretch of the imagination. They were these hard plastic things, but it puffed my shirt out and it felt amazing.

Although surgeons can sometimes fill expanders during the first surgery and women can wake up with air in their expanders, this was not the case for Samantha. She went to sleep with breasts and woke up without any air in her expanders, leaving her with a completely flat chest. Samantha discussed her positive feelings about the decision to have the surgery, even after the necrosis and

other challenges. For Samantha, the privilege to live her daily life is worth more than the challenges that she faced during her surgeries. Though she does not regret her decision, Samantha's surgery and complications provided challenges to her self-esteem and identity.

Oh, I have never wavered in my decision, even after the necrosis, or the moment I looked down when I woke up. I remember waking up and looking at my dad and my boyfriend and started to cry because I woke up and saw two, giant concave dents in my chest. And that was about the only time I felt bad about it. I never felt like I made the wrong decision. I have thought 'wow, this could have been easier,' but never have I questioned it. I always remind myself, it could be cancer, and between this and worrying about if I am going to be around or not with children or a marriage...I have never felt bad, never felt sorry for myself just because I remember with my mom... it was her last week in the hospital. It was so rough on her body...when I was trying to convince the doctors as to why I wanted to get the surgery so quickly, I said 'look, I just watched my mom rot in a hospital bed, not a human being, she was a shell, a piece of a human. I watched her rot away in a coma.' I get up every day, I go to work, I go hang out with friends. Those are things she couldn't do for years, so yeah, there is just no other option. I don't question it, to me it is the only decision.

Family Planning

Family planning was a theme that emerged for Samantha when she talked about her future. She was in the process of getting her exchange surgery for her double mastectomy when we completed the interviews, and she explained that making decisions about family planning was her next step once her surgery was complete. Samantha began by talking about a new procedure called PGD that allows women to test embryos for the BRCA gene before implantation. The

process requires an IVF- like procedure; the doctor collects eggs and sperm to make an embryo. Then the doctor tests the embryos to see which embryos have the BRCA gene mutation and which do not, and implants in the uterus only the embryos without the BRCA gene. Samantha discussed what it would be like to get pregnant naturally versus using a procedure like PGD.

My genetic counselor said you can test your eggs and then implant them. I am like 'that's great because I don't want to give that to my children.' I am not sure what would happen if I just got pregnant and didn't know if I have passed the gene on or just go for it without knowing... If it was a girl, I wouldn't want to go through with it. I like the idea of freezing eggs. For me the idea of being pregnant is cute and fun, but I am not attached to how I get pregnant. I like to plan and be in control, so this procedure kind of fits my personality.

When making the decision to freeze eggs, it is also an option to remove the ovaries after doing so, to reduce the risk of ovarian cancer. A woman can keep her uterus to carry a pregnancy, while still removing the ovaries preventatively. Samantha processed the option of getting a bilateral salpingo-oophrectomy (BSO) and what that would mean for her family planning choices. Samantha is still making decisions regarding her family planning. She acknowledged that she is working through one thing at a time and that family planning and making a 10-year plan are next on her list:

Knowing what I know now, I don't think I could just do this naturally without the BSO. I need to learn a lot more about it and because I have just been trying to do one thing at a time, I haven't done too much research. Right now, it sounds like I could freeze my eggs and then get the BSO...I plan on developing a prevention plan for this in the next 10 years.

Experiences with Doctors

Samantha spoke often of her experiences with doctors throughout her BRCA journey. This theme was present throughout both interviews and Samantha had both positive and negative experiences with medical professionals. After Samantha's mother died, she was quickly put in touch with several doctors to discuss her options. The first surgeon with whom she met questioned her decision. She shared that *"the first general surgeon I met with seemed to question my decision or just question whether I was on the right path. So, I didn't like him and I didn't stick with him."*

Samantha expressed some clear preferences with respect to doctors. She wanted to trust that the doctor would be good at her job and she did not care as much about his or her bedside manner. Samantha confided that she had a great relationship with this particular plastic surgeon and she was going to be sad after her exchange surgery when they would no longer see one another.

My plastics surgeon is a very tough chick and I picked her because of that. She was really tough with me and really got to the point very quickly... I needed her to be tough throughout this process... I really just needed her to be skilled at her job, rather than comfort me with good bedside manner.

Samantha had a negative experience with a general surgeon. She did not want doctors making personal decisions for her or placing judgment on whether she should get certain procedures. She valued her doctor who was steadfast and good at her job, and she felt the other two doctors who offered their opinions were working outside the scope of their job description.

I don't really have a relationship with my general surgeon, but he was just a little bit creepy, which is why I had issues with him. He was concerned about me losing sensation

in my nipples. I really wanted to keep my nipples. It blew my mind that they thought that they had the opportunity to weigh in on that and I was like 'not your fucking decision?' I was like 'no.' I don't see why this pertains to you at all and you will either do the surgery or not, regardless of whether I choose to keep my nipples... I really wanted to keep my nipples as a semblance of recognition from the old versions. I get that there is a tiny risk, but I am taking a pretty drastic measure, so I can be okay with that itty-bitty risk.

Identity as a Woman

The theme of Samantha's evolving identity as a woman arose throughout her narrative, especially when she reflected on ways she has changed since learning her BRCA diagnosis. Samantha discussed her profession and her identity in regards to her gender. Samantha is involved in the one of the non-profit organizations that supports women with BRCA. She related several times that she and other women are finding that they have similar medical issues, apart from breast and ovarian cancer symptoms. Samantha found power in her gender through her BRCA diagnosis. She reflected on the power that women have when acting together and how BRCA previvors can act as a group to generate a foundation of power.

There were a lot of women lawyer groups and stuff and I never really identified with all of that. But now, I have totally changed all of that. I am a lot more women centric... I am a lot more women power now. Before, I was like screw women power, I am the same as a boy. I can do anything a boy can do. Now, I know women are stronger and cooler than men...As women, we can bind together and fill in holes that even doctors can't. When your doctors don't make the connections, we can use each other and what we have in our arsenals. Some guys may call that bitchy, and I don't care whatever you call it. I am

going to be insistent because it is my body... We aren't by ourselves. We have this foundation and an organization behind us and we are powerful.

Samantha spoke about her identity as a woman and her mother's influence on that identity. She revealed that she used to be more insecure about her body and tried to cover up parts of herself before her surgery, due in part to her childhood and the way she was raised. After her surgery, she explained, she feels that she needs very little to feel like a woman now and that "puff" in her shirt goes a long way.

My mom judged me harshly on my appearance. I wasn't allowed to leave the house without make-up... I still never leave the house without make-up...So, I thought the surgery would affect all of that... I was definitely at my lowest point when I had one expander in and the other was flat. I fiddled with my identity, I dyed my hair, I couldn't get back to feeling like myself...the imperfections don't bother me, but when I didn't have anything to puff up my chest, that was hard. But that was all I needed. I feel like I need very little feel like a woman now. That little puff in my shirt... I felt so sexy and I haven't lost that.

Samantha often spoke of women's strength. After her mother's death and throughout her BRCA diagnosis, she began to realize how strong and powerful women are. Samantha reflected on women in history and how women's strength can be clearly seen in BRCA previvors. Now, Samantha described feeling like one of the girls and being a part of a culture of women. More specifically, she shared that through her involvement in the non-profit organization, she has become an advocate for other women. She found an identity within herself that is closely tied to her gender as a woman and her identity as a BRCA previvor.

I think women are more inclined in history to be quiet and we are only allowed a few gripes. This has really changed my impression of women in general. It is like that Eleanor Roosevelt quote, 'women are like tea bags, you don't know what they are really made of until you put them in hot water' or something that like. That is this in a nutshell. These women are raising children, taking care of husbands, keeping a home, having professional careers and dealing with all of this. I was never a woman power person and I am now because I have seen it in action. It has changed my impression of wanting to be identified as a woman...Now it is much more of a badge of honor. I am proud. I am rubbing it in their faces [men], like 'you couldn't handle this.' Also, I have picked up so many girlfriends along this process. I feel like I am finally one of the girls now...I am definitely one of them now.

Challenges and Changes in Worldview

Along with changes in her identity as a woman and perspective on women, Samantha identified other ways she felt her BRCA diagnosis has changed her. The theme of challenges and changes was especially evident when she spoke of surgeries. She realized that she had patience that she did not know she possessed, prior to her struggles during her surgeries.

Before all of this, I never thought of myself as a patient person. It turns out I really am or I can be when I realize that there is no other option. The necrosis was the hardest experience and I had the realization that this was going to be a long process and I was going to have to be very patient... I had to come in every three to four days right after and it became this huge part of my life.

Samantha went from feeling like a “victim” to becoming an “advocate.” Samantha’s words suggest that she is working through how to acknowledge that BRCA is a part of her life as an advocate for herself and others without having it consume her entire identity.

I am a pretty private person to begin with and one of my biggest fears when my mom passed was I didn't want to be that girl who lost her mom. I didn't want that to be my identity. I didn't want to feel like a victim and the gene is another thing where I didn't want to feel like a victim. Now, after my experiences and my involvement in (nonprofit organization), I will write a post or reach out to someone (in the online support group) every day. I am an advocate. Now, I will tell anyone anything. I guess I realized how much I could help people and help build others' awareness. I just wanted to share with everyone. So, even if I was uncomfortable telling these stories, people wanted to hear it.

Samantha talked often about the support of her boyfriend. She believes her BRCA experience has changed her as a partner, in that she has become more vocal and assertive in communicating her wants and needs in her relationship since her BRCA diagnosis and surgeries.

It has also changed how I talk to [boyfriend] about stuff. Years ago, I wouldn't have talked about children in a relationship, but now I am so upfront about what we need to do about my eggs and all of that other stuff and trying to figure out how he fits into all of that. Whereas before I might have been more reserved and we are not supposed to say what we really want or make guys uncomfortable. We expect them to propose but not talk about it. And I am like 'fuck that whole song and dance routine.' I am going to tell you how I feel about things and when we are ready to do stuff. It has helped me confidence in that way.

Samantha concluded our second interview with a reflection on how she has changed. She believes the BRCA diagnosis has mended the relationships with her mother and has shaped her identity, giving her a cause to fight for. BRCA has not only changed her as a person, but has changed the way she perceives self and others.

I reflected on our first interview and when I said that I thought that I deserved the BRCA gene. I still feel that way, but I feel closer to my mom now, somehow. I feel that this diagnosis has fixed our relationship, which is weird because she is not here. But I feel closer to her and like I understand her now. If she is looking down on me in any way, she knows that I understand in some way what she went through. I have far less anxiety because I have worried about whether or not I was going to wake up from surgery. Once you see that, you don't care about other shit. I have gotten a lot of perspective and I feel pretty fearless these days... I feel so strong and so connected to this whole part of my identity. I feel special, I have a cause... I think about when you write your resume and you have hobbies and interest and they are all bullshit most of the time. I have something that is a big part of my identity now. That's real.

Amy

Amy is a 26-year-old BRCA 2 previvor. She is employed. She was diagnosed with BRCA 2 when she was 24 years old. She inherited BRCA 2 from her mother. While her sister tested negative, her mother, aunt, and two female cousins also had BRCA 2 genetic mutation. Amy completed the prophylactic bilateral mastectomy when she was 24 years of age. She is single, but is in a committed relationship. I recruited Amy from an online support group for BRCA women. The themes that arose during the analysis of Amy's story were diagnosis,

preventative choices, prophylactic double mastectomy, family planning, emotions related to diagnosis, and challenges and changes in worldview (see Figure 3 below).

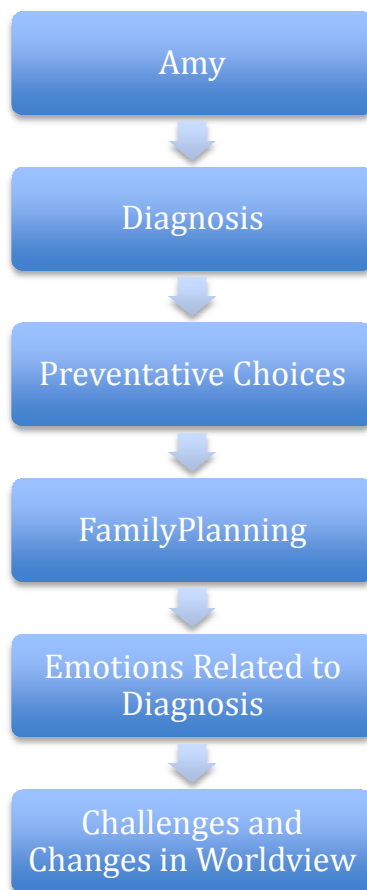


Figure 3. Within-case analysis themes for Amy

Diagnosis

The first theme in Amy’s narrative was diagnosis. Amy was aware of BRCA at a young age and her interest in finding out if she had the gene shifted at different points in her life. Amy began her narrative by speaking about her mother and her mother’s influence in her diagnosis process. Because Amy was young at the time when she learned about BRCA, she had very little interest at the time in finding out if she had the same genetic mutation that her mother had.

Well, my mom was the first person in my family to be tested... When I turned 18, I found out about it. I didn't really care though, at that point. I didn't want to be tested. My mom was like 'you should be tested.'

Both of Amy's sisters tested negative before Amy received her positive diagnosis. Again, Amy explained that at such a young age, she was not ready to process what it would mean to get a positive BRCA diagnosis. She decided to wait until she was 24 to get genetic testing.

My older sister is a lot older than me. She got tested years ago and my little sister got tested when she was 19. I waited until I was 24. My mom would talk to me about it every once in a while and wanted me to get tested when I was still under her insurance. But that is a lot to think about when you are 18 or 19, so I just didn't want to think about it.

When Amy did get tested at age 24, the decision was not based on her own desires. Rather, it was to make her mom "happy."

And then my mom went through cancer two more times after that, with thyroid and lung cancer. I don't know if it's tied to BRCA or not, but I finally gave in when I was 24 to make my mom happy. Honestly, I really didn't want to do it. Both my sisters were negative, so then when I initially saw a genetic counselor to talk about the testing, I just kind of felt I had it. It was just kind of instinctual.

Amy shared her emotional experiences when she received a positive result from her genetic testing. She felt unsure of what to do with the information. She worked through feelings towards her sisters, who both had tested negative for the gene.

Initially, the day I went to get my results, I was really neutral feeling. I had been so anxious leading up and then I just wanted to get it over with. I just started crying as soon as she told me I was positive... Initially, I didn't want to do anything with the information.

I was like 'I don't care.' I was mad, you know? I had some animosity towards my sisters for not having it, but they are so supportive. Not that I wanted them to have it, but it sucks to be the only one.

Preventative Choices

Initially, Amy did not feel that prophylactic surgeries were for her. A key shift in her thinking that resulted in her decision to get the prophylactic surgeries occurred as she spoke with other BRCA women online and realized that she was not alone. In her family, she had been the only sister with BRCA; she now found other women who were facing some of the same decisions that she was facing.

When I first heard about prophylactic surgeries, I was really turned off by it. I was like 'why would you do that if you don't even have cancer?' It seemed crazy and unnecessary. Then I did more research and spoke to women who were in the same boat and my age and had the surgery or were getting the surgery. I learned about the term previvor and found all of the support groups for women like me. And then, I don't know, I just woke up one day and decided that I wanted to get the prophylactic mastectomy. Connecting with women helped me a lot because it made me feel not so alone. I am not the only woman with this mutation. There are thousands of women who have it.

Prophylactic Double Mastectomy

Amy discussed her prophylactic mastectomy throughout both interviews; this theme was important in her narrative. After Amy decided to get the surgery, she told family and friends about her choice. Amy felt that the men in her life initially were less supportive of her decision because it was her perception that men link breasts with femininity. Though Amy was timid at

first to share her decision with family and friends due to fears of what others might think, she eventually decided that her opinion about the surgery was the most important one.

I was nervous about telling my mom. So, I told my older sister first and she talked to my mom for me. But her and my sister have both really been supportive. My dad and like the other men in my life, not so much so. They all thought it was really extreme... I really think it was due to the gender difference because breasts are seen as such a feminine part of your body that choosing to remove them before even having a cancer diagnosis seems crazy to them... In the end, I was scared of telling people because I was worried about what they would think... I had to do what was right for me.

Amy discussed at length her reservations about telling others. When telling others about the surgery, she wanted to be clear that the surgery was not for vanity, but out of necessity. Amy wanted others to know that it was not breast augmentation and she did not want people to misunderstand who she was. She explained, *“I just told people that were close to me. I also wanted people to know I wasn’t just going to get a boob job. I would have never gotten a boob job otherwise. I would never get them for cosmetic reasons.”*

Amy discussed her experience before, during, and after surgery. She was out of work for months and essentially had to halt her life to get the surgery and be taken care of by family members.

Oh man, it was scary. I decided in October to have the surgery, so I scheduled it for January and decided to get the two-step with expanders. They put the expanders in right away. I know some women wake up flat, but they filled me up quite a bit, I think I had 500 ccs in each expander. I was scared of waking up without anything and I remember waking and seeing them and I was like ‘whoa, I have boobs already?’ I had the

expanders for three and a half months. They were pretty hard and it was uncomfortable, mainly because they had to cut my pectoral muscle to put them underneath. I couldn't work for two months... I just put my whole life on hold.

The topic of nipple sparing surfaced while Amy was discussing her choice for the prophylactic mastectomy. Amy chose nipple sparing over tattooed nipples. Keeping her nipples was important to her and helped her feel that her breasts were still hers. She pointed out that while she is doing this to prevent cancer, it is still her “choice” and she chose to keep her nipples knowing the risk involved.

I did nipple sparing, which I am really happy about. Yeah, I know it's controversial. I am doing this so I won't get cancer, so why would I keep my nipples? At the same time, this is a choice, and some women want to at least keep a part of themselves. And for me, it makes me feel like they are still my boobs.

Family Planning

Amy discussed family planning several times throughout her interviews. BRCA has affected her romantic relationships in the past, and it seemed important to Amy that her partner support her decisions and her recovery during surgery. She shared, “*I had a boyfriend during my surgeries, but we broke up mainly because he wasn't there for me the whole time...my boyfriend now is really supportive. He loves the fact that I did that [the surgery]. He thinks I am strong.*”

Amy described telling her current boyfriend about BRCA and her preventative mastectomy. For her, intimacy meant that a BRCA discussion was necessary because of her prophylactic mastectomy. Amy was nervous and unsure of how to bring up the conversation; however, her boyfriend was proud of her decision.

I was nervous to tell him. Because I feel like if a guy sees my boobs, they do look different. They don't look like a boob job, but they don't look real. There are scars and stuff and also in certain positions I get ripples. So, pretty much the first time we were going to be intimate, I told him.

With respect to having children, Amy discussed adoption versus having biological children. Amy is in the beginning stage of thinking about having children, something she believes she would not be thinking about at this stage in her life if not for BRCA. While she is not ready to have children for a number of years, she has thought about the struggle and what it might feel like to have a daughter knowing the heritability of BRCA.

I kind of want to adopt children. I would like to have my own too, but having the BRCA gene makes it difficult because I do not want to pass this on. It's just one of those things. I am not in a place where I am trying to have a child, I am going to wait until I am at least 30. I just try not to think about it, but it comes up. I definitely think about it more than I would have at this point because of having BRCA...if I do have a baby, especially if it's a girl, I would want to know right away and I know you can't do that until they are an adult. I would feel like I would want to know, I would want the best for my children. I am sure that is why my mom really wanted me to get tested.

She realized how her mother must have felt when she was urging Amy to get tested at 18 years old. Amy stated that the idea of adoption came after she learned about her positive mutation status. She realizes that her feelings may change after she gets married, but for now she is considering adoption to prevent the gene from moving further into her family tree.

It came from finding out that I have BRCA. When my mom found out that I had the gene, she blamed herself. I told her it wasn't her fault, it was 50/50, you don't get to choose the

genes you give your kids. So, right now, at my age, I don't want to have my own kids, but maybe when I am older I will want to have a child with my husband.

Amy has considered the PGD procedure to select embryos without the BRCA gene. For Amy, it is important to eradicate the gene through means like adoption, but a process like PGD is not right for her. Amy is not ready to have children, but she has thought through family planning and what that might look like for her down the road.

My genetic counselor told me about this [PGD], I think that is so controversial. I don't think it's essential to have a child that is not BRCA, but is not as extreme as Down syndrome...it is a higher risk for cancer, but your life isn't over. Adoption is a good idea anyways, there are so many kids out there and overpopulation in general. I am a hippie person like that in general. The genetic stuff isn't for me.

Emotions Related to Diagnosis

Amy's feelings related to her diagnosis were expressed throughout her narrative. She likened her BRCA experience to a posttraumatic reaction. She explained that anxiety surfaced after learning about her BRCA status and it changed the way she felt on a day-to-day basis.

Just finding out that I had the BRCA gene caused me a lot of anxiety that I am still dealing with. Like post-traumatic stress for me...I guess I have a family history of anxiety...but I wasn't an anxious person before I found out and now I am more anxious about a lot of things. It feels like no matter what I do, I cannot get away from it.

Amy likened her experience to having cancer, in that she almost felt that she did or that she was preparing herself to get cancer. Amy denied that her choices were brave; she saw them as choices that she had to make.

I think finding out that you have the BRCA gene is pretty much like telling someone that they will get cancer in their life, but they don't know when. It is basically like getting a cancer diagnosis, but you don't have cancer yet. That is what it felt like for me. So, it's hard because there are people that actually do have cancer, so you don't want to compare yourself to them, but it's hard to process that you are going to get it probably. A lot of people say 'oh you are so brave, wow, you are amazing.' I don't see it that way. I just see it as something that I had to do to move on and not to worry about it my whole life. I had to be strong to get through it, but it was something I had to do.

Challenges and Changes in Worldview

The theme of changes after a BRCA diagnosis surfaced mostly in Amy's second interview. It seemed that she had reflected in the week since our previous interview. She began our second interview by expressing the ways in which she has changed. Learning about BRCA and being proactive about her health has changed her exercise and habits. Amy described feeling "stronger" and changed as a woman.

I think knowledge is power...I do feel different. More empowered and stronger. Like for example, I never wanted to run before and now getting through my mastectomy and all of that, I am running a marathon in December. I have the strength to recover from surgeries, so I wanted to do better things with my life and grow as a person... I can cry about it all I want, but I just try to get over it and be better.

Amy believes her perspective has changed. Her experience with BRCA affected the way she viewed herself, and it altered her perception of others. Many people in Amy's life did not know that she was struggling with BRCA and the BRCA choices, and she now realizes that we never

really know what others are going through. BRCA has colored the way she looks at the world and Amy relayed that it was in a positive light.

One of the things that has affected me...is that you never know what struggles people are going through. So, I have been trying not to judge people before you know their story. Kind of like I didn't want people judging me for thinking I just got a boob job. If they would without asking me first and then they found out why I have fake boobs, they would feel like assholes when they find out the real reason. I just try to empathize with people and not to judge them and try to fully understand their stories.

Amy spoke about ways this journey has been challenging for her, including some systemic issues and dealing with the health care system. She explained that she thought that she had gotten past the surgery, but would then get a bill to remind her and she had to dispute it, forcing her back in the BRCA mindset all over again. What really seemed to help Amy was her connection to other BRCA previvors.

I think the physical recovery, well, more than that, dealing with health insurance and the financial burden...Even though things are covered, I got so many bills I had to dispute...but it felt that they were trying to get money out of me. It was difficult getting bills paid for. For my first surgery they sent me a bill for \$150,000. I actually went and talked to women [on the social media group] to get their opinion... It brought up a lot of emotions about our health care system. Also, before Obamacare I would have gotten denied for health insurance because of having the BRCA gene.

Amy defined what previvor means to her. She began talking to other BRCA previvors and has felt comforted by other women and by now returning the favor.

I relied on them [other women in the social media support group] a lot before my surgery and recovery ... I used to show photos of my progress to show other women what to expect. I just did it really to help other women...I was googling the term previvor... I found the [social media group]. Basically, instead of being a survivor, something that had cancer and survived, you are surviving it before you get it. You know you are high risk. It is an empowering term.

Linda

Linda is a 30 year-old BRCA 1 previvor. She is employed and works as a yoga instructor and circus performer. Linda was diagnosed with BRCA 2 at age 21, though she has known about the gene and her family's predisposition since she was 14 years old. Linda inherited BRCA 2 from her mother. Her sister, mother, and two aunts all were diagnosed with BRCA and both her sister and her mother had breast cancer. Linda chose surveillance for risk prevention, but is contemplating getting a double mastectomy preventatively in the near future. Linda is single, but is in a committed relationship. I recruited Linda from an online support group for BRCA women. The themes that arose during the analysis of Linda's story were diagnosis, preventative choices, prophylactic double mastectomy, family relations and family planning, traditional versus alternative medicine, and changes and identity (see Figure 4 below).

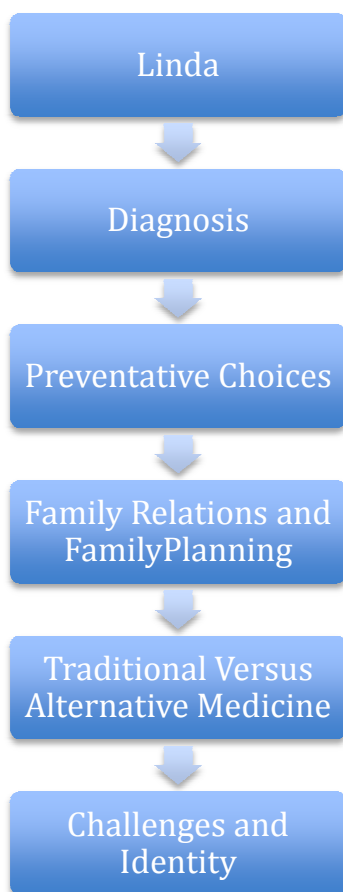


Figure 4. Within-case analysis themes for Linda

Diagnosis

Linda's narrative differed from that of the other participants in that she has known about the BRCA gene since she was in early adolescence. She explained that her family was one of the first families to take note of the genetic component of breast cancer and she cannot remember a time when this was not a part of the life of someone in her family. Linda and her family suspected that there was a genetic component to their cancer diagnoses prior to understanding what BRCA was. Linda began her narrative by detailing when she first learned about BRCA, when her aunt said "*there seems to be something hereditary going on here.*"

I have known about it for a long time, since I was really young. So, it is something where I don't have a specific memory of when I found out about the gene. I was probably 14.

...My mom and two aunts have the gene, so they were going through that when I was really young. I think my family was one of the earlier families to start researching the gene. My mom and my aunt, who both had cancer, found out about the gene after [their cancer diagnosis].

Linda discussed her decision to get genetic testing. Linda and her sister wanted to test together. Linda said that, while it was an appropriate age for her sister to find out that she was BRCA positive, she still felt that she was fairly young to learn this information.

I have a sister that is 8 years older than me... I first remember we had a serious conversation about testing when I was 17 and I remember deciding not to do it then and I decided to do it a few years later. So, my sister was 28 and I was 20 or 21, and we decided to test together. So, it was a good age for my sister, but I was pretty young.

Of the four previvors I interviewed, Linda learned that she was BRCA positive at the youngest age. At 17, Linda had already made the assumption that she would test positive, so years later at 21, she was not surprised to receive a positive diagnosis.

I remember when I was 17 and decided not to test, I kind of just assumed that I had it. So, I was already assuming that I had it and testing really was just to confirm or find out that maybe I don't. So, finding out that I did have it, I was not surprised.

Well, since I found out when I was so young, it has been a really long process, really. I found out when I was 21 and at that time they said that you can take Tamoxifen preventatively or you can get a double mastectomy. And I was 21 and remember thinking 'well, fuck you. I don't want to do any of it.' It was shocking. Like, what? Surgery? Stop talking to me.

Linda's words suggest that she felt her options seemed unreasonable when she heard them for the first time at the age of 21. Her experience with the genetic counselor was not positive. Linda expressed frustration with the impersonal nature of the call and the limited amount of information that she was provided. Later, Linda discussed less traditional options for BRCA women and cancer survivors. She felt that, in traditional medicine, she felt limited to the options that doctors presented to her to prevent cancer.

It was all done over the phone. And so, it was a guy on the phone and it was pretty impersonal, really. The fact that it was over the phone and the way that he delivered the information. It was very cut and dry. We got a packet...and it was really just repeating the information in the pamphlet and that was it. I guess I need to put this in context for you too. My mom kind of rides the line between conventional and traditional medicine and then my aunt is adamantly dedicated to alternative medicine. So, I was really young and I didn't really know. So, just to have someone tell me you can get a mammogram or take this chemotherapy drug, like right off the bat. Like that is it? That is all of the information you are going to give? They didn't tell me about F.O.R.C.E or give me any resources.

Preventative Choices

Linda has been active in her surveillance in recent years and though she has contemplated getting the prophylactic mastectomy, she has yet to complete the surgery. She has chosen surveillance over surgery since her diagnosis.

The hardest part is right now where I am really thinking about doing the surgery. I have everything set up, so I am almost planning to do it. I am overwhelmed by it...It's a lot...I guess I am 90 percent sure that I am going to do it but I am still really deciding. My main

question is still what does it feel like after you heal? I am fine spending a year trying to recover, but what is it really like once you are healed?

Linda expressed concerned about her range of motion and appearance after the surgery, especially because she works as a fitness instructor. Linda contemplated that the choice to get surgery would affect her ability to do her job. Movement is important as a yoga teacher and she worries that she will not be able to move in the same ways if an implant is placed below her pectoral muscle.

My job six days a week, I am in a tank top in front of 30 people doing push-ups. Especially push-ups because they put the implants underneath your peck muscles. So, I think I would probably have to take 6 weeks to two months off... for each surgery. So, I don't even know. That is a huge question that I have to answer in what can I really expect.

Linda expressed firm opinions on the controversial topic of nipple sparing. It was important for her breasts to appear normal, even if they did not feel like her original breasts did. Linda was also concerned that the appearance of her breasts might affect her sex life. Linda is the only previvor of the four I interviewed who had not yet gotten a double mastectomy preventatively. She had contemplated what the experience might be like and her concerns regarding the procedure.

Yeah, I really want to do the nipple sparing. If I can't do the nipple sparing, it would be a harder choice. Because just the images that I have seen from the people that have done the nipple sparing, it still seems really real and natural. Which for me feels important. It is like I know it is going to feel weird inside my body and feel strange and take some getting used to and probably never feel normal. But if I can at least look normal,

especially because I am an active person. I am used to getting dressed in a locker room full of people all of the time. I think just with my sex life, if they look normal, it would allow me to let that go. I don't know.

When I spoke with Linda after our second interview, she revealed that she was on her way to travel to meet a team of doctors to discuss setting up appointments to get the prophylactic mastectomy.

Family Relations and Family Planning

All BRCA diagnoses are tied in with familial experiences, but in Linda's case breast cancer touched the lives of many of her immediate relatives, which affected her decisions regarding risk prevention. Linda said that her sister's cancer diagnosis affected her in a way that was different from when her other female relatives got cancer. It seemed that when her sister got breast cancer, it was truly personalized for her.

My sister found out she was pregnant with her third child and then found out that she had breast cancer four days later. It affected me like crazy... It was so crazy, they found a specialist in the field and she had a double mastectomy while she was pregnant and went through chemo while she was pregnant... basically after that, I started being super on top of my surveillance and really thinking about doing the prophylactic surgery. That was the end of 2008 and I am still active in my surveillance now.

Linda also witnessed her mother be diagnosed with breast cancer twice. While Linda did know while she was growing up that her mother had one breast, when her sister lost her breasts and hair while pregnant, it really "hit home" that this could happen to her. After her sister's diagnosis, she was much more active in her surveillance and research regarding surgery.

So, my mom had it first when she was 27, so she had a single mastectomy and nursed us on the other boob. She got cancer before we were born. So, I grew up seeing my mom with one breast and that didn't bother me, it seemed normal. But then when I saw my sister lose her breasts, and lose all of her hair and be pregnant at the same time and just the trauma with all of that. And the fact that this was my sister, so it hit home so much harder.

Linda reflected on the fact that BRCA is a family diagnosis. She described BRCA as a “family experience” and something that she shares with all of her female relatives.

It is such a family experience. So, getting ready for the doctor's appointments, I have spent all of this time getting my family history organized. It is like 'Jesus, my great-great grandmother died from breast cancer and my other great-great grandmother died from breast cancer' and like when you start going back and there are more relatives and they have all died from breast cancer. There is something there about this thing that I have in common with all of the women in my family.

As we were talking about her family, Linda began to explore the topic of family planning and how BRCA has affected her own plans for children. Linda went back and forth throughout the interview wondering if BRCA affected her desire to want to have children. For as long as she can remember, she has not wanted children and it was not part of her life plan. However, because she has known about BRCA from such a young age, she wondered how much her knowledge of BRCA affected her desires to start a family. Linda stated that, if she changed her mind and did want children, she would want to adopt due to BRCA and other medical issues.

It is a weird thing. I wonder since I found out about the gene at such a young age... if it has affected my desire to want to have children. But I don't think it has, I just don't think

I am a kids person. I have another health issue going on with my uterus. So, I think if I did have children, it would be really premature or I would have to take a lot of drugs to make sure it went full term. I am not a heavily medical person, so I would rather adopt if we want to have kids.

Traditional and Alternative Medicine

From the outset of our interviews, Linda was very passionate and interested in the differences between traditional and alternative medicine to both prevent and treat cancer. This played a role in her BRCA decisions. Linda noted that doctors' support is contingent on their tie to traditional medicine. She felt that the surgeons and medical professionals with whom she had previously met were supportive, as long as she was following "their" plan, and when other options were suggested, doctors were not as supportive.

I guess where the problem is that I feel that the system is broken. There isn't a connection between alternative medicine and more conventional medicine. So, as long as I am going to the doctor and thinking about the surgery and absorbing the information that they are giving me, they are supportive, but if I start to say that I want to do something off the grid, there is nowhere for that conversation to go.

Through witnessing her sister go through chemo while pregnant, Linda realized that modern medicine can be extremely effective. However, she believed traditional medicine is presented as the only option, whereas other viable treatment options that are less traditional are not even included in the discussion or are cast off as not viable.

I think the thing that frustrates me the most now, when I was younger I was anti-establishment about medicine. Now, I can see the miracles that modern medicine can do,

but it is more so frustration about the lack of integration between traditional medicine and alternative medicine.

Linda explored alternative medicine after her mother was diagnosed with breast cancer for the second time. Linda felt that there were systemic issues that kept traditional and alternative medicine as separate practices rather than integrating them while her mother was deciding how to treat her cancer. Linda shared ways she wanted things to change systemically.

My mom was first diagnosed when she was 27 and she was actually diagnosed again when she was 54....She went through a lot of stress around what she was going to do. She said, no, she wasn't going to do chemo. We helped her research other options. I can't really remember specifics but it was kind of insane- like there would be a really effective alternative cancer treatment. And it would be kicked out of the country because it was really effective and it was just like a really natural herb. And the chemo companies had like specifically completely kicked the entire thing out of the country and you had to go to Tijuana to get the medications.

Challenges and Identity

Linda knew about BRCA from a young age; this knowledge has affected her growing up and her formation as an individual and a woman.

I feel it is so weird to even think about the fact that I have this gene that gives me this risk. And I guess I am supposed to be thankful that I know ahead of time...but it is kind of heavy information. In some ways it is totally fascinating and crazy.

Linda has felt oppressed as a woman with BRCA. She likened her experience to the gay community in her city and said that she felt that she could relate because she, too, felt disenfranchised while dealing with a scary thing without support or understanding. She believes

the system does not support BRCA women. While doctors may understand the medical aspects of the surgeries, they may not be able to relate to the psychosocial effects of surgery or living with a BRCA diagnosis.

I have many friends that are queer and have grappled with their sexual identity. So, I think I gravitated toward that. But I am totally straight, but I gravitated toward that because I empathize with dealing with a hardship with something that might affect your gender. If only because you are dealing with this very huge kind of traumatic situation with very little support. It can be really alienating in some ways. It is like, who can I talk to about this? Who gets it? Trying to deal with insurance to see if they are going to cover an MRI, the system is not set up to deal with these kinds of questions. So, whether they are setting it up to be that way or not, it is a big headache. Doctors don't even know. Maybe it is a surgeon who has done this surgery a million times, but they have never had the surgery done to them.

According to Linda, the hardest part of her journey has been the isolation and feeling that she is not in the same place developmentally as her peers.

There are so many different ways it has been challenging. I guess I would say the hardest part is that isolation combined with how it seeps into every part of your life. So, knowing that I have that risk affects all of the different parts of my life and then because of that it is really alienating...the people around me in my community and my peers aren't affected by the same thing. So they are making different decisions and life choices. Or there is this very significant way in which they are choosing their life and it's different than mine and that difference is really alienating. I think that is the hardest part, really.

Linda expressed the resentment that she felt towards friends who did not have to experience the same things.

It makes me kind of angry and depressed at the same time where like my friends are still young and partying and being carefree and before any of my friends, I felt like I couldn't keep doing that and I had to get a better job to pay for health insurance and keep better organized, so I could be on top of this whole surveillance thing and this mental effect of having to do that. I felt like I couldn't be carefree or go party with my friends. I got angry that they didn't have to do that.

At the end of our second interview, Linda questioned how much BRCA has shaped her identity. She found it difficult to tease out her identity apart from BRCA because she grew up knowing about her risk. She began to ask questions regarding the extent to which her choices about family planning and career were due to managing her BRCA risk or whether those were the choices she would have made regardless of whether she was BRCA positive. In the end, Linda said she accepted who she was and that BRCA was a part of all of that, so essentially, she did not feel that she could separate the two.

For me, I think it kind of pushed me towards not having kids or not a family or not to do any family planning at all. Also, I have been so athletic my whole life and I have a natural passion for that, but I heard the statistics that exercising reduces your risk [for breast cancer] by 50 percent. When I found out that I had the gene, I was doing hardcore competitive rowing and I was horseback riding. I remember thinking 'oh well, if exercise reduces your risk so much, then maybe that is what I should do with my career and become a fitness instructor.' I think that has done weird things to me. Like I am a yoga and Pilates instructor and was an aerial circus performer. But it has kind of given me

this obsession with exercise because then that has become my career. I love it, I totally love it, but at the same time I think 'how much has this cancer risk totally affecting me doing this?' And sometimes I just want to break out and do something totally different.

Across-Case Analysis

After conducting the within-case analysis of each participant's narrative, I completed a cross-case analysis through coding. Initially, the data were coded for each individual narrative. Then in a second step, I began to look for how the codes converged across narratives. Through this process, I began to identify overarching themes that existed for multiple participants. I then labeled all of the overarching themes that existed for two or more participants and also paid attention to the degree of emphasis that the participants placed on the themes. After taking a step back from looking at the overarching themes, I chronologically ordered them to get a better understanding of the across-case themes. The overarching themes began to form a cumulative narrative of the participants that included the overarching themes of diagnosis, preventative choices, from isolation to connection and empowerment, family planning, and challenge and changes in worldview.

Diagnosis

Claire, Samantha, Amy and Linda all shared the overarching theme of a diagnosis experience. This overarching theme is presented first because each previvor's BRCA narrative began with her diagnosis story. Without being prompted, the participants shared the ways in which they had learned that they were BRCA positive. They recounted several components within their diagnosis experiences, including when they first learned about the BRCA gene, when they decided to get genetic testing, how some of them sensed that they would get a positive

diagnosis before hearing their results, and what their reactions were after learning of their positive mutation status.

Learning about BRCA

Claire recalled when she heard for the first time that BRCA runs in her family. *“When I heard my dad had BRCA 1, I just don’t think I knew what it meant... I don’t really remember feeling strong one way or the other about it.”* Along a similar vein, Amy remembered that when she first found out about the BRCA gene, she didn’t have a strong reaction. She stated that, *“When I turned 18, I found out about it. I didn’t really care though, at that point. I didn’t want to be tested.”* Samantha heard about BRCA *“in passing,”* as a result of her mother’s concern about Samantha’s genetic predisposition. *“Right after she got ovarian cancer, she said, ‘this might be an issue for you.’ So, I think she was always concerned about my predisposition for breast cancer.”* Linda learned of BRCA at such a young age that she does not specifically remember when she first heard of BRCA. *“I have known about it for a long time, since I was really young. So, it is something where I don’t have a specific memory of when I found out about the gene. I was probably 14.”* All four participants learned of BRCA from family members. Claire’s father tested positive before she received testing, Samantha’s mother suspected that Samantha might have the gene, Amy’s mother alerted her about testing when she was 18, and Linda has known about BRCA since the age of 14 due to her family’s history with breast cancer. The overarching theme of learning about BRCA highlights the fact that BRCA is a familial diagnosis and that previvors often first hear about the gene from a family member.

When to Get Tested

After Samantha, Amy, and Linda learned about the BRCA gene, a significant decision for them entailed whether to get the genetic testing to learn if they had the gene. For Samantha, it was

witnessing her mother's struggle with breast and ovarian cancer that impacted her decision and the timing of her testing. Samantha shared that *"it was the trauma of seeing her in her last days and it was time. It wasn't time when she was going through her thing. It wasn't a time or place for me to take the energy away from her when she was dying."* Although Amy learned about BRCA at 18, she waited to get tested until she was 24. She shared her reasons for getting the testing: *"I finally gave in when I was 24 to make my mom happy. Honestly, I really didn't want to do it."* Linda's reasons were different from those of Samantha and Amy. She wanted to test with her sister, so that they could share the experience. As she stated, *"So, my sister was 28 and I was 20 or 21, and we decided to test together. So, it was a good age for my sister, but I was pretty young."* For Samantha, Amy and Linda, family members were important in the decision on when to get tested. Samantha wanted to wait to get tested until after her mother died, as to not take attention away from her and safeguard her from dying with the knowledge of Samantha's diagnosis. Amy explained that she got genetic testing to make her mother happy. Linda said that she wanted to get the testing at the same time as her sister, despite their eight year age gap. For these participants, the overarching theme of when to get tested was based on family dynamics, again reaffirming the fact that BRCA is a familial diagnosis.

BRCA Intuition

Claire, Linda, and Amy all felt an intuition that they had the gene, prior to receiving their results. Claire said that, when she received the call from the genetic counselor, *"I knew before she even said anything."* Similarly, Amy stated, *"I just kind of felt I had it. It was just kind of instinctual."* Linda "assumed" that she had the gene prior to her testing at age 21; she stated that *"I remember when I was 17 and decided not to test, I kind of just assumed that I had it. So, I was already assuming that I had it and testing really just to confirm or find out that maybe I don't."*

Claire, Linda, and Amy all knew of their parents' positive mutation status before seeking out their own testing and they therefore knew that they had a 50/50 chance of inheriting the gene. However, the women seemed to feel that they would have positive results based on their instincts and assumptions.

Reaction to a Positive Result

Claire, Samantha, and Linda discussed their reactions to receiving a positive result after getting tested. Claire recalled the intimate details of the moment she found out that she was positive for BRCA 1 genetic mutation when she stated, *"It was dark outside and I remember she told me, and I was okay on the phone and I called my mom and started crying. My mom came over and we talked about how it was better to know."* Samantha, due to her mother's breast and ovarian cancer diagnosis, acknowledged that she was going to be at risk for breast and ovarian cancer with or without a BRCA diagnosis. She explained that the BRCA diagnosis gave her a sense of control. *"I cried a little bit because I was like 'God, this is going to suck,' but I had the steering wheel."* Like Samantha, Amy cried when she learned that she had tested positive, but she also felt angry. *"I just started crying as soon as she told me I was positive... Initially, I didn't want to do anything with the information. I was like 'I don't care.' I was mad, you know?"* Linda's feelings were more akin to confusion, and feeling limited in her choices after learning of her positive mutation status. She shared, *"So, I was really young and I didn't really know. So, just to have someone tell me you can get a mammogram or take this chemotherapy drug, like right off the bat. Like that is it? That is all of the information you are going to give?"* When explaining what happened after learning of their positive results, all four participants focused on feelings to describe their experiences. Claire, Samantha, and Amy all shared that they cried, while Linda explained that she felt angry about her limited prevention choices.

Preventative Choices

After learning of their positive mutation statuses, Claire, Samantha, Amy, and Linda were faced with preventative choices. Surveillance did not surface as an overarching theme because it was significant only in Claire's narrative. Previvors choose to monitor their risks for both breast and ovarian cancer through surveillance. Often surveillance precedes decisions about getting the prophylactic surgeries. Linda was active in her surveillance at the time of the interview; however, it did not emerge strongly throughout her narrative. Among the themes that did arise when discussing preventative choices were prophylactic double mastectomy, nipple sparing, and previvors' experiences with doctors.

Prophylactic Double Mastectomy

After a surveillance scare, when a spot had to be re-checked after reviewing one of Claire's mammograms, Claire decided to get the surgery. She explained "*I don't want to have to deal with this and... I didn't want to live in the anxious place anymore of going through surveillance.*" Claire had a two-step surgery, with expanders. She explained her choice: "*So, I ended up doing the expanders. I could have done the one-step, but it made more sense to do the expanders because you get to play around with the size. I felt like I had more control with the expanders.*"

Samantha, in contrast to Claire, chose surgery without any period of surveillance. "*The choice for the surgery wasn't as hard for me... I knew because of my experience that I needed to be there for my future children.*" Samantha also opted for a two-step procedure with expanders, but her surgery had complications, which she discussed. "*I have had my expanders in for a year. One came out and then they had to put another back in. I had necrosis all over my chest after surgery. So, that was like a pretty big complication that set time back.*"

Amy, like Samantha, chose to have the surgery with little to no surveillance period. *“When I first heard about prophylactic surgeries, I was really turned off by it...It seemed crazy and unnecessary. Then I did more research and spoke to women who were in the same boat and my age and had the surgery or were getting the surgery.. I just woke up one day and decided that I wanted to get the prophylactic mastectomy.”* Amy also elected for a two-step procedure with expanders and *“had the expanders for three and a half months. They were pretty hard and it was uncomfortable, mainly because they had to cut my pectoral muscle to put them underneath.”*

At the time of the interviews, Linda had not yet gotten the prophylactic surgeries. She discussed her reservations, stating that *“the hardest part is right now where I am really thinking about doing the surgery. I have everything set up, so I am almost planning to do it. I am overwhelmed by it... My main question is still what does it feel like after you heal?”*

For Claire, her choice to get the surgery was prompted by surveillance fatigue, while Samantha seemed propelled by observing her mother’s death. For Amy, it was connecting with other previvors who had previously had the surgery that pushed her to make her decision. Linda had reservations about the surgery because of fears of what it would be like long term, in terms of her mobility and appearance. Claire, Samantha and Amy elected for a two-step procedure with expanders versus a one-step procedure where the implants are put in directly following breast tissue removal.

Nipple Sparing

Nipple sparing is a choice that previvors can make to keep their nipples when opting for a prophylactic double mastectomy. Some participants described nipple sparing as controversial because there is a small risk of a cancer diagnosis when choosing to spare the nipple. To eliminate risk to the greatest extent possible, doctors may recommend removing the nipple and

using tattooed nipples as a replacement. Also, sometimes it is impossible to keep the nipples due to complications like necrosis. Each of the participants discussed her feelings and thoughts on nipple sparing.

For Claire, the choice to keep her nipples was directly tied with her relationship status. Because she was not currently in a relationship, it was important for her to keep the appearance of her breasts. Some of those close to her questioned her decision to remove her breast tissue, yet still keep her nipples. Claire explained her choice, stating that *“it was important for me to keep my nipples because I am single, for me I don’t want to have to deal with dating and tattooed nipples. It was important for me to keep a normal appearance of my breasts.”*

Samantha was surprised that doctors felt that they could weigh in on her decision on whether or not to keep her nipples. She stated, *“It blew my mind that they thought that they had the opportunity to weigh in on that and I was like ‘not your fucking decision.’”* Similar to Linda, Samantha wanted to keep her nipples *“as a semblance of recognition from the old versions. I get that there is a tiny risk, but I am taking a pretty drastic measure, so I can be okay with that itty-bitty risk.”*

Amy acknowledged that, when she elected to have the surgery, the choice to keep her nipples was hers. She wanted to keep a part of herself and her nipples were a way to feel like she had the same breasts as before the surgery. She stated that she was *“really happy about”* her choice, as it made her *“feel like they are still my boobs.”*

Linda has yet to have a preventative double mastectomy, but without the nipple sparing, she is not sure she would go through with the surgery. She wanted her breasts to appear normal and she was also worried about how losing her nipples would affect her sex life. It was important to her to “look normal” even though she is concerned that she may *“never feel normal.”* All four

participants wanted to keep their nipples for appearance reasons and to still feel like themselves, despite their choice to get their breast tissue removed.

Experiences with Doctors

All four participants discussed their experiences with doctors at different points in their stories. Claire, Samantha, Amy, and Linda presented both positive and negative experiences they had throughout the diagnosis, surveillance, and surgical processes.

Claire discussed a positive experience she had with a doctor. She wanted to feel supported in her decisions and she did not want her doctor to make her feel “crazy” for making certain risk prevention choices. She wanted her doctor to have a vested interest in BRCA and her case. As she stated,

She didn't make me feel like I was crazy or making this radical decision when I decided to get the double mastectomy. She thought that it was a good decision to make. That was probably the biggest part for me, she was really backing me on it...

Claire expressed a gender preference for doctors based on her experiences. *“I generally prefer female doctors. I feel that they have better bedside manner. Maybe I just feel that they are a little bit more comforting, where the male doctors are more straightforward.”*

Samantha described a negative experience with a general surgeon. She did not like that this particular doctor felt that he could weigh on her decision making process around the decision to keep her nipples. *“It blew my mind that they thought that they had the opportunity to weigh in on that and I was like ‘not your fucking decision?’”*

Amy discussed her experience with her surgeons who performed her prophylactic mastectomy. It was important to Amy that the doctors did not question her choice to get the

surgery. Amy said, *“they were both really good... They never questioned my choice, so I felt comfortable with them.”*

Linda, when asked about her experience with doctors, relayed her experience after her diagnosis and her first conversation with a doctor about BRCA. Her experience was unique among my participants in that her first conversation with a doctor about BRCA was over the phone rather than in person. She explained, *“it was all done over the phone. And so, it was a guy on the phone and it was pretty impersonal, really...It was very cut and dry.”* Linda also discussed her perception of doctors prior to her sister’s cancer diagnosis, stating that *“Before my sister’s diagnosis [cancer], I was much more in the camp of not trusting doctors and the insurance system in general, thinking it is corrupt that it is awful and broken.”*

All four participants discussed both positive and negative experiences that they had with various doctors. Claire, Samantha, and Amy, the three participants who have had the surgeries, expressed that they wanted to feel supported by their doctors in their decision to get the surgery. Linda felt at times that she could not trust doctors due to the corrupt system. The participants had varied experiences with doctors but it seemed that they wanted to feel validated in their decisions and “backed” by their doctors, regardless of their decisions or course of treatment.

From Isolation to Connection and Empowerment

All four participants experienced a spectrum of feelings that progressed from isolation to feeling connected to other women and empowered in their diagnosis.

Isolation

An overarching theme for all four participants was feelings of isolation. BRCA is a rare diagnosis and, although there are women all over the world with both BRCA 1 and BRCA 2 gene mutation, the participants expressed feeling alone at different points in their journeys.

Claire and Samantha expressed feeling isolated at the beginning of their stories, directly following a diagnosis, whereas Linda explained that she continually feels alienated from her peers due to the ongoing struggles related to her BRCA diagnosis. Amy's sense of isolation was more in relation to the fact that her sisters both tested negative for BRCA, while she tested positive.

When Claire first learned of her BRCA diagnosis, she did not know any other women with the diagnosis. For the first year, or longer, she felt alone. As she stated,

For me, it took a year, or maybe a year and a half, to fully digest it and really think what I was going to do. And I didn't know anybody either at the time that had BRCA, so I felt kind of alone.

Samantha described feeling like “a rare mutant” when doing initial research about BRCA 1:

I felt so rare, like a rare mutant at first. I couldn't find anything about it. I found some really weird websites and some astounding number of how few people actually had BRCA 1. I thought I am alone and I will never find anyone that is going through the same thing.

Amy's sense of isolation related to being different from her two sisters. She reflected, “*I had some animosity towards my sisters for not having it, but they are so supportive. Not that I wanted them to have it, but it sucks to be the only one.*”

Linda expressed that she felt isolated throughout her BRCA journey.

I guess I would say the hardest part is that isolation combined with how it seeps into every part of your life. So, knowing that I have that risk affects all of the different parts of my life and then because of that it is really alienating, and then the same thing doesn't affect the people around me in my community and my peers.

After Claire, Samantha, Amy and Linda received their diagnoses, they looked to those in their immediate circles: friends, sisters, and peers. When they realized that very few or none were having the same experiences, they felt alone and isolated. Samantha and Linda shared that they were not given the resources to find other previvors at the time of their diagnosis; they sought out fellow previvors on their own through social media, websites, and support groups.

Connecting with Other Women

Both Samantha and Amy discussed connecting with other women throughout their BRCA journey. At different points in their narratives, both expressed feeling alone and then finding other women to relate to, changing their perspectives.

Samantha perceived a shift in her connections with other women after learning of her BRCA diagnosis. She used other previvors not only for emotional support, but also as fellow experts, stating that “...we can use each other and what we have in our arsenals...We aren’t by ourselves, we have this foundation and an organization behind us and we are powerful.”

Amy was unsure of the surgical process until she talked to other previvors online. Connecting with women helped her feel that she could relate to others and that she was not alone. Amy explained that “*connecting with women helped me a lot because it made me feel not so alone. I am not the only woman with this mutation. There are thousands of women who have it.*”

Amy and Samantha felt comforted and empowered in knowing that they were not alone and that there were other women having similar experiences. This helped Samantha post-surgery and helped Amy make the decision to get the surgery. Both used other women as resources to make informed decisions.

Power and Empowerment

Power and empowerment are feminist concepts that explore the power dynamics in relationships and within certain groups. All four of the participants expressed feeling powerless at certain points in their journeys, but both Samantha and Amy used the words “strength” and “empowerment” when describing their BRCA journeys.

Samantha explored the concept of “woman power” and related it to her profession as an attorney. Pre-BRCA, Samantha tried to play down the fact that she was a woman because she felt that separating herself from men might imply that she was “less than” as a professional. Samantha discussed how that shifted after her BRCA diagnosis. She said that *“I am a lot more women centric, especially in my involvement with (a non-profit organization). I am a lot more women power now.”*

Amy found that “knowledge is power” when it comes to her BRCA diagnosis and made some changes in her everyday routine after learning of her BRCA diagnosis. She stated, *“I think knowledge is power...I do feel different. More empowered and stronger.”*

For both Amy and Samantha, their renewed sense of power has affected their professional and personal lives and the choices they make. Both expressed feeling “stronger” after their BRCA experiences.

Family Planning

After learning of their diagnosis and continually making preventative choices about risk prevention, survivors are left to face the future. A common thread discussed by all four participants when looking towards the future was family planning. This included connecting with a partner and sharing their BRCA journey with someone else, as well as potentially expanding a family to include children.

When thinking about facing the future, Claire, Samantha, Amy and Linda discussed partnership and extending their families to possibly include children. They all reflected on when to have children, adoption, and fertility treatments that could protect future generations from inheriting the gene.

At the time of our interviews, Claire had completed her surgeries and explained that she was now moving on to think about family planning. She expressed concerns about sharing her accelerated plans with a potential partner. *“I don’t want them to think that we have to get married and have kids right away. I don’t want there to be a ticking time bomb in their head too where the relationship is concerned, but I am on a time line.”*

Samantha was pondering PGD, a new procedure that allows women to test embryos for the BRCA gene before implantation. She liked the *“idea of freezing eggs. For me the idea of being pregnant is cute and fun, but I am not attached to how I get pregnant. I like to plan and be in control, so this procedure kind of fits my personality.”* Amy was considering adoption to prevent her future children from having the chance to inherit the genetic mutation. *“I kind of want to adopt children... having the BRCA gene makes it difficult because I do not want to pass this on.”* Linda questioned whether or not she wanted to have children. Linda said *“I just don’t think I am a kids person,”* yet she questioned where her lack of desire to have children originated. *“It is a weird thing. I wonder since I found out about the gene at such a young age, I sometimes wonder if it has affected my desire to want to have children.”*

Samantha, Amy and Linda were in long-term relationships. Their partners knew of their BRCA diagnosis. Both Linda and Amy had considered adoption or not having children due to the heritability of the gene. Samantha discussed getting a BSO and using PGD testing to implant

embryos without the BRCA gene. Claire was anxious about making these decisions without a partner and about having those conversations and making those choices once she is in a committed relationship.

Challenges and Changes in Worldview

Late in their interviews, the four participants discussed various challenges that they have faced on their BRCA journeys, ways in which they have been changed by learning of their diagnosis, and how they have made meaning of what it means to be a previvor.

Challenges

At the end of our interviews, all four participants reflected on the challenges that they had discussed at some point in their BRCA narratives. Claire felt that her current life position is the most challenging aspect of her BRCA narrative thus far. She explained that *“right now is the hardest time. The ticking time bomb. I just turned 32 and I am supposed to get my ovaries out at 35 or shortly after, so I just feel like you know each year that goes by is getting closer and closer to that.”*

Samantha felt challenged regarding her femininity during the surgical process, *“There has been a lot of tears and sometimes, you just don’t recognize yourself...I just didn’t feel like myself. I didn’t feel like a girl.”*

Amy believed her challenges stemmed from realizations about our healthcare system. She explained that *“dealing with health insurance and the financial burden... I got so many bills I had to dispute...But it felt that they were trying to get money out of me. It was difficult getting bills paid for... It brought up a lot of emotions about our health care system.”*

For Linda, the most challenging aspect was feeling that she was in a different place than her peers. She stated,

It makes me kind of angry and depressed at the same time where like my friends are still young and partying and being carefree and before any of my friends, I felt like I couldn't keep doing that and I had to get a better job to pay for health insurance and keep better organized, so I could be on top of this whole surveillance thing and this mental effect of having to do that.

While all four participants expressed different challenges, the theme of challenge was present throughout each participant's narrative. This overarching theme seems to suggest that being diagnosed with the BRCA gene mutation is challenging in many different ways and the challenges are ongoing rather than existing only at certain points in the BRCA journey.

Changes

Samantha realized her perspective towards women has changed. *"I was never a woman power person and I am now because I have seen it in action. It has changed my impression of wanting to be identified as a woman...Now it is much more of a badge of honor. I am proud."*

Amy looks at others differently after her BRCA experience. *"One of the things that has affected me...is that you never know what struggles people are going through. So, I have been trying not to judge people before you know their story."* Linda wondered if BRCA has been altering her life path and choices since her knowledge of the gene at age 14. Along with her fears that BRCA affected her desire to have children, she also worried that BRCA has affected her career path. *"I heard the statistics that exercising reduces your risk [for breast cancer] by 50 percent. I remember thinking 'oh well, if exercise reduces your risk so much, then maybe that is what I should do with my career and become a fitness instructor.' I think 'how much has this cancer risk totally affecting me doing this?'"* Samantha feels that she is more connected with her own identity as a woman and she has had a shift in perspective when it comes to looking at her own

gender. Linda questioned how much her identity has been changed by her knowledge of the BRCA gene at the age of 14. Their narratives illustrate the potential impact that BRCA can have on individuals and their life paths.

Meaning of Previvor and BRCA

Claire, Amy and Linda reflected on what it means to be a BRCA previvor.

Claire expressed that it is different from going through a cancer diagnosis:

I am not trying to get through cancer, it is different. It is more about being a previvor. It is just different. It is just remembering that you have information to prevent things, but you still have the thought in the back of your mind that it could happen, but it hasn't happened. But it is always there and affects so much.

Amy also differentiated her diagnosis from a cancer diagnosis, but explained that BRCA can sometimes feel like an illness experience.

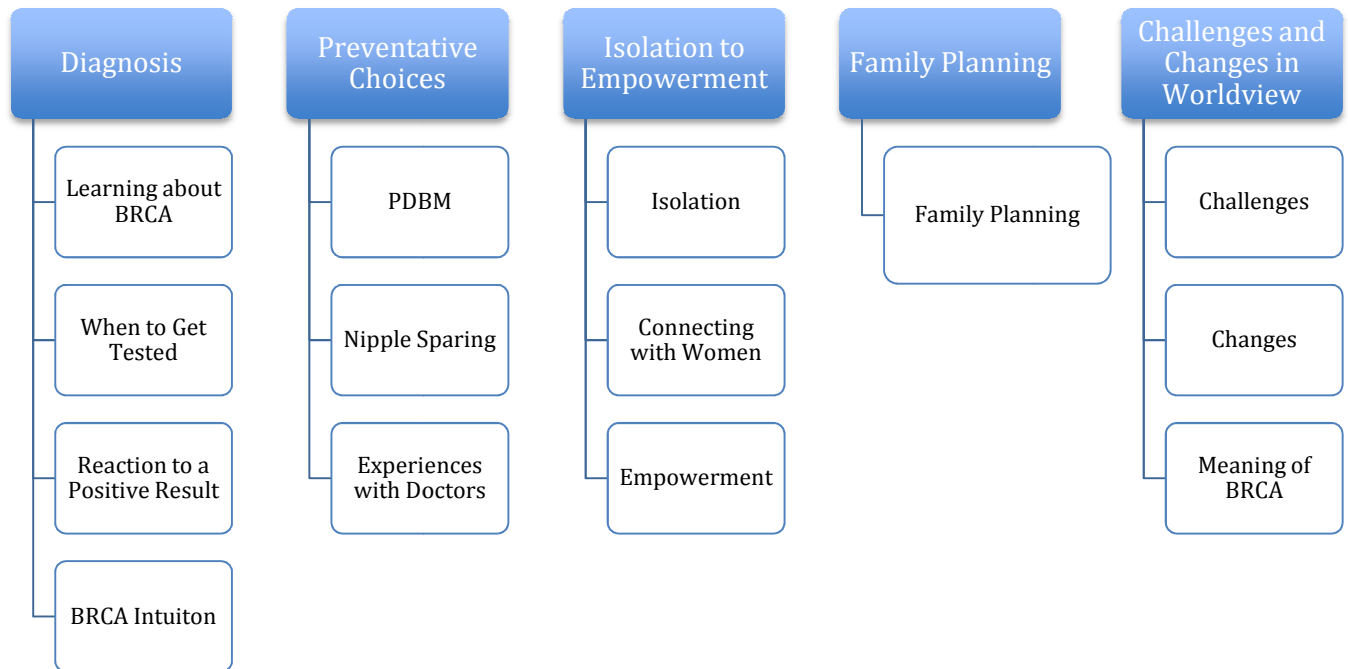
I think finding out that you have the BRCA gene is pretty much like telling someone that they will get cancer in their life, but they don't know when...So, it's hard because there are people that actually do have cancer, so you don't want to compare yourself to them, but it's hard to process that you are going to get it probably.

Amy continued by describing what the word previvor means to her. “*Basically, instead of being a survivor, someone that had cancer and survived, you are surviving it before you get it. You know you are high risk. It is an empowering term.*”

Linda reflected on her mixed feelings about her positive mutation status.

Well, just so often I feel it is so weird to even think about the fact that I have this gene that gives me this risk. And I guess I am supposed to be thankful that I know ahead of time...but it is kind of heavy information. In some ways it is totally fascinating and crazy.

Claire, Amy and Linda commented on the unique nature of receiving information that they had a high chance of getting cancer. There are many choices that one can make regarding what to do with that risk, but it is a risk that is always there and does not go away. While previvors are pre-survivors of cancer, they are survivors of the BRCA experience. (See Figure 5 below for overarching themes.)



5 Across Case Analysis Themes

Summary

In this chapter, I presented the results of my qualitative inquiry into the narratives of four women diagnosed with BRCA1 and BRCA2 genetic mutation. Through coding and data analysis, I organized the information into within-case themes and across-case overarching

themes. These themes and overarching themes highlighted where the previvors' stories converge, honoring each woman's individual and unique voice while also illuminating their shared bonds.

CHAPTER FIVE

DISCUSSION

In this chapter, the research findings are discussed. The purpose of the study is reiterated and procedures are summarized. Findings are discussed as they answer the research questions and as they relate to the existing literature. The significance of the findings, implications for counselors and other mental health professionals, implications for friends and families of BRCA previvors, implications for researchers, and limitations of the study are included in this chapter. The chapter ends with a summary and a final note.

Purpose of the Study

The purpose of this study was to honor the voices of women with BRCA1 and BRCA2 gene mutation through a qualitative narrative study and to provide useful information to mental health and medical professionals working with BRCA previvors. The preponderance of existing research focuses on medical data, rather than on the emotional and psychological effects that accompany a lifetime BRCA diagnosis. BRCA women must make difficult choices regarding their physical and emotional health, family planning, and course of treatment. Medical professionals and mental health professionals need to understand what women experience when trying to make these life-altering choices so that these professionals will be able to provide more effective treatment when working with BRCA1 and BRCA 2 previvors.

Summary of Procedures

Four participants were selected who met the following criteria: are (1) women, (2) BRCA1/2 genetic mutation carriers, (3) aged 18 to 35 years, (4) have learned of their BRCA diagnosis no less than 6 months prior, (5) do not have children and are not currently pregnant, and (6) have an absence of a cancer diagnosis. The participants were each interviewed twice;

each interview lasted one hour. The interviews were all completed via Skype and the interviews with each participant were spaced about a week apart. I transcribed all of the interviews, wrote memos throughout the process, and coded the interviews by hand. Each participant was asked to tell me her story. At the beginning of the interviews, participants were asked how they first came to understand what BRCA is. At the end of their second interview, they were asked what the most challenging part of their BRCA journey has been. The other interview questions formed organically as each individual previvor shared her story.

The preliminary step to data analysis was transcribing the interviews verbatim. This process was key in my understanding of the data. After transcribing each interview myself, I felt I had a true understanding of each woman's narrative voice, perspective, and story. I coded the interviews and through the coding process it became clear that there were both similarities and differences in the participants' narratives. The codes were organized into themes within each individual woman's narrative. Using a cross-case analysis, codes were organized into overarching themes that existed across the participants' narratives.

Discussion of Findings

In my analysis, I found individual themes within each woman's narrative that offered unique insights into her individual story. I also found overarching themes that existed across the narratives. These themes and overarching themes were discussed and illustrated in chapter four. In this section, I revisit my research questions to assess whether they were adequately answered from the data. I also reflect on the literature discussed in chapter two to determine in what ways my results support or contradict the literature on BRCA previvors and what new insights my results might offer.

Research Questions

The research questions for the study served as a guide for the overall framework of my study and were born out of my own anecdotal experiences, gaps in existing literature, and my conceptual framework. Three primary research questions guided this proposed study:

1. What are the narratives of women aged 18 to 35 who have been diagnosed with BRCA 1/2 genetic mutation?
2. How do issues of family planning present themselves in BRCA previvors' narratives?
3. How (if) has their knowledge of BRCA changed their worldview or life course/plan?

Narratives of BRCA Previvors.

The first research question, what are the narratives of women ages 18 to 35 who have been diagnosed with BRCA1/2 genetic mutation, was answered through the exhaustive narratives of the four women whom I interviewed. Although the participants did not encompass the full age range of 18-35, nor did the four narratives address all possible outcomes for the lived experience, their narratives were descriptive representations of these four women's experiences with BRCA1 and BRCA2 diagnosis. Through the coding process, themes and overarching themes emerged. The themes that were present within the individual narratives of Claire, Samantha, Amy, and Linda were diagnosis, preventative choices, prophylactic double mastectomy, family planning, emotions related to diagnosis, experiences with doctors, identity as a woman, traditional versus alternative medicine, and challenges and changes in worldview. The themes were derived from each woman's individual narrative.

The overarching themes existed across cases. These overarching themes included diagnosis, preventative choices, from isolation to empowerment, family planning, and challenge and changes in worldview. The overarching themes tell a chronological story of the participants.

Claire, Samantha, Amy and Linda represent BRCA previvors aged 18 to 35; thus, the overarching themes represent the stories of young BRCA previvors. BRCA previvors may first learn what BRCA is in the context of their own diagnosis or they may learn about the gene from family members or others. Once a previvor is aware of her familial risk, she may decide when she will seek out genetic testing. The diagnostic process includes the actual testing and reactions to a positive result. In the context of this study, three of the participants expressed having an intuitive feeling, before they received their results, that they would be positive. After previvors learn of their positive mutation status, they must make preventative choices of surveillance, medication, or preventative surgeries. Within the context of the stories of Claire, Samantha, Amy, and Linda, there was a theme of transitioning from feelings of isolation at the time of their diagnosis, to empowerment after learning more about BRCA, connecting with other women, and making preventative choices. Next, young BRCA previvors begin to make choices about family planning, which may include options like PGD, adoption, and freezing eggs. BRCA previvors may face many challenges and experience changes in their worldviews due to the BRCA diagnosis and the experiences that accompany the diagnosis. The overarching themes tell this story as represented by Claire, Samantha, Amy, and Linda.

Family planning

The second research question was: How do issues of family planning present themselves in BRCA previvors' narratives? The questionnaire that the participants completed prior to the interview contained a question about family planning. Therefore, the participants may have been primed that this would be a topic of conversation. However, the topic of family planning arose in each interview and was usually initiated by the participants. Each participant had a unique

perspective on family planning, but it was clear that all of them had thought about it in depth prior to our interview.

Three of the participants were in committed relationships, and one was single at the time of the interview. Claire, Samantha, and Amy all felt an urgency to have children sooner than they would have, if not for the BRCA gene. All four participants discussed their feelings regarding the heritability factor of BRCA. Linda and Amy were considering adoption in order to avoid passing on the gene, while Claire and Samantha were contemplating genetic predetermination procedures to select embryos that were devoid of the BRCA gene. How to spare future generations from being diagnosed with the BRCA gene was a concern for all four participants. Linda even wondered if her knowledge of the BRCA gene at a young age had impacted her lack of desire to have children. Family planning issues were present in both the themes and overarching themes and were significant components of the narratives of Claire, Samantha, Amy, and Linda.

Life View

The third research question asked: How, if at all, has participants' knowledge of BRCA changed their life view or course plan? This question was answered primarily at the end of our second interviews. Each of the participants reflected on her overall BRCA journey and how it has affected her as a woman.

For Claire and Linda, the way they relate to others has changed after learning of their BRCA diagnosis. Claire now struggles to open up to romantic partners. Linda has difficulty relating to her peers who are not facing the same BRCA stresses that she is.

Linda and Claire also both discussed how BRCA has potentially changed their future lives with respect to family and children. The ticking time bomb has affected the way Claire

thinks about her future. At age 32, her decision about an oophorectomy is looming and she realizes that this decision “*is going to lead to more serious choices about my life.*” Linda questioned the ways BRCA has affected her major life choices. Regarding family planning, her diagnosis has pushed her “*towards not having kids or not a family or not to do any family planning at all.*” Linda also questioned how her professional choices were affected by her BRCA diagnosis. At a young age, Linda read information that exercise reduces breast cancer risk. She began to wonder if this information affected her choice to become a circus performer and fitness instructor. Linda differed from Claire in this way because she was not reflecting on how BRCA affected her worldview currently; rather, she was wondering how much her knowledge of the BRCA gene at a young age has affected her life course regarding personal decisions like family planning and professional aspirations.

Samantha and Amy related their changes to personal growth and shifts in perspectives. For Samantha, the shift in perspective was about her identity as a woman and her view of women in general. She described herself as being “*a lot more women centric*” after her diagnosis. Amy “feels” different after her BRCA diagnosis, and more specifically, after her prophylactic mastectomy. She stated that “*knowledge is power...I do feel different. More empowered and stronger.*” She wants to do “better things” with her life and continue to grow as a person. Amy also spoke of a shift in perspective regarding her health; she is running and more motivated now. Both Samantha and Amy described their changes as positive growth experiences.

Conceptual Framework

Elements of the conceptual framework of feminist theory (discussed in chapter 2) surfaced in the answers to the research questions and more specifically in the overarching themes across the participants’ narratives. Of the overarching themes, several could be categorized as

feminist themes. These themes included nipple sparing, ideas of femininity and womanhood, connecting with other women, and power and empowerment. The participants often spoke about their identities not only as previvors, but as female previvors.

As discussed in Chapters 1 and 2, feminist theory honors the voices and lived experiences of individuals who have been relegated to the margins and who have been given the term “other” by those in power (Brown, 2010). BRCA-positive women have been defined as an “other” based on the gendered nature of the gene mutation. BRCA women may feel powerless, especially with respect to choices about their own bodies. However, when a shift in perspective is made towards feminist ideals, BRCA women may become empowered and take charge of their bodies and choices, as was reflected in the overarching themes. Within the overarching theme of preventative choices, all four participants discussed their right to choose their risk prevention plan. For Claire, Samantha, and Amy, this included a double prophylactic double mastectomy; however, along with this choice came the choice of whether or not to keep their nipples. All three participants discussed the controversy and judgment of others as these related to both their decision about the surgery and the choice of whether to spare their nipples. Power analysis is a key tenet in feminist theory (Brown, 2010) and each participant discussed the power struggle between BRCA previvors and doctors and family when previvors were deciding whether or not they should keep their nipples. Further, Claire, Amy, and Samantha all discussed how their prophylactic double mastectomies affected their perspectives of the own personal womanhood. Amy discussed how she felt that the men were more disapproving of her choice to get surgery because they were more attached to her breasts as a part of her feminine identity.

The overarching theme of isolation to empowerment is clearly pertinent to the feminist tenets of oppression and power dynamics. According to feminist theory, women have limited

access to power and on how to assert power because of their limited exposure (Herlihy & McCollum, 2011). BRCA women may have access to even less power, especially directly following a diagnosis. Participants described feeling isolated due to being different from their non-BRCA counterparts. Participants explained that they felt helpless due to the lack of information and knowledge that they had at the time of their diagnoses. They became empowered through connecting with other BRCA women, becoming more educated about BRCA, and through their preventative choices. Samantha, in particular, emphasized how she felt empowered and connected with her identity as a woman after her BRCA diagnosis. In changes in identity, Samantha and Claire both discussed how at times within their diagnosis and surgical experiences, they felt that they had lost pieces of their feminine identity. Amy and Samantha discussed ways in which they have been changed and empowered by their diagnoses. They both shared how they now advocate for other BRCA previvors who may feel disenfranchised or powerless.

Discussions of family planning touched on several feminist concepts. As discussed above, women have limited access to power in a patriarchal society. A woman's value may be determined by her ability to bear children. Claire discussed her fears of being devalued as a partner because of the complications that BRCA brings. Further, BRCA previvors may choose to or have to start a family in unconventional ways that may not be as accepted within the patriarchal world.

In feminist theory, women's voices, experiences, and perspectives are valued and inform theory. The theory revolves around women's lived experiences and feminist counseling gives power to those experiences as sources of knowledge for future practice (Herlihy & McCollum, 2011). This research study is a clear representation of how these four participants could inform

others and help them better understand and value BRCA previvors' experiences. A belief inherent in feminist theory is that "the personal is political," meaning that individual issues are reflective of a greater social disenfranchisement, oppression, and typecasting (Herlihy & McCollum, 2011). These four participants' struggles may be reflective of other BRCA previvors' struggles. One of the main ways that the participants overcame feeling disempowered was through advocacy and connecting with other women. Samantha and Amy stated that after connecting with other women, they felt more empowered. Further, Samantha and Amy both revealed ways in which they are now advocating for other BRCA previvors who may be in the earlier stages of diagnosis and feeling powerless.

Feminist concepts are reflected throughout the themes and overarching themes for Claire, Samantha, Amy, and Linda. The conceptual framework gives an added understanding to the participants' narratives and a unique perspective from which to understand the themes and overarching themes.

Relationship to Previous Research

A review of the literature revealed a paucity of research related to young BRCA previvors' narratives. Much of the literature related to BRCA is focused on medically significant information rather than understanding the psychosocial effects of a BRCA diagnosis on women. Only a few researchers, including Hoskins, Greene, Roy, Werner-Lin, have studied BRCA previvors through a qualitative lens.

In the literature review in chapter 2, five research studies were discussed that comprised the existing qualitative literature on BRCA previvors. Hoskins, Roy, Peters, Loud and Greene (2008) explored the dynamics between young BRCA positive women and their partners. Many of their participants felt that a cancer diagnosis was "inevitable" (p. 303) and therefore felt the

need to share their diagnosis with partners and friends. There was a consensus that they felt fearful or anxiety-ridden before disclosing their BRCA status. In their study, many participants feared that it might complicate their relationships or make them seem “less viable” as partners (p. 304). Three of the participants in my study - Samantha, Amy and Linda - were in committed relationships at the time of the interview. Though Claire was not in a relationship at the time of the interviews, she reflected on what it would be like to discuss her BRCA diagnosis and surgeries with a potential partner. Claire expressed feelings of fear or anxiety that seem similar to those of Hoskins, Roy, Peters, Loud, and Greene’s (2008) participants when she said, “ *when I start dating someone, are they going to be disgusted by it or are they going to be turned off by it? It is like dealing with the new me and going about it dating and trying to feel comfortable opening up to someone. I am nervous about exposing myself.*” Hoskins, Roy, Peters, Loud, and Greene (2008) did not address the issue of disclosure in the aftermath of surgery. The findings of this study help to fill this gap, as Claire, Samantha, Amy, and Linda all discussed how the surgeries affected their sex life and disclosure with partners. Amy said “*...the first time we were going to be intimate, I told him.*” For Amy, disclosure was tied with becoming intimate because “*I feel like if a guy sees my boobs, they do look different. They don’t look like a boob job, but they don’t look real. There are scars and stuff and also in certain positions I get ripples.*” Linda had already disclosed her BRCA status to her boyfriends, but worried about how the surgery would affect her love life when she said “*I think just with my sex life, if they look normal, it would allow me to let that go.*” In the Hoskins et. al study (2008), most participants wanted their disclosure to emerge in the natural context of a conversation, whereas for the participants in my study the conversations were more intentional and centered around the previvors’ risk prevention choices such as surgery. Claire and Amy believed that, due to their surgical procedures, they had

to disclose their BRCA mutation status before becoming intimate with partners because of the appearance of their breasts. Participants in Hoskins et al.'s (2008) study described disclosure as a process rather than as a moment in time, acknowledging that the diagnosis will continue to affect their relationships at various stages in their lives. In my study, this description was present in Linda's narrative. She had shared her BRCA status with her partner years ago, but as she was weighing the option of a prophylactic mastectomy, those conversations with her partner recurred.

Hoskins and Greene (2012) continued to explore their interest in young previvors through the exploration of anticipatory loss and early mastectomies in women with BRCA mutation. They aimed to discover the reasons that young previvors chose risk-reducing bilateral mastectomy (RRBM) instead of monitoring BRCA through surveillance methods or other risk-reducing options. Hoskins and Greene (2012) found these themes: view of risk reducing bilateral mastectomy as an alternative to cancer, an urgency to complete surgery, surveillance fatigue, and timing of surgery relative to family formation. The first theme, view of the surgery as an alternative to cancer, surfaced most strongly in my results in Samantha's story. Explaining why she chose the surgery, she said "*I always remind myself, it could be cancer, and between this and worrying about if I am going to be around or not with children or a marriage... there is just no other option. I don't question it, to me it is the only decision.*" The second theme found by Hoskins and Greene (2012), an urgency to complete the surgery, also was addressed by Samantha when she said, "*I knew the same day I found out about my results that I wanted to meet with a surgeon. They said 'don't you want to wait?' and I said 'no, I want to do this as soon as possible.'*" The third theme, surveillance fatigue, was one of the main reasons that Claire chose to get a RRBM. She said, "*I decided it was time for me to just do it. I don't want to have to deal with this and... I didn't want to live in the anxious place anymore of going through*

surveillance.” Because my study focused on women who did not yet have families, none of the participants spoke about timing the surgeries around family formation, although Claire, Samantha, and Amy discussed wanting to get the surgery to be alive and present for their future children.

Hoskins, Roy, and Greene (2012) studied risk perception among young BRCA previvors. Through grounded theory analysis, the authors found that young women’s risk perceptions and choices are different from those of their older BRCA mutation counterparts in the ways in which they understood risk and made decisions about risk management. While I did not have any data from participants older than 32, my results support the finding of Hoskins, Roy, and Greene (2012) that younger previvor have unique concerns, especially in regards to family planning, when compared to previvors who might have already completed their family formation.

Lastly, Werner-Lin (2009) explored the compressed family life cycle of young women with BRCA and the pressure to beat the biological clock after learning of a BRCA diagnosis. Many of Werner-Lin’s participants explained that coming from a “cancer family” (p. 427) pushed them to think about their own family development in ways that their peers were not required to think. Of all the prior research studies, the results of my narrative analysis most closely mirror Werner-Lin’s results. Claire discussed her compressed cycle when thinking about risk prevention: *“I think about being 32 and technically they want me to get my ovaries out at 35, which isn’t realistic any more, but I do think about I am going to end up having to get pregnant right away. I used to always think I would be able to be married for a while and then get pregnant, and that can’t happen anymore.*” Amy revealed that she is thinking about children much sooner than she might have without a BRCA diagnosis. *“I just try not to think about it, but it comes up. I definitely think about it more than I would have at this point because of having*

BRCA. “Werner-Lin (2009) did not address how the heritability of *BRCA* affects women’s desire to have biological children. Claire and Samantha discussed getting fertility treatments to select out the *BRCA* gene, while Amy revealed that she may adopt to avoid passing the gene down to her children. Linda even questioned whether her knowledge of having the *BRCA* gene at a young age had affected her desire to want to have children. The findings regarding the compressed life cycle and urgency to have children in my study support Werner-Lin’s findings. The question of how to prevent future generations from inheriting *BRCA* came up in the narratives of all four of my participants. This new information adds to the literature, which heretofore has not addressed concerns about the heritability of *BRCA* when family planning.

In summary, the findings of my study lend support to the existing research regarding choices about risk prevention, anxiety surrounding the disclosure process, reasons for choosing risk reducing bilateral mastectomy, and the compressed family life cycle. The feminist theoretical framework was not present in previous studies and differentiates my study from previous findings. The findings of my study contribute to filling a gap that has existed concerning the gendered nature of *BRCA* and how the diagnosis affects childbearing-aged women. Specifically, the issue of nipple sparing was raised by Claire, Samantha, Amy and Linda. All four participants shared distinct and passionate views on the subject. The participants expressed wanting to keep a piece of their old identities. Ideas of femininity and womanhood also surfaced in the narratives of three of my participants and an overarching theme of connecting with other women appeared in two of the participants’ narratives. The participants’ connectedness with fellow *BRCA* previvors and with their own identities as women was a powerful component of their stories that has not been presented in the literature.

The feminist conceptual framework of this dissertation adds a unique perspective to the existing literature.

Implications and Recommendations

The narratives of the BRCA previvors interviewed for this study and the findings may help inform mental health professionals and medical professionals working with BRCA previvors and also may help friends and family members of BRCA previvors better understand previvors' experiences.

Implications for Mental Health Professionals and Medical Professionals

It can be anticipated that mental health professionals may work more frequently with BRCA previvors in the future, as medical knowledge about our genetic backgrounds is increasing. Participants in this study shared information that could be helpful for mental health professionals. Claire discussed her experience with several therapists, but wondered how it might be to work with a therapist who had a deeper understanding of BRCA and what it means to be a previvor. She shared, *"I haven't found the right person to connect with. When I went to go see the lady before surgery, she worked with cancer patients, but it is different. I am not trying to go through getting cancer and dealing with it, it is more about being a previvor."* The overarching themes derived from the across-case analysis may help mental health professionals understand some of the common issues that BRCA women face, like decisions around diagnosis, feelings of isolation, disempowerment, difficulty in making choices about proactive health, and issues surrounding family planning. Counselors might suggest to previvor clients that they share or write their own narratives in therapy for both the counselor and previvor to get a greater understanding of their individual experience. Further, counselors can serve as a bridge between medical professionals, friends and family, genetic counselors and previvors and encourage a

team approach to better accommodate previvors' needs. Counselors can facilitate communication among all parties to form a more comprehensive treatment plan for previvors, which could help previvors get their needs met more appropriately. As gaining access to our genetic information becomes more common in the general public, counselors may need to gain specific training in working with previvors of many different genetic predispositions, not just BRCA. While genetic counselors serve as a support during the initial diagnosis process, longer term care is needed and counselors can help fill this void.

Medical professionals may benefit from these findings in similar ways. They will be working more often with BRCA previvors after previvors learn of their diagnosis. Though the four participants shared different characteristics that they appreciated in medical professionals, they strongly expressed that they wanted to feel supported for their preventative choices. Claire wanted to feel "*backed*" by her doctors and know that her doctors did not think she was "*crazy*" for making certain preventative choices. For Samantha, the doctors who rubbed her the wrong way were those who made decisions that she felt were outside the bounds of their role as doctor, such as the choice of whether or not to keep her nipples. In Amy's contrasting experience, she appreciated that her doctors never "*questioned my choices,*" which made her feel comfortable with them. Linda felt supported by doctors only when she went by their "*plan*" of traditional treatment and medicine and she felt unsupported when discussing less orthodox types of treatments. Medical professionals might benefit from extending their knowledge of the experience of living with a BRCA diagnosis and how it affects the aspects of women's lives outside the medical sphere. This broader understanding might lead to more sensitive and appropriate interactions with previvors as they explore their treatment options.

Further, these results may also be helpful for both medical and mental health professionals when working with other young women with similar diagnoses or genetic predispositions. Recently, a new breast cancer gene has been identified and it is likely that other cancer genes will surface in the near future. Individuals can learn if they have predispositions for neurological disorders like Parkinson's disease or ALS. It is clear that there is an upward trend in learning more about our genetic make up and with this trend, it is clear that we need a greater understanding of how to support the psychosocial impacts of these predispositions.

Implications for Family and Friends

Family and friends can be supportive forces throughout the BRCA previvor's experience. The four participants discussed ways in which their family and friends were both supportive and unsupportive throughout their journeys. In a way similar to the participants' experiences with medical professionals, the findings suggest that the four previvors wanted to feel supported by families and friends in their decisions regarding their BRCA choices. Claire shared that while her parents supported her decisions, initially her father questioned her after she shared that she would be getting the surgery. *“Even when he got on board after we had talked about it and digested it, even after I had scheduled the surgery, he said look I am still on board but I think it is a big major surgery to have, he was suggesting to get re-tested again for the BRCA gene.”* Claire shared that her father was *“shell shocked”* by her decision and took a while to come to accept her choices. Samantha told a story about a close friend who questioned her decision to get the surgery. Samantha explained that after the friend learned more about BRCA and the statistics, she better understood and supported Samantha's choice. Amy revealed fears about telling the people she was close to in her life. She stated, *“In the end I was scared of telling people because I was worried about what they would think, but I had to do what was right for*

me.” Linda explained how isolating it can feel to have the BRCA gene, especially when previvors are making choices that their peers are not having to make. She said, “*there is a very significant way in which they are choosing their life and how it is different than mine and that difference is really alienating.*”

Friends and families can be more supportive through educating themselves and working to understand BRCA experiences. The participants expressed that this diagnosis and their choices seemed to open up their decisions to scrutiny from families and friends. The participants wanted to feel respected in their choices, just as they would respect individual choices that their friends and family would make.

Implications for Future Research

Limited narrative qualitative research has focused on young BRCA previvors, and this study is the only known study with an underlying feminist conceptual frame. The results from this study illuminate the rich data in the stories of individual women.

Future research might include both quantitative and qualitative studies. The current quantitative literature about BRCA women focuses on medically significant data rather than psychosocial effects of dealing with a BRCA diagnosis. Future researchers could use a quantitative approach to focus on BRCA women rather than the BRCA diagnosis. For example, it would be beneficial to see the results of a large-scale quantitative study that focuses on the psychosocial impacts of a BRCA diagnosis. Due to medical advances, many childbearing-aged women who have BRCA are now considering medical interventions to eliminate the BRCA gene for future generations through procedures like PGD. A study focused on family planning might reveal some of the new ways in which BRCA women are creating families.

Future qualitative studies might focus on individual women's stories regarding family planning. As women try to eradicate the BRCA gene through their own family planning choices, it might be beneficial to explore BRCA women's choices qualitatively as they choose to start families. Another qualitative study that might shed light on BRCA experiences would be an ethnographic study to explore the culture of BRCA. There is much room left for research on BRCA previvors' experiences.

Limitations

Because my participants were limited to a sub-set within the BRCA population, the findings may not be a true representation of the entire BRCA community and their struggles. Further, as I interviewed only four women, the study is not generalizable to the BRCA population. However, the intent of my study was to serve as a platform for a small number of women to share their specific narratives. Generalizability is not the goal of qualitative research (Creswell, 2007).

Another possible limitation of the study is related to my close tie with the research topic. I worked to bracket my own experiences through peer debriefing, member checking, and journaling. My personal experiences served as a strength throughout the interview process and study, but the potential for researcher bias in analyzing the results remains present.

Final Note

My own BRCA narrative existed far before this dissertation process began. However, it is also important to acknowledge the ways in which I was personally affected by my role as a researcher. I was changed in many ways by hearing the heroic stories of the four participants in this study. Often their reflections prompted introspective thoughts within me. I worked to maintain my role as a researcher through peer debriefing, but continually reflected on my own

narrative throughout this process. It is important to acknowledge that I was inevitably affected throughout this dissertation process, as my role as researcher and my identity as a previvor coexisted throughout the study.

The idea to conduct this study was born out of my own personal experiences with BRCA. When collecting stories from the participants, I realized that much of what they said confirmed my own experiences, yet much of what they shared was unexpected because it was different from my personal experience or projected themes. I found it important to honor both experiences that mirrored my own and those that differed greatly from my personal narrative. Overall, I believe that I owned my biases and worked to honor each participant's story.

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Appendix A
IRB Approval

Appendix A

IRB Approval

**University Committee for the Protection
of Human Subjects in Research
University of New Orleans**

Campus Correspondence

Principal Investigator: Barbara Herlihy
Co-Investigator: Drew David
Date: April 2, 2014
Protocol Title: "Narratives of Young Women with BRCA 1/2 Gene Mutation:
A Qualitative Analysis"
IRB#: 03Apr14

The IRB has deemed that the research and procedures described in this protocol application are exempt from federal regulations under 45 CFR 46.101 category 2, due to the fact that any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

Exempt protocols do not have an expiration date; however, if there are any changes made to this protocol that may cause it to be no longer exempt from CFR 46, the IRB requires another standard application from the investigator(s) which should provide the same information that is in this application with changes that may have changed the exempt status.

If an adverse, unforeseen event occurs (e.g., physical, social, or emotional harm), you are required to inform the IRB as soon as possible after the event.

Best wishes on your project.
Sincerely,



Robert D. Laird, Ph.D., Chair
UNO Committee for the Protection of Human Subjects in Research

Appendix B
Informed Consent

Appendix B

Consent to Participate

Research Project: *The Narratives of Young Women with BRCA1/2 Genetic Mutation: A Qualitative Analysis.*

Please carefully read the following information prior to signing this form.

1. Drew David Reilly, M.Ed. (214-662-4969; d david@uno.edu) a doctoral student in the Counselor Education program, under the direct supervision of Dr. Barbara Herlihy (504-280-6662 or bherlihy@uno.edu), a faculty member at the University of New Orleans, is requesting your participation in a research study entitled, the Narratives of Young women with BRCA1/2 Genetic Mutation: A Qualitative Analysis. The purpose of this study is to honor the voices of young BRCA previvors through narrative analysis. Your participation will involve being interviewed face-to-face for approximately 60 minutes at which time you will be asked open-ended questions. A second interview will be required for clarification purposes. You will be audio-taped during the interview process. Once the study is complete, the tapes will be discarded. Your real name will not be revealed in the study. Anything you say can be used in the study.
2. One risk associated with this study is that you will be asked to share personal information regarding your experiences. You do not have to answer any question that you do not wish to answer. Due to the length of the interview (approximately 60 minutes), you may become tired or fatigued. Should that happen, you may take a break or choose to discontinue this interview. Due to the sensitive nature of this topic, a licensed counselor will be available to provide services at no cost to you if needed.
3. The benefits of participating in this study for you personally are minimal; however, you will be contributing to the scholarly research about the lived experiences and narratives of young women with BRCA1/2 Mutation.
4. You do not have to participate and are free to stop the interview at any time without consequence. Additionally, you are free to withdraw from this study at any point.
5. The results of this study will be used for dissertation purposes, conference/presentation

and publication/ journal articles; however, your name and identity will not be revealed. You will be assigned a pseudonym and it will be used in any reporting of your comments. The researcher will only know your name and any transcriptions of this interview will be kept in a locked file cabinet accessible only to the researcher.

6. Your participation in this research study is voluntary and you will not be compensated. Refusal to participate will involve no penalty. You may withdraw from participation in this research study at any time.
7. If you have any questions about your rights as a participant in this research, or if you feel you have been placed at risk, please contact Dr. Ann O’Hanlon, Institutional Review Board, at the University of New Orleans at 504-280-3990 .

By signing the Consent to Participate form, you acknowledge having read this document and understand the conditions of participation in the research study.

Participant:

Researcher:

Date

Drew David Reilly, M.Ed. Date

Appendix C
Interview Protocol

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Age(yrs): _____

Age diagnosed with BRCA: _____

Other known relatives with BRCA: _____

Marital Status:

Never married or partnered/single: _____

Dating: _____

Married or Partnered: _____

Divorced or Separated: _____

Widowed: _____

Family Planning:

Planning on having children within the next 2 years: _____

Planning on having children within the next 5 years: _____

Planning on having children within the next 10 years: _____

Planning on having children, but more than 10 years from now: _____

Not planning on having children: _____

Education:

Employed and/or currently working: _____

Currently enrolled in school: _____

Unemployed or not currently working: _____

1. Tell me your story, as it relates to BRCA:

Prompting Questions:

- a. When were you diagnosed?
- b. What was your diagnosis experience like?
- c. What choices have you made in terms of risk management?
- d. How have you handled your risk management options?
- e. If you have made decisions about your risk management, how did you do so?
- f. How have you coped with your diagnosis?
- g. What has been most challenging?
- h. What has your emotional experience been like?
- i. What has your experience been like with medical professionals? Family? Spouse or significant others? Friends or other support groups?
- j. How (if, at all) has BRCA changed your worldview or life plan?

Vita

Drew David Reilly was born in Dallas, Texas. In 2008, she graduated from Vanderbilt University with her Bachelors degree in Child Studies. In 2010, Drew earned a Masters of Education in Human Development Counseling from Vanderbilt University. Drew entered the graduate program at the University of New Orleans to earn her PhD in Counselor Education in 2011. Drew is a licensed professional counselor and practices at a private practice in New Orleans.