When Bad Genes Ruin a Perfectly Good Outlook: Psychological Implications of Hereditary Breast and Ovarian Cancer via Narrative Inquiry Methodology

Cammi Clark
Antioch University - PhD Program in Leadership and Change

Follow this and additional works at: https://aura.antioch.edu/etds

Part of the Alternative and Complementary Medicine Commons, Applied Behavior Analysis Commons, Educational Leadership Commons, Family, Life Course, and Society Commons, Health and Medical Administration Commons, Health Communication Commons, Health Psychology Commons, Journalism Studies Commons, Leadership Studies Commons, and the Medical Education Commons

Recommended Citation
https://aura.antioch.edu/etds/501
When Bad Genes Ruin a Perfectly Good Outlook: Psychological Implications of Hereditary Breast and Ovarian Cancer via Narrative Inquiry Methodology

Cammi Clark
ORCID Scholar ID #0000-0003-0505-0149

A Dissertation

Submitted to the Ph.D. in Leadership and Change Program of Antioch University in partial fulfillment for the degree of Doctor of Philosophy

July 2019
This dissertation is approved in partial fulfillment of the requirements for the degree of PhD in Leadership and Change, Graduate School of Leadership and Change, Antioch University.

Dissertation Committee

- Elizabeth Holloway, PhD, Chair
- Jon Wergin, PhD, Committee Member
- Piri Welcsh, PhD, Committee Member
Acknowledgements

I am writing this acknowledgement as a public thank you to the many people in my life who helped push me across the finish line—whether they realize it or not.

I would like to start by thanking my immediate family who sacrificed many late night snuggles, fun family times out on the water and shopping sprees, to ensure they never have to hear me utter the words, “I can’t today, I have to work on my dissertation,” again. I encourage them to look toward the glimmer of hope for post-dissertation normalcy.

I’d also like to thank my dissertation committee members for not letting their frustration show when I relentlessly hovered over them, waiting for their feedback on each revision. I appreciate their extreme patience in allowing me to think outside of the box to make my research my own and accepting nothing less than completion from me.

Without doubt, I’d like to thank all my cohort members—those who have moved on, those in the quagmire, and those just beginning—for their support, friendship, and always being at the other end of my texts, whether it be to wallow, encourage or empathize. Your efforts gave me the confirmation I needed to know I was not alone, and that this really was challenging. Lastly, but of course not least, I must thank Mary Claire King, Ph.D. Without her life-changing research, my own research would not exist.
Dedication

This research is dedicated to my insanely large (or is it largely insane?) family for being on the front lines with HBOC and not backing down. It is your strength that keeps me going.
Abstract

Scientists debunked the belief that breast cancer is always viral with the mid-90s discovery of the first hereditary genetic mutation linked to a significantly higher-than-average chance of breast and ovarian cancer. This genetic condition, called Hereditary Breast and Ovarian Cancer (HBOC), passes the mutation from generation to generation in a family. Thousands of variations of such mutations exist, and carriers account for 10 to 15% of all breast cancer, and up to 20% of ovarian (Childers et al., 2017). In addition, genetic testing uncovered a rapidly rising number of healthy people (never had breast/ovarian cancer) who are also carriers, flooding healthcare providers seeking potential options to reduce their elevated risk. Those prophylactic measures are invasive, permanent and can cause physical—and emotional—scarring. As a newer medical phenomenon, few, if any, studies address the potential psychological implications, which include fear, anxiety, guilt, family tension, and more. Using narrative inquiry methodology, this study analyzes the authentic lived or felt experiences of individuals when they learn that they have inherited a mutation that significantly increases their risk of breast, ovarian and related cancers, and their choices that directly affect their effort to outrun a cancer that may never come. This dissertation is accompanied by the author’s MP4 video introduction and is available in open access at AURA: Antioch University Repository and Archive, http://aura.antioch.edu/ and Ohiolink ETD Center, https://etd.ohiolink.edu/

Keywords: Breast Cancer, Breast Reconstruction, HBOC, Hereditary Breast and Ovarian Cancer, Narrative Medicine, Narrative Inquiry, Psychology of Cancer, Story, Storytelling
# Table of Contents

Acknowledgements ......................................................................................................................... i  
Dedication ........................................................................................................................................ ii  
Abstract .......................................................................................................................................... iii  
List of Tables ................................................................................................................................. viii  
List of Figures ................................................................................................................................. ix  
Chapter I: Positionality and Statement of the Problem ................................................................ 1  
  Research Question ....................................................................................................................... 5  
  Choosing Narrative Inquiry Methodology .................................................................................... 5  
  Overview of Remaining Chapters ............................................................................................... 7  
Chapter II: Critical Review of Hereditary Breast and Ovarian Cancer ..................................... 8  
  Incidence of Breast and Ovarian Cancer ..................................................................................... 9  
  History of the Discovery of HBOC ............................................................................................ 10  
  Biology and Incidence of BRCA1 and BRCA2 ........................................................................ 11  
  Genetic Exceptionalism .............................................................................................................. 13  
  Genetic Screening ....................................................................................................................... 14  
  Reducing Risk ............................................................................................................................ 17  
  Psychological/Emotional Implications ....................................................................................... 17  
  Celebrity Public Awareness ....................................................................................................... 21  
  Where Do We Go Now? ............................................................................................................. 23  
  Methodological Approaches to Psychological Ramifications ................................................... 24  
  Vulnerable Groups ..................................................................................................................... 26  
    Men With HBOC ...................................................................................................................... 26  
    Global Perspective of HBOC .................................................................................................. 27  
  Genetic Counseling ..................................................................................................................... 28  
  Other Hereditary Cancer Syndromes .......................................................................................... 29  
  Narrative Medicine ....................................................................................................................... 34  
    “Keep Calm and Tell Me Your Story” .................................................................................... 41  
  Narrative Medicine in Practice ................................................................................................... 42  
    Writing Workshops ................................................................................................................. 43  
  Award-Winning Narrative Medicine ........................................................................................... 44
Sophie: “I’m Very Alone, No One in My Family Wants to Know” .................................................. 79
Bessie: “When I Found Out, Most Doctors Had No Clue; And They are Still a Few and Far Between” ................................................................................................................................. 80
Marissa: ‘I’ve Been Frustrated With Recovery and That Process, But I Just Feel It’s Better Than Chemo, as Far as I Know, Because I Watched My Mom Go Through All That” .... 81
Pam: “It’s Still Hard to Look at the Mirror and We’re Almost Two Years Later, It’s So Bizarre. It’s Just a Daily Reminder” ........................................................................................................... 82
Alisha: “BRCA Positive, Is Truly Not for the Faint of Heart. It’s Kind of a Little Cloud That is Constantly There”.......................................................................................................................... 83
Danielle: “I’m Crying About Her (Daughter) Experience Because It Was So Much Harder Than Mine and I Felt So Badly” .............................................................................................. 85
Gigi: “Now I Know Why My Mother Died.” ...................................................................................... 86
Summary and Reflection .................................................................................................................. 88
Chapter V: Analysis .................................................................................................................... 89
Purpose of Plot Analysis ............................................................................................................. 89
Purpose of Thematic Analysis .................................................................................................... 90
Findings: Integration of Plot and Themes .................................................................................. 92
Character as the First Plot Element .......................................................................................... 94
Setting as the Second Plot Element .......................................................................................... 94
Initiating Action as the Third Plot Element ............................................................................. 95
Complicating Action as the Fourth Plot Element ........................................................................ 97
High Point as the Fifth Plot Element ....................................................................................... 99
Resolution Strategies as the Sixth Plot Element ...................................................................... 102
The Ending as the Seventh Plot Element .................................................................................. 104
The Coda, or Reflection, as the Eighth Plot Element ................................................................. 105
Summary of Analyses ............................................................................................................... 106
Commonplaces .......................................................................................................................... 110
Temporality ................................................................................................................................... 110
Sociality ......................................................................................................................................... 111
Place ............................................................................................................................................ 112
Checking on the Retelling Experience ..................................................................................... 114
Chapter VI: Discussion .............................................................................................................. 117
Discussion of Key Findings .................................................................................................................. 117
Preivors’ Story Arc ................................................................................................................................. 118
Proactive Decision-Making .................................................................................................................. 118
Guilt ...................................................................................................................................................... 118
Losing One's Breasts .............................................................................................................................. 119
Reconstruction Ambivalence ............................................................................................................... 120
Value of Retelling .................................................................................................................................. 120
Empowerment ...................................................................................................................................... 121
Comparing Findings to Literature ....................................................................................................... 122
Summary .............................................................................................................................................. 124
Limitations of the Study ......................................................................................................................... 124
Implications for Leadership and Change ............................................................................................. 126
Conclusions .......................................................................................................................................... 134
Final Reflexive Comments .................................................................................................................. 134
References ............................................................................................................................................ 139
Appendix A: National Comprehensive Cancer Network Guidelines for Genetics Referrals .... 151
Appendix B: Hereditary Cancer-Related Syndromes ........................................................................ 153
Appendix C: Notice of Opportunity to Participate ........................................................................... 155
Appendix D: Email in Response to Interested Participants Including Consent Form ............... 157
Appendix E: Survey Approach and Question .................................................................................... 162
List of Tables

Table 3.1 Participants’ Pseudonyms and Relevant Demographic Information ................................................. 60

Table 5.1 Plot Elements, Topical Themes, and Subthemes ........................................................................... 93
List of Figures

Coggle (Mind Map) of Plot Elements, Themes, and Subthemes Derived From the Stories........ 107
Chapter I: Positionality and Statement of the Problem

Here’s the secret: Your life has marked you in unique ways, and these marks—whether you know it or not—will determine how you live your life, what quests you pursue, and what you are equipped to say with passion and authority through a story.

– Michael Rabiger (in Rabiger & Hurbus-Cherrier, p. 10)

In this chapter, I introduce the importance of this work, situate myself by stating my positionality and research stance, situate the topic in the complex world in which it exists, provide the rationale for the study, state my research questions, and provide a layout of the rest of the dissertation.

My mom is one of eight children—seven sisters and one brother. I never met my Aunt Jeanette, my mom’s oldest sister. She died in 1969, the year before I was born, from two dirty words: breast cancer. She was only 31 and left behind four young children under the age of 10. It was more than a decade before I would hear the words breast cancer again. This time, it was my grandmother who succumbed to the disease. I had just turned 15 a few weeks before she died. Over the next few decades, I would watch as breast cancer claimed the life of two more aunts and a younger male cousin (who died at 31), and another aunt diagnosed with ovarian cancer.

I remember my mom saying dramatically, “It’s going to get us all.” At the time, I dismissed her “silly” notion because we all knew that breast cancer was considered sporadic, meaning there is no rhyme or reason, it just happens—or so we thought.

Years went by, and in October 2013, breast cancer reared its ugly head again. This time, its victim was my mother. It was the first time a doctor asked if we had a family history of breast cancer. “Yes,” we answered, and we proceeded to rattle off every person in our family inflicted with breast/ovarian cancer, before asking, “Why does that matter?”
The doctor explained that recently, scientists had proven that a small percent of breast cancer occurrence is hereditary, stemming from a gene mutation passed down through the generations. And, the doctor continued, if the genetic testing for a mutation is positive, that means each of that person’s biological children have a 50/50 chance of inheriting the mutation—a mutation that secures an almost 90% chance of getting breast cancer, and drastically increases your chance of getting ovarian and other cancers.

But, along with these scientific discoveries also came opportunities—sort of—to change your fate. Removing your breasts and ovaries reduces the chance of developing the cancers to the same risk level as a person without the mutation. For breast cancer, that statistic is still one out of eight.

The results of my mom’s genetic testing showed she inherited a mutation, increasing her chances of getting breast, ovarian and other cancers. Next, it was my turn. I was the first healthy person in my family to undergo genetic testing for the breast cancer gene mutation. And, after I also received positive results, I became an advocate for other members of my family—my very large family—making sure they knew of their risks, their options and that they had a support system. To date, we have more than 24 family members who are positive for the mutation, including my teen daughter (Some family members still refuse genetic testing, mostly because of fear of knowing).

Testing for individual knowledge about personal inheritance of a potential high-risk fate, and the life-changing, body-altering, conscious decisions that accompany this knowledge, are not experienced by the “average” person. And, while breast cancer risk classifications are useful for prognosis, little is known of their effect on patients (Rapport et al., 2018).
With the recent capability to now determine one’s risk for breast or ovarian cancer, prior to any apparent symptoms, this has created a potential new state of being: genetic vulnerability, built from the experiences of those who have chosen to have genetic testing for HBOC (Hamilton & Bowers, 2007). This invisible state of being is hard to identify, particularly because the knowledge may require carriers to figuratively put an asterisk on life, continuing to live and plan until the cancer comes.

And, while knowledge is power—power to beat cancer before it starts—this knowledge may also come with an array of psychological implications. They can include:

- acknowledging that this mutation is the root cause of deaths in their family;
- facing the reality that they could also have inherited this mutation;
- an anxious choice for genetic testing to find out if they did;
- fear of facing their own mortality when they discover they test positive for the same mutation responsible for killing their family members;
- a state of limbo wondering what do to with this future-predicting information,
- and while they technically are not sick with breast or ovarian cancer, they now face an option of prophylactic surgeries to decrease their elevated risk of getting a cancer that may never come.

And, the answers to psychological implications are subjective. For example, beyond the issue of facing their own mortality, there is the decision to be tested, and with that knowledge, make the “right” decisions. But how do they decide what’s “right?” In these situations, there are no right or wrong answers. It is not black and white, hot or cold, good or bad. The so-called right choice is subjective and there is no easy choice, just the right one at that time. And, for as many
shapes and sizes of breasts there are, there are just as many choices to make when facing what to do with them when there is a chance they could kill you.

Another example: if a woman does choose surgeries to voluntarily remove the parts of her body that society supposedly deems are a woman’s most desirable features—her breasts—she may also face psychological issues around body image. In addition, with no breasts, no ovaries, no true “girl” parts, participants can be left with a sense of no longer feeling connected to this gender group. If she chooses increased surveillance, she may put herself in a state of limbo, waking each morning wondering if today is the day—she waited too long—the day she finds out she has cancer.

Beyond concern for her own wellbeing, discovering this information extends beyond her own health and thoughts of their own mortality, to that of her beloved family—her mother, her sister, and, unfortunately, her daughter. The guilt of passing this on to her children can be unfathomable.

Despite the psychological implications, knowing if you have a genetic mutation that drastically increases your cancer risk, is life-saving information that can change a person’s destined fate, and drive down mortality rates worldwide. The first genetic mutation related to HBOC was discovered in the mid-90s when Dr. Mary-Claire King, then at UC Berkeley, identified a region on chromosome 17 that harbored a gene she called BRCA1 (the acronym originally stood for Berkeley, CA., but now commonly stands for BReast CAncer), the first gene linked to a higher than average chance of developing breast cancer and ovarian cancer. Scientists later discovered BRCA2.

Identification of cancer-causing mutations in BRCA1 and BRCA2 has clear and actionable implications for reducing cancer risk. BRCA1 and BRCA2 screening as part of routine health care for young adult women is sensible and feasible. For women who learn that they carry mutations in BRCA1 or BRCA2, the consequences are enormous,
addressable, and life-saving. Until there are no more breast or ovarian cancers among women with BRCA1 or BRCA2 mutations, the real race is not over. (King, 2013, p. 1465)

Unfortunately, in a nationally representative sample just last year,

fewer than one in five women with a history of breast and/or ovarian cancer meeting select National Comprehensive Cancer Network (NCCN) eligibility criteria (see Appendix 1) have undergone genetic testing. This represents a deficit of at least 1.2 to 1.3 million women who have not received genetic testing. Most women meeting criteria have never even discussed genetic testing with a health care provider. Large national efforts are needed to address this unmet need. (Childers et al., 2017, p. 3805)

**Research Question**

Helping to close this gap, along with serving as vital educational companion for carriers and healthcare professionals, is behind the purpose of this dissertation research. I used narrative inquiry methodology to analyze the answers to the interview question, what is the authentic lived or felt experience of individuals when they learn that they have inherited a mutation that significantly increases their risk of breast, ovarian, and related cancers? What are the psychological implications of knowing this information? How do they make meaning of this, their lives, and their future?

**Choosing Narrative Inquiry Methodology**

Based on my background and expertise, I believe by using narrative inquiry methodology, my research results also provide healthcare affiliates with valuable, real, practical, inside knowledge of this relatively new phenomenon that will positively affect their practice, understanding and connection with patients.

My passion and desire to unveil the healing power of one’s narrative story is grounded in my personal path of research and storytelling practice. First, life narratives involve organizing things—actions, happenings, events—in time. “Narrating inevitably involves reframing these particulars in temporal sequences. Although capable of great robustness, narrative by its nature
will never generate certainties. A narrative account is always tentative and revisable” (Bold, 2012, p. 107).

Writing life’s stories began with my career as an investigative journalist at a major daily metropolitan newspaper in New York. From there, I branched out to found and lead content-driven women’s magazines created to tell authentic stories that really made a difference, and empowered, and inspired others. I have spent years of highlighting the incredible human ability to overcome adversity in the darkest of situations. Beyond any professional titles, I became a storyteller, telling life stories that were just as healing for the person featured in the story as they were for those reading the stories. And, now, I work at Florida Atlantic University’s Division of Research, conveying the story of research, writing the stories of the investigators and their cutting-edge passions that change our world.

Lastly, adding vigor to my research is my Master’s degree in “narrative medicine,” a term recently created by Rita Charon, a Columbia University professor of clinical medicine and director of the narrative medicine program. Charon is a pioneer and national authority in the field of narrative medicine, and has written extensively on provider-patient relationships, medical ethics, and empathy in medical practice. Guided by her leadership, Columbia University became the first medical school to establish a program in narrative medicine, competence, and humility. Narrative and medicine are deeply about human troubles and expectations gone awry, according to Charon. Narrative is critical because we make sense of the world through the stories we tell, and narratives are one of our main ways of communicating (Riessman, 2005). The allure of narrative, most agree, is that it expresses personal experience.

Analyzing those experiences in a qualitative study of how different humans experience the world around them, is narrative inquiry methodology using narrative accounts to provide
insights about the person, his or her group, and a person’s deeply held understandings of the subject of interest (Daiute, 2014). The methodology allows people to tell the stories of their lives. It collaboratively explores a phenomena or issue with an individual “in an effort to understand how the individual’s past experiences impact the present, and potentially, the future” (Mills & Gay, 2016, p. 347.)

**Overview of Remaining Chapters**

In Chapter II, I critically examine the history of and empirical literature surrounding HBOC and identify the gap in the research of little to no analysis of the psychological implications of HBOC. I consider research on other genetic conditions and differentiate between those that offer potential action to change one’s fate and those (most) which do not. I also look at the research behind narrative and action, and narrative medicine. Lastly, this chapter focuses on addressing the potential implications for leadership and change in this field.

In Chapter III, I delve into narrative inquiry methodology, in particular identify plot analysis, why its theories and my positionality lend themselves well to the research and outline the proposed steps of the data collection.

Chapter IV reports in depth on the stories of the 14 participants in this study, relying extensively on what was told during the interviews. In Chapter V, I use plot analysis to examine recurring elements and variations in the stories. Chapter VI is a review of the key findings and compares these to what came from earlier studies. My study’s limitations, implications for leadership and change are discussed along with final reflexive comments that position my experience in relation to the process and outcomes of the dissertation.
Chapter II: Critical Review of Hereditary Breast and Ovarian Cancer

To identify a woman as a carrier only after she develops cancer, is a failure of cancer prevention.

–Dr. Mary Claire King, 2018 FORCE conference

First, it is important to note that much of the review of literature regarding BRCA1 and BRCA2 is predominately scientific and does not include potential topics that may emerge from the narratives of the women who are living with such mutation. Therefore, because we know so little about the psychosocial ramifications of those testing positive for the hereditary condition, it is more appropriate to broaden the scope of the literature review. I collected additional knowledge of potential psychological and sociological experiences stemming from the women’s very personal and unique stories such as facing the choices of removing body parts to outrun an illness that may never come, not only disfiguring, but also being thrust into early menopause, which can effect health in different way via bones, heart and cognition, as well as stories of women who are struggling with the reality that they have passed this mutation onto their children.

In addition, I have broadened the review to include relevant topics that help shape the overall research field. This includes, but is not limited to, a critical review of HBOC, the history of the discovery of HBOC, incidence of BRCA1 and BRCA2 genetic mutations, genetic screening, reducing risk, psychological, and emotional implications of living with HBOC, celebrity public awareness of HBOC and the public’s reactions, methodological approaches to the psychological and emotional implications of living with HBOC, genetic counseling, other hereditary cancer syndromes, narrative affecting action, narrative medicine, pilot studies and using narrative medicine as approach, narrative medicine in practice and implications for leadership and change in these fields.
Incidence of Breast and Ovarian Cancer

With 3.8 million women in the United States with a history of breast or ovarian cancer (Childers, Childers, Maggard-Gibbons, & Macinko, 2017), chances are, most Americans personally know at least one of them. The statistics behind the number of people affected by breast and ovarian cancer are astonishing. According to BreastCancer.org (2019) about one in eight women will develop breast cancer over the course of her lifetime; In 2019 alone, more than 335,000 new cases of breast or ovarian cancer will be diagnosed; and over 41,000 women are expected to die from breast cancer this year. So, the question is, what can help lower these astronomical numbers, ultimately saving millions of lives?

While most breast and ovarian cancers are sporadic—meaning they occur by chance with no known cause—about 10 to 15 percent of breast and up to 20 percent of ovarian cancers are hereditary (Childers et al., 2017).

This genetic condition, called Hereditary Breast and Ovarian Cancer (HBOC), passes the gene mutation from generation to generation in a family. It is important to understand that one can inherit a mutation from either biological parent. And, when a person inherits a mutation in a gene, it can significantly increase the chance of developing breast, ovarian and related cancers. For example, a woman with a BRCA1 mutation has an 85 percent chance of developing breast cancer over her lifetime. Inherited mutations also elevate the risk for cancer in male carriers (male breast, advanced prostate, and pancreatic cancer and melanoma). Early detection of mutations associated with HBOC may give carriers a fighting chance—a chance to take preventative measures that would drastically reduce cancer risk.
History of the Discovery of HBOC

In the 70s, King, a geneticist, decided she needed to figure out why women some families were much more likely to get breast cancer. It took her almost two decades before she identified the single gene that could cause both breast and ovarian cancer. While many people discounted her work, saying that genes couldn't cause complex diseases like cancer, she proved them wrong by mapping the location of the gene she named BRCA1.

Knowing that such a gene existed and approximately where it lay triggered efforts by public and private groups to clone and sequence it. The press baptized the competition ‘the race’ and reported on it in detail for the next 4 years. (King, 2014, p. 1462)

In 1994, after this international “race” of four years among competing laboratories, the BRCA1 gene was successfully cloned. At the American Society of Human Genetics in Montreal, King (2014) stated:

Reality is having the gene, not knowing what it does, and the realization that in the 20 years that we have been working on this project, more than 1 million women have died of breast cancer. We very much hope that something we do in the next 20 years will preclude another million women dying of the disease. (p. 1462)

King’s discovery revolutionized genetics and cancer treatment by creating the ability to identify the mutations related to HBOC, and the first gene linked to a higher than average chance of developing breast cancer and ovarian cancer. And now, genetic tests let people know if they have mutations in their BRCA genes that increase their cancer risk, and, if they do, there are options on what to do with this knowledge.

Soon after, scientists also discovered BRCA2. They found that a loss-of-function mutation (Miki, et al., 1994; Wooster et al., 1995) in either of these genes (BRCA 1 or BRCA 2) can affect the normal function of these genes which is to repair damaged DNA. These DNA repair proteins protect the body by limiting cell growth when damaged DNA is present and repair the damage. When a DNA repair tumor gene is mutated, meaning the protein it encodes is
not functioning properly, DNA damage accumulates allowing cells to grow uncontrollably and may eventually form a mass called a tumor (American Society of Clinical Oncology, 2015).

Thousands of different disease-causing mutations have been detected in BRCA1 and BRCA2. Each loss-of-function mutation is individually rare (except for a few mutations that are found at higher frequencies in certain populations), and each independently confers very high risk for breast and ovarian cancer. ... There are more breast cancer genes to be found. (King, 2013, p. 1465)

**Biology and Incidence of BRCA1 and BRCA2**

At the annual FORCE (Facing Our Risk of Cancer Empowered) conference in San Diego, in October 2018, King (2018) was the keynote speaker. She explained to an audience\(^1\) of more than 750, the biology of the BRCA1 and BRCA2 genes, and their sensitivity of tumors, by pointing out the following:

1. Everyone has BRCA1 and BRCA2 genes—normal cells have two copies of each gene.
2. BRCA1 and BRCA2 play key roles in homologous recombination repair—they repair damaged DNA, specifically double stranded breaks.
3. Most tumors in BRCA1 and BRCA2 mutation carriers have lost of the second wild type, copy of the respective gene. This results in no functional protein.
4. Pathologic BRCA1 and BRCA2 mutations decrease a cell’s ability to repair double stranded breaks.
5. Certain drugs cause double stranded breaks, which BRCA1 and BRCA2 mutated cells find it very difficult to repair.

She continued, stating that mutations are individually rare, but collectively common. And, when critical genes are mutant, it leads to a loss of DNA repair.

\(^1\) Information from the address by King at the FORCE 2018 sessions at San Diego is based on a personal audio recording I made along with notes that I took while in attendance. There are no transcripts of the presentations.
Mutations in BRCA1 and BRCA2 are primarily associated with the majority of HBOC families. (There are other less common genes also associated with an increased risk of developing breast, ovarian and other cancers, but, for the sake of this dissertation, we will focus on the BRCA gene mutations.) For example, a child with a parent who has the gene mutation has a 50% chance of inheriting the mutation. A brother, sister, or parent of a person who has a mutation also has a 50% chance of having the same mutation. This helps explain why HBOC is most frequently diagnosed when there are multiple cases of breast and/or ovarian and related cancers on the same side of the family, usually in first-, second-, and third-degree relatives, and at a young age of onset (age 50 or younger). It may also include male breast cancer cases, especially associated with BRCA2 mutations (American Society of Clinical Oncology, 2018).

Some BRCA mutations are relatively common in certain populations. For example, those of Ashkenazi Jewish ancestry have an increased chance of carrying one of three BRCA or “founder mutations” (Shaag et al., 2005). It’s estimated that about one in 40 individuals with Ashkenazi Jewish ancestry have a mutation in BRCA1 or BRCA2 (Centers for Disease Control and Prevention, n.d.).

compared to one out of every 400 to 800 hundred people in the general population according to the Centers for Disease Control and Prevention (2015).

With the discovery of the BRCA1 and BRCA2 genes in the mid-90s, carriers began to be identified and associated risks were generated. A recent large study estimated that about 72% of women who inherit a harmful BRCA1 mutation and about 69% of women who inherit a harmful BRCA2 mutation will develop breast cancer by the age of 80 (Kuchenbaecker et al., 2017). In addition, it was estimated that about 44% of women who inherit a harmful BRCA1 mutation and
about 17% of women who inherit a harmful BRCA2 mutation will develop ovarian cancer by the age of 80 (Kuchenbaecker et al., 2017).

Even though the number of identified carriers is on the rise, there is still a deficit of 1.2 to 1.3 million women with a history of breast or ovarian cancer who have not received genetic testing. And, according to a study from 2017, “most women meeting criteria have never even discussed genetic testing with a health care provider. Large national efforts are needed to address this unmet need” (Childers et al., 2017, p. 3805).

Genetic Exceptionalism

Genetic exceptionalism is the belief that genetic information is special and must therefore be treated differently from other types of medical information. For example, patients are able to obtain information about their blood pressure without involving any medical professionals, but obtaining information about their genetic profile might require an order from a physician and expensive counseling sessions. Disclosure of an individual's genetic information or its meaning—for example, telling a woman with red hair that she has a higher risk of skin cancer—has been legally restricted in some countries providing medical advice (Helmes, 2002).

The unique aspects of genetic knowledge have led to ‘genetic exceptionalism,’ the separate treatment of the ethical implications of genetic testing. This genetic exceptionalism is a dangerous ethical position that can lead to segregation of a group of people at risk (Meiser et al., 2002). But genetic knowledge also raises complex questions of autonomy, privacy, and responsibility.

Beyond the ethical implications of genetic testing, experts and the public have expressed different views on the value of BRCA testing, from stressing the importance of genetic knowledge for high-risk women as a means to enhance control of their lives, to worrying about
the potentially negative repercussions of genetic information (Wang, 2004).

Genetic information has had little impact on health outcomes, because it has been used primarily to diagnose conditions for which treatment was limited or lacking. This bleak history has provided a justification for genetic exceptionalism. But, as genetic information increasingly becomes medically useful, it challenges the concept of genetic exceptionalism, and it must be looked at as the productive use of genetic risk factors for prevention.

Genetic Screening

King (2014) raised an ethical push that genetic screening for BRCA1 and BRCA2 should be offered to all young women, regardless of family history of cancer.

To identify a woman as a carrier only after she develops cancer is a failure of cancer prevention. . . . My proposal is that we offer population screening for unambiguously damaging mutations in these genes to all women at about age 30. In other words, we move beyond testing only women in severely affected families to testing women regardless of family history of breast or ovarian cancer—who can then undertake preventive action if they learn they carry a mutation. . . . Every breast or ovarian cancer patient with a BRCA1 or BRCA2 mutation detected after diagnosis is a missed opportunity to prevent a cancer. No women with a mutation in BRCA1 or BRCA2 should die of breast or ovarian cancer. (King, 2018)

Tossing aside the idea of genetic exceptionalism, King indicated that population-based screening meets the World Health Organization criteria: The disease is an important health problem in the target population, the risk of disease due to the mutation is high, mutations responsible for the disease can be accurately identified, and effective interventions exist (Helwick, 2015). But, part of the identified deficit may be attributed to the initial costliness of the genetic screening.

For nearly 20 years, while Myriad was the only commercial source in the United States for genetic testing of BRCA1 and BRCA2, cost was a major deterrent to widespread screening. The cost to women of BRCA1 and BRCA2 testing is now dropping, due both to the end of the monopoly and to two scientific developments that have changed the landscape. (King, 2013, p. 1465)
In addition to now being able to effectively implement multi-gene screening panels, genomic technology now allows for more cost-effective and less time-consuming sequencing. Previously, as noted by Walsh et al. (2011),

Clinical genetic testing was carried out gene by gene, based on specific clinical indications and family histories, with each test costing thousands of dollars. With the advent of massively parallel sequencing, large panels of genes are now screened simultaneously at far lower cost. (Walsh et al., p. 18032)

In June 2013, the U.S. Supreme Court ruled unanimously that genes are products of nature and therefore cannot be patented nullifying the Myriad patents on BRCA1 and BRCA2 (Association for Molecular Pathology et al. v. Myriad Genetics, Inc. et al., 2013). The ruling immediately led to wide availability of clinical genetic testing.

In addition, there are laws that protect the rights of people with an inherited mutation or hereditary cancer.

The Genetic Information Nondiscrimination Act (GINA) prohibits discrimination by health insurance companies and employers based on genetic information. “In this case, genetic information is defined as: your genetic test results; your relatives’ genetic test results (up to and including fourth degree relatives); and/or information about family history of any disease or disorder. Information about your participation in research that includes genetic testing, counseling, or education is also protected. (FORCE, 2016).

And, in March 2018, the FDA approved the first direct-to-consumer (DTC) test for three specific (founder) mutations in the BRCA genes. The test is offered by 23andMe, a laboratory that originally focused on the genetics of ancestry.

But, by circumventing the need to consult a health care professional, DTC genetic testing falls below standard-of-care, according to FORCE, which is the first, largest, and longest sustaining community devoted to adult hereditary cancers, according to Friedman (2018) Here is why: The 23andMe test is an incomplete test for cancer risk because it only tests for the three founder genes most frequently observed in people of Ashkenazi Jewish decent. To date, more
than 6,100 different BRCA mutations that increase cancer risk have been identified in BRCA1 and 2.

In addition to BRCA1 and BRCA2, there are other genes that have been linked to increased risk for breast, ovarian and related cancers. The FDA report fails to mention that more complete clinical tests are available to help people understand their cancer risk, and that the cost for these tests are often covered by insurance if criteria are met; in addition, other low-cost testing options are available; for example, through Color Genomics, a company that produces an at-home saliva kit test that can determine if you have one of the three most common founder genes that increases your risk of HBOC. Lastly, individuals who receive a negative test result from 23andMe may have a false sense of confidence about their cancer risk. On a positive side of this latest development, those with no known family history, who do not meet the criteria for testing, can now turn to 23andMe to easily find out if they inherited one of the three founder BRCA mutations.

Furthermore, another barrier to genetic testing for inherited breast and ovarian cancer was the concern that a positive finding would lead to loss of health care coverage. “In consequence, mutations were not identified in some women who could have been saved by risk-reducing surgery. The Genetic Information Nondiscrimination Act of 2008 (Public Law 110-233), which protects mutation carriers against loss of health care coverage, should have removed fear as a barrier to testing, so that women with mutations in BRCA1 and BRCA2 can be identified without economic reprisal” (King, 2013, p. 1465).

With a variety of options now for genetic testing for HBOC, carriers are able to use the knowledge to help guide decisions in the management of the risk of developing cancer and communicating the powerful information to at-risk family members. If positive for a HBOC
mutation, carriers and their medical team can use the knowledge to create a proactive plan to reduce the cancer risks.

**Reducing Risk**

One avenue to reduce risk is undergoing prophylactic surgeries such as a risk-reducing bilateral salpingo-oophorectomy (RRSO), which removes the ovaries and fallopian tubes, usually recommended after the completion of childbearing years to decrease the risk of both ovarian cancer and breast cancer, and the bilateral risk-reducing mastectomy (BRRM; Kauff, Satagopan, & Robson, 2002; Rebbeck, Kauff, & Domchek, 2009). A BRRM, which is the preventive surgical removal of both breasts, has been shown to reduce the risk of breast cancer by at least 95% in women who have a deleterious (disease-causing) mutation in the BRCA1 gene or the BRCA2 gene and by up to 90% in women who have a strong family history of breast cancer (Domchek et al., 2010; Hartman et al., 1999; Meijers-Heijboer et al., 2004; Rebbeck et al., 2004). A RRSO, which is the preventive surgical removal of the ovaries and fallopian tubes, has been shown to reduce the risk of ovarian cancer by approximately 90% and the risk of breast cancer by approximately 50% in women at very high risk of developing these diseases (Guillem et al., 2006).

But these surgeries are not without potential implications. Risk-reducing prophylactic surgeries are invasive and permanent, so many carriers struggle with these very difficult and personal decisions. Facing these decisions is just one potential psychological implication of discovering you have inherited a mutation that drastically increases your risk of cancer and uncovering the essence of such psychological implications has become the focus of this research.

**Psychological/Emotional Implications**
Research shows that long-term consequences for women of being informed about an increased risk of breast cancer in terms of the effect on their everyday lives, their coping strategies, and their unmet needs in terms of the current service, emerges in the following key issues, which provide valuable insight into the long-term consequences of living with an increased risk:

- psychological adaptation,
- behavioral adaptation,
- family issues,
- clinical surveillance,
- provision of information, and
- peer support (Appleton, Fry, Rees, Rush, & Cull, 2000).

While more must be written about the translation of genetic testing for cancer risk into providing additional psychosocial (interrelation of social factors and individual thought and behavior) services to patients, research suggests that individuals will have varied emotional responses to the process of genetic testing, as well as its results. Positive BRCA1 and BRCA2 testing results are associated with greater distress in women with who undergo genetic testing closer in time to a breast cancer diagnosis (Douglas, Hamilton, & Grubs, 2009).

Nonetheless, women who test positive for BRCA1 or BRCA2 are also often met with resistance, shock, and other negative emotions from family members (Kenen, Arden-Jones, & Eeles, 2004). So, while the genetic testing may give them the knowledge they need to save their lives, this knowledge also comes with potential risks for other biological family members, causing additional stress on the carrier, as well as the family members.
Other important risk factors for future distress include being the first member of the family to obtain genetic testing, having children, and experiencing the death of a relative from hereditary cancer (Meiser, 2005; Schlich-Bakker et al., 2007; van Oostrom et al., 2006). And, studies also show that managing and acknowledging emotions surrounding a patient’s BRCA-related health decisions is in the top three advices offered to newly diagnosed previvors\(^2\), from previously diagnosed previvors (Rauscher & Dean, 2017). Additional advice included the importance of engaging in two-way dialogue with partners/spouses across the life span of the partnership and seeking information on new technologies and information regarding family-planning and genetic-cancer-prevention decision-making, as well as recognizing where to go for different support needs, (Rauscher & Dean, 2017). This means that discovering one is a carrier is not the end of the conversation. There are decisions to be made throughout life. For example, if one finds out before child-bearing years, there are choices to decide not to have children or wait and have surgery after children. And, more often than not, if reconstruction of the breasts is involved, this may lead to multiple surgeries over a span of many years. Many health-related and lifestyle related choices exist at various ages throughout life that could be affected by this knowledge.

Werner-Lin (2007) found that families frequently relied on multi-generational stories to make sense of the inherent ambiguity as they face medical decisions and navigate life’s journeys in relation women who carry a BRCA mutation. The findings revealed that beliefs about risk are more firmly grounded in family experiences with cancer than in biomedical research. Pervasive meanings included the presence of ‘‘danger zones’’—specific ages at which cancer risk was

\(^2\) According to FORCE (2018), “Cancer previvors are individuals who are survivors of a predisposition to cancer but who haven’t had the disease” (para.1, emphasis added)
believed to increase dramatically—and the experience of “the wait and the worry,” in which participants felt increased urgency to achieve family development goals (e.g., child bearing) and limited control over relational factors influencing when these goals could be met (i.e., meeting a life partner).

The American Society of Clinical Oncology has suggested that, beyond the decision of whether or not to get genetic testing and to consider prophylactic steps to reduce risk, there are emotional implications throughout the entire process, including potential depression, anxiety, guilt, an increase sense of considering yourself sick, family tension, high cost, discrimination, privacy, unclear results, and more (as cited in Metcalfe, Narod, Eisen, & Lerner-Ellis, 2016). For example, the carrier feels obligated to tell family members about test results, which could complicate family dynamics.

And, even if a person receives negative genetic testing results, this may cause difficult emotions too. For example, some people may experience guilt if they do not have a gene mutation that other family members have. A negative result, which just means a specific genetic mutation is not present, may also give a false sense of security because people with negative results may still develop cancer. The negative result only means the person’s risk is average—which is still one out of eight for breast cancer.

Despite increased public awareness, availability, and knowledge that genetic testing can arm at-risk individuals, prophylactic measures to reduce risk remain low among of BRCA1 and BRCA2 carriers. For example, those opting for prophylactic mastectomies range between 0% to 37% (Botkin et al., 2003; Hirschberg, 2015; Schwartz et al., 2012). The majority of individuals opt for and use increased breast cancer surveillance (Botkin et al., 2003; Hirschberg, 2015; Metcalfe, Esplen, Goel, & Narod, 2005; Schwartz et al., 2012). However, prophylactic surgeries
not only decrease the risk of cancer, but they also appear to decrease distress in BRCA1 and BRCA2 carriers (Hirschberg, 2015).

**Celebrity Public Awareness**

In 2013, actress Angelina Jolie wrote an op-ed piece published in *The New York Times* opinion section. She disclosed that she had a BRCA1 mutation and underwent a prophylactic risk-reducing bilateral mastectomy.

Jolie (2013) wrote:

I carry a “faulty” gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer. My doctors estimated that I had an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer. … I wanted to write this to tell other women that the decision to have a mastectomy was not easy. But it is one I am very happy that I made. My chances of developing breast cancer have dropped from 87 percent to under 5 percent. I can tell my children that they don’t need to fear they will lose me to breast cancer. (para. 2, 3, & 11)

She also encouraged others:

For any woman reading this, I hope it helps you to know you have options. I want to encourage every woman, especially if you have a family history of breast or ovarian cancer, to seek out the information and medical experts who can help you through this aspect of your life, and to make your own informed choices (Jolie, 2013, para. 14)

A study that documented the impact of her disclosure on information-seeking behavior, specifically that regarding online genetics and risk-reduction resources available from the National Cancer Institute, showed a dramatic and immediate increase in internet traffic to the National Cancer Institute’s online resources. According to the research, the fact sheet on preventive mastectomy received 69,225 page views on May 14, a 795-fold increase compared with the previous Tuesday (which had fewer than 90 page views). There was also a fivefold increase in page views observed for the Physician Data Query Genetics of Breast and Ovarian Cancer summary in the same time frame, and a substantial increase, from 0 to 49%, in referrals from news outlets to four resources from May 7 to May 14. This research showed that celebrity
disclosures can dramatically influence the public’s awareness, in particular online information-seeking behaviors (Juthe, Zaharchuk, & Wang, 2015).

In addition, following Jolie’s (2013) op-ed piece about her medical condition and choices, another study showed that BRCA testing rates among women ages 35 and older enrolled in a large U.S. health insurance carrier increased. According to the research, the increase was higher among women who had no personal history of breast, ovarian, or pancreatic cancer—women with the same profile as Jolie—than women with a cancer diagnosis. And, while the study cannot verify that Jolie’s story was the only cause of the increase, results strongly suggest that it was likely the main contributor to increased BRCA testing rates.

Prior to Jolie’s story, most women were likely unfamiliar with the BRCA1 and BRCA2 genes. Because of her story, more women now know that a woman with a harmful mutated copy of one of these genes has a significantly higher risk of developing breast and ovarian cancer during her lifetime. (Walker & Morin, 2015, p. 7)

Further research alluded to the fact that Jolie’s impact was bigger than other celebrity medical-related announcements, according to Evans et al. (2014) possibly due to her “glamorous image and relationship to Brad Pitt” (p. 5). That said, they also stated: “This may have lessened patients’ fears about a loss of sexual identity post preventative surgery and encouraged those who had not previously engaged with health services to consider genetic testing” (p. 5).

Whatever the reason, Jolie’s public announcement seemed to bring needed awareness. Another study took a look at how such a personal story (Jolie’s story) affected the public and cancer genetics clinics. Raphael, Verma, Hewitt, and Eisen (2016) conducted a retrospective review using data from the clinical database of the Familial Cancer Program the Academic Cancer Centre in Canada. The researchers assessed the impact of Jolie’s story on genetic counseling referrals and the appropriateness of such referrals. They found that the number of women referred for genetic counseling increased by 90% after six months, and remained high one year after
Jolie’s story, with an increase of 88% from baseline. The number of women who qualified for genetic testing increased by 105% after six months; this increase persisted after one year with an increase of 68% from baseline. Furthermore, the number of BRCA1/2 carriers identified increased by 110% after six months and by 42% after one year. The next challenge for that particular health care system was to then meet the increased demand for cancer genetic services, as well as ensure appropriate use of referrals and genetic counseling resources (Raphael et al., 2016).

**Where Do We Go Now?**

With the increase in public awareness, healthcare professionals are also attending to a greater number of individuals, currently without cancer, who are considering cancer genetic testing, or have questions about results or options; therefore, they must be prepared to meet the mental health needs of this new population. Psychological challenges can occur throughout the process of genetic testing for cancer risk, from the beginning stages of discussions about referrals for testing, to medical decisions based on results.

The health care infrastructure also has its limits, given the severe shortage of qualified cancer genetic counselors and general practitioners who are unprepared to address genetics, creating a demand for creative approaches to service delivery. The combination of individual salience, low health literacy, the consumer movement, and important policy problems, then makes genomics the perfect information seeking research problem. (Johnson, Case, Andrews, & Allard, 2005, p. 323)

With this relatively newer available knowledge comes potential psychological implications when considering communicating the information with biological family (immediate and extended). When talking to biological children about this, potential risks include, burden and guilt of passing risk to children, surveillance options, risk-reducing surgery (mastectomy and oophorectomy) decisions that are invasive and permanent, body image/sexuality/menopause, possible future family issues, insurance struggles, and, of course, mortality. But research shows that it is a person’s personal and family history with breast (and ovarian) cancer that can often
influence the outcome of their potential psychological implications. Healthy women living with the high risk for hereditary breast cancer are living within the context of their family cancer story, which, in turn, influences how they define themselves and engage in self-care (Underhill, Lally, Kiviniemi, Murekeyisoni, & Dickerson, 2012). Heiniger, Butow, Charles, kConFab Psychosocial Group, and Price’s (2015) findings concurred: “Risk comprehension and risk management were largely influenced by the individual’s experience of coming from a high-risk family, with both tested and untested women relying heavily on their intuition” (p. 727).

**Methodological Approaches to Psychological Ramifications**

Little is known about women’s views of the psychological outcomes of a bilateral prophylactic mastectomy (BPM), a controversial cancer prevention strategy for women at high-risk of familial breast cancer, and studies to date have often been carried out on small (and, therefore, possibly unrepresentative) samples (Hopwood et al., 2000). For example, in a single case report, Hopwood et al. (2000) reported that the patient revealed that her BPM surgery resulted in a loss of femininity and sexuality with considerable pain over a long recovery period. Hopwood et al. observed that while one report is not enough to draw conclusions, the findings are disturbing.

Lloyd, Watson, Oaker, Sacks, Rovere, and Gui (2000) reported on a qualitative discovery-orientated study in which they interviewed 10 women who had undergone a prophylactic mastectomy, and eight of their partners, with the aim of exploring the personal experiences of surgery, factors associated with psychological adjustment, and the impact on the family. Information was transcribed and systematically analyzed using grounded theory. Among themes that emerged, representing women’s key experiences were: deciding, telling, experiencing surgery and recovering, maintaining womanliness, processing the loss, moving on, and isolation and being
In addition, psychological response may also be determined by how much the individual believes they had a choice in the decision-making process. The psychosocial ramifications may be different for women who felt they had a “forced choice,” as a result of genetic testing, compared to those acting on the basis of greater uncertainty (Lloyd et al., 2000). But, the lived experiences of the psychosocial ramifications have yet to be fully explored. For example, my research aimed to provide a detailed understanding of the personal experiences of women faced with positive BRCA results, what or how they felt when they found out and what led them to the decisions they made, in an effort to comprehend how their experiences contribute to psychological adjustment, and assist healthcare professionals in more sensitively communicating and address emerging issues with this growing population.

In another study Hallowell (2000) focused specifically on high-risk pre-menopausal women who had undergone prophylactic bilateral oophorectomy to manage their inherited risk of ovarian cancer. Hallowell discovered this “although the benefit of risk reduction was perceived as outweighing the costs of surgery, many women reported that they would have liked more information about the physical and emotional after-effects of oophorectomy prior to and following surgery” (p. 486). This qualitative study included in-depth interviews with 23 high-risk women following surgery and identified five types of information needed by women making surgical decisions: about ovarian function and menopause, hormone replacement therapy (HRT), surgical procedures, convalescence, and the risk of inheriting a genetic mutation and developing cancer. But, again, the article did not address any potential psychosocial implications.

Aside from the molecular genetic quantitative research related to carriers, much of the qualitative research focused on the initial decisions of potentially high-risk patients to opt for genetic testing. And, most of the investigators were from the psychology profession, hospitals,
psychological medicine groups, family history clinics, and family research centers at universities and health policy organizations.

**Vulnerable Groups**

Since there is a 50/50 chance of inheriting a genetic mutation that causes one to be a carrier of HBOC, women are not the only group susceptible to becoming carriers. While being a carrier is often considered more common in women, men have an equal chance to be carriers as well, because every person has a 50/50 chance of inheriting a genetic mutation from a biological parent.

**Men with HBOC.** While most of the existing studies regarding HBOC syndrome focus solely on women (mostly because of a more significant cancer risk elevation in women), it is important to recognize that men can also inherit the cancer predisposition syndrome. Suttman, Pilarski, Agnese, and Senter’s (2018) study focused on how men share the information or their dissemination patterns regarding the familial genetic risk information. They interviewed 21 people, primarily men, obtained through FORCE, regarding their family cancer history, experiences with cancer and genetic testing, motivations to pursue genetic testing and, subsequently, disclosure of genetic test results, information-sharing patterns, healthcare provider response, and participants’ emotional support systems. Five main themes emerged, including concern about cancer risk for their children and female family members, the belief that the discovery of being HBOC positive provided them with increased personal awareness, but also the view that having this risk information has negligible impact on their life overall. There was an interest in a male-focused support group to discuss HBOC and gain knowledge and information, specific to their gender. Participants claimed to take on active and open communication roles with family members and health care providers, and they expressed the need for knowledge and
awareness among the health care community and general population regarding male HBOC risks. “This study serves as a pilot study and provides important and novel insights into psychosocial impacts, communication patterns, encounters with health care professionals, and expressed needs of males with HBOC” (Suttman et al. 2018, p. 886).

**Global perspective of HBOC.** Similar to the lack of studies with men with HBOC, there are also less studies outside of the United States, and/or ones that address specific minority populations living with or at-risk for HBOC. In an effort to connect to an underserved targeted population, one study aimed at developing a culturally-targeted educational brochure to promote awareness of hereditary breast and ovarian cancer (HBOC) among black women. They tracked the dissemination of the brochure over a five-year period using self-addressed postcards contained inside the brochure that included several open-ended questions about the use of the brochure, and a field for written comments. They found that this strategy among pre-existing social networks proved to be a useful and sustainable method for increasing knowledge of HBOC among black women (Scherr, Bomboka, Nelson, Pal, & Vadaparampil, 2017).

In the United Kingdom, a similar effort to connect and raise awareness with an at-risk demographic was initiated as a one-day pilot study support forum created to inform and support women at high risk, living with HBOC (Harris & Ward, 2011). The goal was to create and hold a daylong workshop that would serve to reduce their sense of isolation through connecting with others in a similar situation, allowing them to share experiences, offer support and information, and give them the opportunity to support each other. The majority of the evaluations from the day’s event, either strongly agreed or agreed that the pilot support forum was a success.

The greatest demonstrable impact was on feelings of isolation. The overwhelming majority (29 out of 30) of participants strongly agreed that they had been feeling isolated and that being at the pilot support forum gave them a sense of belonging. They were proud of themselves, and of others, for their willingness to share sensitive stories, fears and
anxieties, and their ability to support each other. Some of the women (seven out of 30) described the day as having given them a sense of empowerment. (Harris & Ward, 2011, p. 822)

Overall, these studies show that addressing these issues with different populations, different demographics and even those from different countries, takes thinking outside the box in order to connect with them on their individual group level.

**Genetic Counseling**

The phenomenon of genetic testing and discovery of HBOC has also driven the increased need for genetic counselors, professionals who have specialized education in genetics and counseling to provide personalized help patients may need as they make decisions about their genetic health, according to the National Society of Genetic Counselors (NSGC, 2018). There are 4,000 certified genetic counselors in the United States who have advanced training to interpret genetic test results, and to guide and support patients seeking more information about such things as how inherited diseases and conditions might affect them or their families, how family and medical histories may impact the chance of disease occurrence or recurrence, which genetic tests may or may not be right for them, and what those tests may or may not tell, and how to make the most informed choices about healthcare conditions.

A solid all-inclusive support structure is what drives the creation of organizations like the non-profit FORCE, whose mission is to improve the lives of individuals and families affected by adult hereditary cancers.

The closest semi-relevant research to my study deals with the psychological, social, behavioral, or ethical aspects of cancer, primarily from the field of psycho-oncology, which examines the relationships between cancer and the mind. Similarly, psychosocial oncology recognizes the implication that cancer concerns not just individual patients, but for their family, friends, colleagues, and the community where they live. According to Barraclough (1999)
psychosocial oncology—which he refers to as psycho-oncology—examines the psychological response of patients to cancer at various stages of the disease, and that of their families and caretakers, and the psychological, behavioral, and social factors that may influence the disease process.

While rare, the phenomenon of genetic testing and discovery that one is a carrier of a genetic mutation, is not isolated to breast and ovarian cancer.

**Other Hereditary Cancer Syndromes**

Hereditary cancer syndromes are rare (Roukou & Kappas, 2002). Cancer.net lists approximately 30 hereditary cancer-related conditions, which raise affected families’ cancer risk for specific types of cancer (See Appendix B for a complete list). And, even more rare are the hereditary cancer syndromes that allow carriers to opt for prophylactic surgeries and lessen their risk. And, even with such options, there’s still controversy and psychological implications.

Traditional surgical resection of specific organs for the protection of individuals at very high risk of developing inherited cancer in the breast, colon, and stomach is increasingly receiving considerable attention. However, although surgery is the only preventive intervention able to eliminate the risk of cancer at a specific organ, surgical prophylaxis has been controversial for a numerous of reasons and questions have been raised. (Roukou & Kappas, 2002, p. 65)

Due to insufficient quantities of literature surrounding the topic of the psychological implications of those living with HBOC, I decided to look at other studies that, based on hereditary conditions, either address the potential psychosocial that follow prophylactic surgeries to voluntarily remove major body organs and/or bring attention to the potential psychosocial ramifications of other hereditary related conditions.

First example is Hereditary Diffuse Gastric Cancer (HDGC), which has an early onset and poor prognosis, so individuals identified as at high risk (those who carry the gene mutation)
of developing HDGC are advised to undergo prophylactic total gastrectomy (PTG) surgery to have their stomach removed in their early 20s.

A qualitative interview study was administered in an effort to uncover the psychosocial implications of undergoing gastrectomy surgery in order to manage the risks of HDGC (Hallowell et al., 2017). While all participants saw the benefits of risk reduction as outweighing the costs of surgery, the surgery was described as having a range of physical impacts. Those impacts included disrupted appetite, weight loss, fatigue, gastrointestinal symptoms, as well as related psychological, social and economic implications, particularly the impact on quality of life being difficult to predict and may be ongoing for some individuals.

Much like HBOC, little is known about the factors that influence decisions to undergo or decline PTG, making it difficult to provide optimal support for those facing these decisions. And, decisions to proceed with the surgery for prophylactic reasons can be difficult, especially since long-term outcomes are not well defined (Hallowell et al., 2016).

In one study, qualitative interviews were carried out with 35 high-risk individuals from the Familial Gastric Cancer Study in the United Kingdom, exploring the experience of the decision-making process, factors influencing risk-management decisions, and psychosocial outcomes in adults who underwent PTG.

The data suggest that decisions to proceed with PTG are influenced by a number of potentially competing factors: objective risk confirmation by genetic testing and/or receiving a positive biopsy; perceived familial cancer burden and associated risk perceptions; perceptions of post-surgical life; an increasing inability to tolerate endoscopic procedures; a concern that surveillance could miss a cancer developing and individual’s life stage. These findings have implications for advising this patient group. (p. 665)

In a similar study by Muir et al. (2016), participants were asked about health-related quality of life, including body image, psychological distress, regret, and decisional conflict. Most participants experienced a decrease in quality of life immediately post-operatively, climbing up to
baseline, and decreasing again over a 24-month period. Muir et al.’s study emphasized the need for long-term follow-up of this unique population of previvors.

An additional example involves individuals with Familial Adenomatous Polyposis (FAP), which is characterized by multiple adenomas in the colorectum with a high risk to develop colorectal cancer, have an inherited condition that requires prophylactic surgery (colectomy) followed by a lifetime program of endoscopic surveillance to prevent colorectal cancer. In a descriptive qualitative content analysis study, Fritzell et al. (2010) using three group interviews with people living with FAP, aimed to gain a deeper understanding of how FAP affects life by exploring the patients’ view of what it is like living with the illness and being committed to a lifelong screening program. The results showed that most participants expressed unmet needs, such as lack of healthcare providers with good knowledge about FAP, practical and psychosocial support, FAP educational programs, and organized meetings with other persons with the condition.

Douma et al. (2010) explored whether individuals at risk of FAP experience distress due to this potentially life-threatening disease. In this cross-sectional study, all individuals from families at high risk for FAP registered at the Netherlands Foundation for the Detection of Hereditary Tumours were invited to complete a questionnaire assessing the prevalence of psychological distress and the need for and use of specialized professional psychosocial support. A substantial number of the 525 participants reported moderate to severe distress levels associated with FAP. However, only one-third of those received specialized professional psychosocial support.

In a study on young adults, Mireskandari et al. (2009) explored the psychosocial impact of either having FAP, or being at risk for FAP. In-depth interviews were conducted with 11
participants, ages 18 to 35, with a clinical or genetic diagnosis of, or at risk of developing FAP. While being at risk did not seem to have a major psychosocial impact upon clinically unaffected participants, clinically affected individuals discussed a number of major stressors including issues in relation to changes in body image and physical functioning as a result of surgery, concerns about discussing FAP with new partners, difficulties in relation to childbearing decision-making, and impact on employment.

Underhill, Hong, Lawrence, Blonquist, and Syngal (2018) looked at descriptions of relationships between self-reported personal demographics or familial characteristics and psychosocial outcomes, cancer risk perception, and cancer worry, in participants with inherited or familial pancreatic cancer risk. In a multi-site, cross sectional survey of adults with elevated pancreatic cancer risk based on family history, there was a moderate to high frequency of cancer worry and perception of a lifetime risk for pancreatic cancer. Results showed that individuals with inherited or familial pancreatic cancer risk experience cancer worry, distress, and have increased risk perception, particularly in the period following caring for a loved one with cancer.

Palmquist et al. (2010) looked at the social context of hereditary cancer risk perception in three families—an African-American family, a Mexican-American family, and a Caucasian family, each with Lynch Syndrome which is documented by a mismatch repair gene mutation. Participant narratives were evaluated to gain insight into how family cancer experiences and genetic testing information have shaped perceptions of cancer risk. The results showed that understanding how different types of family communication influence the formation of perceived hereditary disease risk may enhance efforts to tailor genetic counseling services for families.

While not cancer-related, there have been studies that focus on the psychosocial implications of hereditary conditions. For example, Huntington’s disease (HD) is a progressive
neuro-genetic disorder that also has a 50% inheritance rate. The ability to obtain confirmation of the illness came with the 1993 discovery of the gene. Schwartz (2010) explored the meaning of being diagnosed with HD using narrative inquiry. Ten participants in their first year after diagnosis, were asked to tell their story of what it meant to be diagnosed with HD. A holistic-content approach was used for data analysis. An integrated narrative of the predicaments described: discovering the existence of HD, confirming the diagnosis of HD, revealing the diagnosis to others, and experiencing the reverberations of HD. The results showed the psychological impact of receiving a positive genetic diagnosis has implications for patients and their extended families.

The essential point with hereditary diseases is the decision to initially undergo the genetic testing as way to cope with both the cognitive and affective concerns that arise from living at increased risk of developing a disease in the future (Gooding, Organista, Burack, & Biesecker, 2006). Gooding et al.’s (2006) study addressed the basic concepts of four theories of health behavior and stress and coping to help highlight ways to cope with outcomes of genetic testing that lead to adult-onset diseases such as Huntington's disease, Alzheimer's disease, HBOC, and hereditary colorectal cancer. Gooding et al. concluded that there is potential value of genetic testing for reducing uncertainty and gaining a sense of control over one’s risk of developing disease. They further concluded that genetic testing also assists patients when dealing with the potential stress of the situation, as well as coping with decisions for adult-onset disease risk.

There has also been much debate about the psychosocial effects of predictive genetic testing in minors. In a related study, Duncan et al. (2008) did in-depth interviews with 18 young people, ages 14 to 26 (they were 10 to 25 years old when they were tested), who had undergone
testing, to explore the range of harms and benefits that they perceived were associated with their tests. Participants included eight individuals who were tested for Huntington disease and 10 who were tested for familial adenomatous polyposis.

Harms described included knowledge of future illness, witnessing distress in parents, negative effects on family relationships and friendships, effects upon employment and school, experiencing regret, feeling guilty and having to confront difficult issues. Benefits included knowledge of gene-negative status, relief from uncertainty, witnessing relief in parents, feeling able to plan for the future, positive effects on family relationships and friendships, feeling empowered and experiencing a sense of clarity about what is important in life. (Duncan et al., 2008, p. 47)

In a more recent study, O’Neill et al. (2018) focused on identifying the unique set of challenges that young women from HBOC families face and obtaining essential information to inform decision making is key. They suggested that this health information comes at a time of “heightened distress and greater individuation from family” (p. 351) and offered behavioral intervention for this population, by piloting a three-session telephone-based peer coaching intervention. Of the 100 participants, who were 25 years old or younger and had a first or second degree relative who was a BRCA1 or BRCA2 mutation carrier, 63 reported moderate levels of cancer-related distress. This, and the previous study results dictating potential value, suggest that young adult women from HBOC families have unmet cancer genetic information and support needs. The pilot intervention was able to reduce levels of decisional conflict and promote the use of effective coping strategies

**Narrative Medicine**

Narrative medicine is increasingly popular as a powerful tool that helps connect and create like bonds and supportive networks. Rita Charon (2006), founder and executive director of the program in narrative medicine at Columbia University, said: “If sickness calls forth stories, then healing calls forth a benevolent willingness to be subject to them, subjects of them, and subjected to their transformative power” (p. 216).
Since stories convey values and emotions, and can reveal similarities between people’s experiences, sharing those experiences can help form bonds and supportive networks, which can help build resilience, particularly health-related. Charon (2006) posits narrative medicine fortifies clinical practice with the knowledge of what to do with stories and how to be moved by them enough to act, both creatively and receptively. This medical approach can utilize people’s narratives in clinical practice, research, and education, stating that using narrative requires the ability to recognize, absorb, interpret, and act on the stories and plights of others. Further, Charon claims that narrative medicine fortifies clinical practice with the knowledge of what to do with stories and how to be moved by them enough to act, both creatively and receptively. This medical approach can utilize people’s narratives in clinical practice, research, and education. She suggested that using narrative is a model for humane and effective practice because it requires the ability to recognize, absorb, interpret, and act on the stories and plights of others. Charon stated: “Narrative and medicine are deeply about human troubles and expectations gone awry,” adding that narrative medicine fortifies clinical practice with the knowledge of what to do with stories and how to be moved by them enough to act, both creatively and receptively (as cited in Harter & Bochner, 2009, p. 114).

Integrating humanities and medicine in an educational endeavor such as a writing workshop may promote the observational skills, self-awareness, reflection, and empathy that help to form the healing relationship. Based on this, effective narratives will easily show, not tell, inspiration. In effective narrative medicine, the story makes observations and lessons of importance evident, letting you see what they storyteller sees or feels, without telling you what to do, but often compels one into action. This action is what gives the story purpose and meaning. And, not only would narrative medicine benefit the ill through such transformative power, but one
would think that a compelling personal narrative could cause people to think and wonder about their own life and if they should take action; particularly those at high-risk, ultimately embracing it, instead of fearing it.

While few studies exist related to individuals’ stories relative to the essence of living with HBOC, it seems it would benefit to convert such a powerful experience to scholarship so we can contribute to the wellbeing of a broad community.

A qualitative study by Miller, Balmer, Hermann, Graham, and Charon (2014) was aimed at better understanding what medical students gain from training in humanities, social sciences, and the arts in a narrative medicine curriculum, and to explore the value the students placed on narrative medicine as it relates to their professional development. The question Miller et al. addressed was: “What of value for their development as physicians do the students find they take away from these intensive seminars?” (p. 337). The seminars reflect the conceptual frameworks of narrative medicine itself because they were designed and directed by those who have developed the field. The researchers invited 146 second-year medical students at Columbia University College of Physicians and Surgeons to participate in focus group discussions of their experiences. The medical students in the focus group had already completed a required, half-semester narrative medicine seminar.

The students were asked the following questions:

- Thinking back to your Narrative Medicine seminar, what stood out for you? What do you remember?
- Looking back on your seminar, what do you think it was for? What was the purpose?
- Does it fit into the rest of your medical education?
- What can you apply to your clinical experience? What have you already applied, or what do you hope to apply, if anything? (Miller et al., pp. 337–338)
Focus group facilitators led the discussion, and transcriptions were submitted to close iterative reading by a team who performed a grounded-theory-guided content analysis, generating a list of codes into which statements were sorted to develop overarching themes.

As a result, 130 students’ comments articulated the known features of narrative medicine—attention, representation, and affiliation—and endorsed all three as being valuable to professional identity development. Most agreed on the importance of narrative medicine, and the connection between narrative medicine and clinical practice was evident to students. Overall, students reported that narrative medicine seminars support complex interior, interpersonal, perceptual, and expressive capacities. The themes that emerged from the qualitative analysis of the focus group transcripts included connections to medicine/medical education, affiliation, pleasure, course mechanics, critical thinking, reflection, attention, critiques of seminars, representation, and definitions. One of the strengths of this study is unearthing the direct outcome of the seminars they’ve created, from the students they were created for, allowing the researchers to experience the effects and improve, if needed—in other words causing action.

Narrative writing in a variety of forms has been shown to encourage reflection among physicians and physicians-in-training. Healthcare providers at all stages may improve their humanistic skills and become better caregivers by first reflecting on patient care experiences, then writing, sharing, and discussing. The medical literature contains many reports of the use of writing to promote personal growth and professional development in medicine. That’s why I’m also looking at narrative medicine in this literature review as an additional opportunity to enhance leadership in this newly found field. Creating narrative medicine frameworks puts in place an approach that would focus on the how and why the inspirational framing of experiences
—particularly health-related experiences—ultimately creating a powerful tool to minimize similar negative effects and maximize the healing effects.

This framework stems from the perspective of the value of narrative medicine using narrative or storytelling to affect action. In order to be effective in causing action the narrative needs to have a beginning, a series of unfolding events, an anticipated ending, and it needs to be concerned with individuals; rather than simply reporting what they do or what is done to them. The narrative should show how those individuals feel and how people feel about them. Good narrative also provides educational information that may not pertain to the unfolding events. The narrative is also scintillating, engaging the listener and allowing for interpretation, giving the experience of living through, not simply knowledge about the characters in the story.

The beauty of the narrative is that the same sequence of events can be told by another person to another audience, and might be presented differently, but still true. With this in consideration, how do we know what is relevant to the story and what is not? Since the choice of what to tell and how to interpret is entirely up to the narrator and listener, how can we truly drive the outcome of a narration, particularly narrative medicine?

Because interpretation is central to the analysis of narratives, I believe the answer lies within the framework of how we approach the problems; by understanding the narrative context, a framework for approaching the issues holistically is provided. We dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticize, construct, gossip, learn, hate and love by narrative (Holstein & Gubrium, 2000). So, it makes sense that we would heal in narrative, too.

Despite the growing popularity of narrative communications or narrative medicine, there is a lack of quantitative research, utilizing rigorous study methods, to examine the effect patient
narratives have on behavior change (Campbell, Dunt, Fitzgerald, & Gordon, 2013). The purpose of the study, titled “The Impact of Patient Narratives on Self-Efficacy and Self-Care in Australians with Type 2 Diabetes: Stage 1 Results of a Randomized Trial,” was to evaluate the impact of patient narratives on the study outcomes, self-efficacy and self-care. A randomized-controlled trial was conducted over a two-year period with 670 National Diabetes Services Scheme (NDSS) registrants who were diagnosed with type 2 diabetes and were between the ages of 30 and 70. It was a three-week intervention with follow-up at four weeks and six months. Data were collected using self-report questionnaires in the participant’s homes. The intervention group received diabetes factsheets and a DVD with patient stories (narratives) of type 2 diabetes management. The control group received factsheets only. Campbell et al. (2013) designed the socio-demographic questionnaire to capture data relating to age, gender, marital status, level of education, employment status, time since diagnosis, family history of diabetes and co-morbidities or the simultaneous presence of two chronic diseases or conditions in a patient. The intervention group improved dramatically in self-efficacy and self-care, showing narrative communication’s promise as a valuable component of type 2 diabetes self-management programs. In this sense, narratives are means by which knowledge, acquired from day-to-day management of chronic conditions, can be conveyed to those who are seeking answers. They can be described as written or spoken expressions of a person’s lived experience (Frid, Ohlen, & Bergbom, 2000).

In Campbell et al.’s (2013) research, self-efficacy was measured using the Australian/English version of the Diabetes Management Self-Efficacy Scale (A/E DMSES). The UK/English version of the DMSES was adapted and validated by McDowell and associates (2005) for use in Australia. It is made up of 20 questions which ask study participants to rate their confidence to undertake certain diabetes self-management activities on a scale from 0 to 10.
The questionnaire asked how many of the last seven has the participant engaged in a range of specified self-care activities, with scores for each question ranging from 0 to 7 (days). The Summary of Diabetes Self-Care Activities Measure (SDSCA) was used to capture data relating to self-care. The revised SDSCA measure is a brief self-report questionnaire of diabetes self-management developed by Toober, Hampson, and Glasgow (2000). According to Campbell et al. the work added quantitative evidence to the existing body of theoretical literature on narrative communications and filled a gap in current knowledge about the impact of narrative communication or narrative medicine on self-efficacy and its role in self-management interventions. This demonstrates an approach to peer support that shows promise as a feasible and effective approach to intervention and a growing interest in narrative approaches as a promising set of tools for motivating and supporting health-behavior change (Hinyard & Kreuter, 2007).

As a newer discipline of healthcare, narrative medicine aims to help patients and healthcare professionals communicate the complex and unique stories of illness, with the goal of improving healthcare. It encourages patients to see themselves at the center of their own stories and in this way, can help patients continue to “renegotiate” their sense of self and essential identity through the assaults of the disease and treatment. It also works best in a collaborative and interdisciplinary context of patient care, standing at the interface of quality of life concerns and clinical management of patients (Charon et al., 2017, Stanton et al., 2002; Steiner, 2005).

Understanding narrative medicine sessions can help encourage patients to rediscover personal identity and meaning by telling or writing their stories. Slocum, Howard, and Villano, (2017) explored this process to improve care and quality of life for brain cancer patients, which often threatens a patient’s quality of life and sense of self. Healthcare professionals successfully
used narrative medicine applications to assess patient needs, attitudes, and abilities, in cases that include: managing frontal lobe syndrome of loss of initiative and pervasive emotional apathy for a patient’s wide and young children and regaining meaningful activity; re-establishing self-identity for a young woman with ependymoma; and improving spells with coexistent epilepsy and psychogenic non-epileptic seizures.

“Keep Calm and Tell Me Your Story.” In 2016, the Italian national association for people with rheumatic and musculoskeletal diseases (RMDs) created a narrative medicine pilot project for young Italians living with RMDs, called “Keep Calm and Tell me Your Story.” It was designed to make sure that the voices of young Italian people living with RMDs are heard, spread, and listened to. A major pilot phase's objective was to launch a booklet presenting the collected stories on World Arthritis Day 2016, of the impact of RMDs on young people’s personal life, working life and education; the experience of transitioning from pediatric to adult rheumatology care services; young rheumatic patients’ unmet needs and priorities. The campaign spread online, allowing ANMAR Young to gather different experiences, expand its network, contribute in the process of empowerment and engagement of Italian young rheumatic patients. Viora and Ostuzzi, 2017).

The campaign Keep Calm and Tell Me Your Story! has proved to be a valuable, peer-to-peer, economically sustainable, easily manageable and repeatable (also abroad) engaging tool for raising awareness about the impact of RMDs on the quality of life of young people. We intend to further develop this narrative medicine experience by keeping collecting new stories, by sharing them weekly through social media, by promoting our printed booklet. We intend to further analyze in detail the collected texts, in order to read them not only as personal experiences but also as a qualitative mapping of Italian young people with RMDs’ unmet needs and priorities. (para. 5)

Graffigna et al. (2017) conducted a qualitative study in Italy, as a narrative medicine pilot project that was implemented to achieve a deeper understanding of how patients suffering from chronic myeloid leukemia (CML) cope with their illness. Further, it aimed to gain insights into the
impact the disease has on patients’ emotions and everyday lives and to explore the psychological impacts. Patients were asked to describe their patient journey in a qualitative narrative diary. The researchers found a wide array of emotions, both positive and negative, giving healthcare professionals a better understanding of patients’ experiences. The research offered insights into developing more sustainable healthcare services and into therapeutic innovation aimed at improving patients’ quality of life and the findings of this study can also help make medical professionals more aware of the patient’s burden and help them identify potential interactions and emotional levers to improve clinical relationships.

To date, too few studies have given voice to patients to help understand their burden of illness: the focus is still very much on the disease. However, more innovative approaches to patient care and patient management are beginning to emerge, and the scientific community is finally starting to take a serious look at patient engagement. Graffigna et al. (2017) were the first to adopt a narrative inquiry approach for in-depth exploration of patients’ perspectives of, and experiences with, CML.

**Narrative Medicine in Practice**

In a clinical practice, narrative medicine fortifies complex narrative skills that equip healthcare professionals to recognize, absorb, interpret and be moved into action by the stories of others. The practice of narrative medicine brings together the theoretical constructs behind this new health care discipline as well as practical knowledge. Narrative medicine is also used outside clinical practices, as a theoretical approach in a variety of health-related settings. Peeters and Giulia Marini’s (2017) suggested that “narrative medicine is an approach to medicine which seeks to combine with and enhance conventional evidence-based medicine by adding perspectives and experience in medical humanities” (p. 259). Peeters and Giulia Marini’s collaborative work is
aimed at showing the importance of effective communication with patients, and the importance of having structured protocols (scripts, interview prompts, and the like) to encourage comprehensive and effective patient narratives, allowing for increased comparability between them, and evaluating the benefits of using Natural Semantic Metalanguage (NSM) in narrative medicine. NSM is a set of words representing the basic core concepts common to all languages and useful to cross cultural communication.

In narrative medicine, there are many possibilities to collect patients’ narratives: it can be a free practice with no given script, or it can be according to a more structured process, known as an illness script. The story could be written according to a linear time development which follows the occurrence of a particular illness: before the illness, the falling ill phase, the being ill phase, and the getting better or getting worse phase. With this plot, given some micro-prompts, narratives can be told and written by patients and caregivers. (Peeters & Giulia Marini, 2017, p. 529)

One of the goals of this pilot project is to get patients to tell their story using relatively simple language to be able to apply findings in the field of social psychology. In addition, they believe that when an illness occurs and times get rough, patients fall back on semantic primes, which are universally embedded in humankind.

**Writing workshops.** HIV in the United States has become a chronic and largely controllable disease in the last decade or so. Barriers to successful treatment can be psychosocial and structural, including social stigma and the high burden of disease in vulnerable communities. To improve clinical outcomes, physicians today must learn to engage with patients on the level of their lived experiences, which include their social backgrounds and personal values and priorities. Schepel, Chou, Kapetanovic, Vo, and Schaff (2018) supported by a Narrative Medicine Fellowship from Columbia University, undertook a pilot project that looked at narrative medicine-based medical education intervention in which patients with HIV, and medical students from the Keck School of Medicine of the University of Southern California, wrote and shared personal narratives. Nine medical students and five patients participated in one
of two five-week long workshop series. Mixed methods were used to evaluate the feasibility and effectiveness of the intervention. This included the development of a grounded theory of participants’ experiences of the workshop series. Participants articulated how the workshop series expanded their sense of agency, humanity, and empathy toward others, enabling them to explore new ideals for therapeutic physician-patient relationships (Schepel et al., 2018).

**Award-winning narrative medicine.** Author Madaline B. Harrison, MD, University of Virginia School of Medicine, won the 2018 Award for Creative Expression of Human Values in Neurology, for her essay called “The 9 o’clock Patient,” based on her detailed narrative recollection of two clinical visits, a year apart, with an elderly country farmer with Parkinson’s disease. Harrison (2017) began the article:

> We could talk about his Parkinson disease, but he does not seem to notice it much. He wants to tell me about the fish he caught in the farm pond, a 6-pound bass, 21 inches long, with a mouth so big you could put your fist in it. (p. 1480)

Harrison began her narrative medicine journey in 2013 when she attended a weekend workshop in narrative medicine at Columbia University, led by Charon, who has explained that narrative medicine applies techniques and analytical approaches to literature to understand and express stories involving illness, recovery, health, death, and the medical encounter between patient and physician. In one exercise, narrative medicine participants develop a parallel chart, rewriting the encounter first from the patient’s point of view, and then from their own, intentionally trying to remove dehumanized language (for example, a 48-year-old left-handed female presents with three-year history of left-handed tremor) to describe patients (Hurley, 2018).

Close listening and observation, she has learned, is as essential to the practice of medicine as it is to the craft of writing. ‘You need to cultivate attention and awareness. It’s not only about the symptoms. There are a lot of other narratives: their interpretations, their hopes, the thing they don’t tell you until the last minute, the thing that’s really on their mind. To
know if you’re making a difference to the patient, you have to know the patient—and to do that, you need to listen. (Huirley, 2018, p. 17)

Harrison, who also participated in a one-year certificate program in Narrative Practice in 2015-2016, conducted by the narrative medicine program at Columbia, has developed a pilot humanities curriculum in narrative medicine for neurology residents at University of Virginia.

These studies and initiatives show the ways narrative medicine is a practice and/or theoretical approach fortifying the work of health care professionals. And, it can be used to further enhance research, particularly research similar to uncovering the true essence of health care experiences, in order to benefit the participants as well as others.

**Implications for Leadership and Change**

Narrative medicine as a framework for healthcare practitioners, benefits the subjects or participants. Using it for foregrounding the human perspective helps in directly understanding and addressing the psychological aspects of previvors, those who are ill or discovering that they are living with a genetic condition such as HBOC.

The term “previvor” became a buzzword and describes an individual who is a survivor with a genetic predisposition for developing cancer (FORCE, 2018). Previvors are often confronted with difficult decisions about management of risks that might include aggressive screening and prophylactic surgery.

Psychosocial challenges exist for the affected individual, their partners, and offspring. Healthcare professionals need to be aware of the complex and special needs of this ever-growing population. This group includes people who carry a hereditary mutation, a family history of cancer, or some other predisposing factor. The term specifically applies to the portion of that community that has its own unique needs and concerns separate from the general population, but different from those already diagnosed with cancer.
The implications for leadership and change in this field are wide. Related to psychosocial genetics, there is great need for family clinicians to design and implement innovative research and treatment protocols to address the holistic experience of hereditary disease (McDaniel, 2005; Sobel & Cowan, 2003). Part of that holistic experience can include paying close attention to an individual’s experience or their story of grief and loss of expectation. According to van Oostrom et al. (2006), their story is important because it may affect the accuracy of their risk, perception, or outlook.

With that in mind, my dissertation delved into the analysis of individuals’ stories, unfolding the psychological implications of how hereditary breast, ovarian and related cancers effect a person, in an effort to educate through shared connections as well as create a framework for health care professionals to more fully comprehend this unique situation so they can, in turn, better assist and guide their patients with hereditary breast and ovarian cancer to make the best decisions for their individual situations.
Chapter III: Narrative Inquiry Methodology

If sickness calls forth stories, then healing calls forth a benevolent willingness to be subject to them, subjects of them, and subjected to their transformative power.

—Rita Charon (2006, p. 216)

As a member of a family with more than two dozen BRCA2+ individuals, including myself, and my teen daughter, I have a vested interest in moving fear of knowledge into action by inviting readers to relate to stories of others on similar genetic journeys. My research explored the lived or felt experiences of individuals when they learned that they inherited a mutation that significantly increased their risk of breast, ovarian, and related cancers. How did they make meaning of this knowledge and of their life? Attention to an individual’s experience and story of grief and loss are important, because it may affect the accuracy of their risk perception and their outlook (van Oostrom et al., 2006).

It was a lack of in-depth, first-person stories to help educate other HBOC carriers as well as health care professionals that drove my narrative inquiry methodological choice for this study. Narrative inquiry is a qualitative methodology grounded in the study of experience and understood narratively. In addition, my rationale for this fit also took into consideration the “internal consistency among elements of a research project—research question, prior work, research design, and theoretical contribution” (Edmundson & McManus, 2007, p. 1155). All this considered, the methodology choice hinged on the lack of exemplars that show qualitative data on the topic, the need for the research to expand knowledge for others, as well as to create a framework for healthcare professionals.

My choice of narrative inquiry methodology was primarily influenced by the need for more open-ended research questions. The type of “research questions conducive to inductive theory development include understanding how a process unfolds, developing insight about a
novel or unusual phenomenon, digging into a paradox, and explaining the occurrence of a surprising event” (Edmundson & McManus, 2007, pp. 1161–1162).

Because little is known, rich, detailed, and evocative information is needed to shed light on this phenomenon. Interviews, observations, open-ended questions, and investigations are methods for discovering this vital information. This is a critical approach to understanding the nuances of this very personal experience, and/or the state of research into psychosocial and emotional effects.

**Background to HBOC and the Role and Use of Stories**

Diagnosis of being at high-risk for breast cancer is a frightening experience for many women with a variety of even more frightening, but risk-reducing strategies presently available for those at high-risk. That’s why it’s vital that first-person narratives are available to inform those at risk of the journeys of others’ experiences.

The objective of using narrative inquiry allowed me to best tell the participants’ stories to educate readers, inform others that they are not alone, and create a framework for healthcare workers to begin to understand the psychosocial implications of their patients who are BRCA+.

It is not a coincidence that stories can heal and connect us, and that every human is pulled in by compelling narrative, according to scientist Edward Wilson (2002), who says our brains function by constructing narratives, adults and children live, learn, and relate to others through stories. Within well-told stories, similarities between people’s experiences are revealed. Sharing those experiences helps form bonds and connections that help build resilience, healing, and give the storyteller clarity of their experiences.

We are the storytelling species. Storytelling is in our blood. We think in story form, speak in story form, and bring meaning to our lives through story. Our life stories connect us to our roots, give us direction, and validate our own experiences, and restore value to our lives. (Atkinson, 2007, p. 224)
In essence, we are all narrators who use story to symbolically give meaning to our individual experiences. In doing so, our interpretation often dictates our perceived purpose of the experience and corresponding actions. “Narrative rationalities are by no means a panacea for life’s difficulties, but they do acknowledge suffering in ways that lie beyond the traditional prowess of biomedicine” (Harter & Bochner, 2009, p. 116).

The narrative itself is a non-random sequence of events that conveys action and movement through time, with a plot and causality. Narrative is critical because we make sense of the world through the stories we tell, and narratives are one of our main ways of communicating (Riessman, 2005). The allure of narrative is that it expresses personal experience.

Analyzing those experiences in a qualitative study of how different humans experience the world around them, is narrative inquiry methodology using narrative accounts to provide insights about the person, his or her group, and a person’s deeply held understandings of the subject of interest (Daiute, 2014). The methodology allows people to tell the stories of their lives. It collaboratively explores a phenomena or issue with an individual “in an effort to understand how the individual’s past experiences impact the present, and potentially, the future” (Mills & Gay, 2016, p. 347.) Narrative inquiry embraces narrative as both the method and phenomena of study, beginning in experience as expressed in lived and told stories; it involves the reconstruction of a person’s experience in relationship both to the other and to a social milieu (Clandinin, 2006).

In addition, this methodological approach offered participants in my research study, a reflection opportunity that may not have been there otherwise. This type of self-reflection can be healing. When a person is aware of their own experiences, strengths, weaknesses, and feelings, it significantly impacts their life, the way they react and interact with others, and their authenticity.
Hesse-Biber’s (2014) book, *Waiting for Cancer to Come: Women’s Experiences with Genetic Testing and Medical Decision Making for Breast and Ovarian Cancer*, shows that although the statistical risk in the medical context is significant for those who test positive for a BRCA mutation, many of women’s psychological implications and choices depend on the individual’s life and her family history, relationships, career, life stage, cultural background, and so forth. “The book is a testament to the value of avoiding the fragmentation of women’s stories and depicting the rich complexity of the fabric of their lives that emerges through their own words,” (Rees, 2015, p. 1124).

Mills and Gay (2016) said narrative inquiry has several key recognizable characteristics. These are that it

- focuses on the experience of individuals, is concerned with the chronological order of someone’s experiences, focuses on the construction of life stories from data collected through personal interviews, uses restorying as a technique for writing the narrative accounts, includes context and place in the story, involves a collaboration between the researcher and the participants in the writing of the final narrative constructed around the question “and then what happened?” (pp 351–352)

The role of the narrative researcher is to collect data about an individual’s life and, in a collaborative process between the researcher and the research subjects, write a narrative retelling of the events. The relationship between researcher and research subject must be one characterized by trust, respect, and equality. What narrative researchers hold in common is the study of stories or narratives or descriptions of a series of events. These researchers usually embrace the assumption that the story is one, if not the, fundamental unit that accounts for human experience (Clandinin, 2006). When considering the use of narrative inquiry for research, Clandinin suggests researchers locate themselves in relation to the four main “turns,” to help readers of narrative research understand the different ways researchers position their work within the overall field:
• change in the relationship between the researcher and the researched,
• a move from the use of number toward the use of words as data,
• a change from a focus on the general and universal toward the local and specific,
• a widening in acceptance of alternative epistemologies or ways of knowing.

Reflexivity helps recognize the changes in those relationships between the researcher and the participants, the way the data is perceived and conveyed, a closer look at specifics, and an open mind to accept other ways of thinking.

**Reflexivity**

Researchers are in a powerful position to say what does and does not constitute knowledge. Given my connection to the area of exploration it will be critical to establish trustworthiness of the study thus my reflexivity is a vital part to this research. Reflexivity involves reflecting on the way in which research is carried out and understanding how the process of doing research shapes its outcomes, the interpretation of my interpretation, and the ethnographer of the content (Alvesson & Skoldberg, 2000; Hardy, Phillips, & Clegg, 2001). In essence, reflexivity entails engaging in critical appraisal of my own work, reflecting on why I frame issues in particular ways, investigate them in particular ways, and how such approaches lead me to particular kinds of solutions and theories versus others. It sheds light on my particular version of reality created through my particular research practices.

It is also important in reflexive analysis to become more consciously reflexive by thinking about our own thinking, by noticing and criticizing our own epistemological pre-understandings and their effects on research, and by exploring possible alternative commitments (Johnson & Cassell, 2001). In essence, reflexive analysis surfaces our assumptions about what we can know and how we can claim to know it—epistemology and ontology.
I also note that reflexivity is not a method or validity technique that someone can learn by following through on particular practices, nor should it be confined to particular kinds of epistemological approaches. In fact, no approach should be immune from considering its origins, commitments, and impacts.

My reflexivity on the topic is important to note when determining the methodology because it influences how my research was designed or conducted to provide a convincing account, and acknowledges the reasons I made certain choices, as well as foreshadowing how they may impact the conclusions reached. Reflexivity on this issue is important because by making the research process transparent, it is made public and therefore accountable (Finlay, 2002).

When considering the purpose of my research, I believe my previvor status, as well as the large number (>24) of my immediate family members who are previvors, offers a uniquely authentic opportunity. And, through my reflexivity, I acknowledge key relationships and the authentic situated nature of my research. Greater reflection serves to help strengthen the interpretation.

**Principles of Dynamic Narrating in Research**

Narrative research has many forms, uses a variety of analytic practices, and is rooted in different social and humanities disciplines. Daiute (2014) suggests that the insight of the narrative is brought to life through dynamic narrating principles, “explaining that narrating is a process of use—to do things in the world in relation to diverse other people and the physical and symbolic environments. The principles of use, relation, materiality, and diversity guide the work of narrative inquiry design, analysis, and integration,” (p. 756).
The design and analysis of narrative inquiry follows four main principles: use, relation, materiality, and diversity to help researchers better see and understand what they might not notice; thus, they can serve as a guide to help researchers develop questions.

In the *use principle*, researchers design activities where participants have an opportunity to use narrating flexibly to interact with and reflect on issues of interest. Research consistent with this principle would sample multiple narratives from diverse positions to learn about meaning by comparing diverse uses, from inside uses that are meaningful to people. This allows for reflection from different perspectives around a common interest, even if for different purposes (Daiute, 2014).

The use principle highlights the fact that discourse is activity. Narrating functions as a tool to mediate individual and societal interactions, so researchers can design activities where participants have the opportunity to use narrating flexibly to interact with and reflect on the issues of interest. Research consistent with this principle would sample multiple narratives from diverse positions to learn about meaning by comparing diverse uses. (Daiute, p. 764, 2014)

The *relation principle* is where narrators interact with present and implied others, objects, and ideas in environments; using this principle, researchers should design narrative research in terms of different narrator-audience-issue relations (Daiute, 2014).

Narrating is a relationally complex process, because for each telling and listening arrangement, the narrator must consider which details to select, how to arrange them to highlight the most interesting points to maintain the listeners’ attention, how to present him- or herself in the telling, how to avoid certain taboos, and how to suggest a better life with the story. (Daiute 2014, p. 777, 2014).

The *materiality principle* accounts for narrating as just being part of real life; so narrative inquiry is also embedded in life. Physical features, like exclamations or repetitions, and the structural features, like prosaic openings (e.g., “once upon a time”), contribute to meaning, so researchers following the materiality principle need to pay attention to those features in narrative analysis (Daiute, 2014).
Therefore, Daiute (2014) suggested:

When designing research, we should, therefore, consider the concreteness of meaning in discursive acts and elements, such as whether the genre is autobiography or fiction and the specific features that go along with each, such as whether the referent of the “I” character is the author or an imagined other. Important messages may or may not be stated (often the most contentious ones are not explicit). . . . Meaning doesn’t float vaguely in the act of narrating to then disappear from the airwaves or into participants’ memories, writings, or transcripts of their speech. Meaning is, instead, material because narratives are symbolic systems inextricably linked to persons, contexts, cultures, and circumstances of their histories and expressive moments. (p. 828, 835)

The diversity principle concerns differences within and across individuals and groups in familiar to the narrator’s purposes, feelings, and thoughts, in relation to their audiences at the time of telling. This kind of diversity is like a network of connections rather than primarily inside the narrator or about narrator identity (Daiute, 2014).

Dynamic narrating also extends beyond prior approaches that emphasize the individuality of each person’s voice, focusing instead on the networking quality that humans use to connect with their social and physical environments. Defining narrating and applying the dynamic process to research design and analysis continue across the chapters of this book. For now, a narrating experience is a step toward understanding the process, (Daiute, 2014, p. 889)

I designed this research study with Daiute’s (2014) four principles of narrative inquiry in mind. In the next sections I introduce the three types of analytic approaches I applied: plot analysis, thematic analysis and commonplaces. I also briefly make note of the impact each has had in shaping this research.

**Plot Analysis**

Plot analysis as part of narrative inquiry methodology, focuses on the structure of individual or multiple stories to provide elements that the researcher uses to support and enhance meaning making. Daiute (2014) defines plot analysis as a way to draw on the features of narrative to learn how narrators are interacting with their environments and integrating those interactions into the very fabric of their stories.

. . . Plot analysis zeroes in on meaning in narrative structure and can be quite satisfying for
learning about how participants in research are using narratives as lenses for understanding their worlds. (p. 112)

Plot analysis identifies the structure of a plot—beginning, middle, and end—comprised of elements: setting, character(s), initiating action, complicating actions, plot conflict/turning point/climax, resolution strategies, ending in some combination. The plot elements recount the basic who, what, when, where, why, and act like lenses to guide the narrator’s memory and interpretation their personal story.

I chose plot analysis because it allowed me to dissect the different elements of the previvors’ story lines from the moment of their first introduction to HBOC. “Plots are like lenses that guide perception, memory, and interpretation of the dramas of life . . . [the] narratives of life experience make sense in part because of plots” (Daiute, 2014, p. 114). Thus, plot analysis allows an overarching look at the process to streamline these unique, yet similar, experiences, including my own reflective actions, and to ultimately create a framework for healthcare professionals to better treat and understand the psychological impact at each point of the discovery and decision-making for their own patients facing HBOC.

Daiute (2014) suggested making an outline of major plot line elements—characters, setting, initiating action, complicating action, high point, resolution strategy(s), ending, and coda or reflection—noting the major plot-turning issues or conflict. In doing so, Daiute advised taking note of similarities and differences across the high points and resolution strategies, as well as patterns among the major elements (initiating actions, complicating actions, high points, and resolution strategies). This helps researchers indicate what the participants are communicating with their narratives, beyond the specific details of the stories. Through the eight plot line elements the arc of the story lines revealed one continuous story that was consistent among previvors, but unique among individuals based on their life experience.
Thematic analysis

Through thematic analysis, following the approach recommended by Daiute (2014), I used metaphors to add an overlay of more texture and feeling, which emphasized the complexity and coherence, feelings evoked by the story, and choice of metaphors and words. This allowed me to take a closer look at the metaphorical images that emerged from the plot analysis. It also revealed topical themes that deepened the understanding and sense-making with the previvors’ discovery of HBOC, and the psychological implications of living with that knowledge.

This provided a thematic map of their journeys, helping to create a larger overall picture of what it is like to live with HBOC. The emergent themes came through similar arcs in their stories through emotional content and metaphors that hinged on the similar paths or pertinent points along their journeys.

Commonplaces

I also used Clandinin and Connelly’s (2000) three commonplaces of narrative inquiry, temporality, sociality, and place, which specify dimensions of an inquiry and serve as a conceptual framework. “Commonplaces are dimensions which need to be simultaneously explored in undertaking a narrative inquiry” (p. 20).

The three commonplaces can create a conceptual framework for different kinds of field contexts, particularly between researcher and participant. “Collaboration between researcher and participants, over time, in a place or series of places, and in social interaction” (p. 20). Attending to experience through inquiry into all three commonplaces is, in part, what distinguishes narrative inquiry from other methodologies. By attending to the commonplaces, narrative inquirers are able to study the complexity of the relational composition of people’s lived
experiences both inside and outside of an inquiry and, as well, to imagine the future possibilities of these lives (Clandinin and Connelly, 2000).

Scope of the Study

In addition to the aforementioned principles of narrative inquiry, one should keep in mind that stories are essentially individual recollections of human experience and may have limitations that could affect objectivity or representation. According to McMullen and Braithwaite (2013), there are three substantive concerns regarding the limitations of narrative inquiry. First, there is concern about research labelled narrative—without any systematic narrative inquiry. Atkinson and Delamont (2006), while stressing the importance of narrative and narrative analysis, also argue for the need to adopt an analytical rather than a celebratory stance on narrative. They believe that “narratives are collected and celebrated in uncritical and analyzed fashion. Common weaknesses are researchers assuming that informants’ accounts ‘speak for themselves’ and also failing to acknowledge the social and cultural context of accounts given (p. 166).

A second concern or limitation in narrative inquiry lies in the differing capacity and interest by people in relation to storytelling. The argument is that not everyone may share the compulsion to weave their lives into a coherent narrative (Strawson, 2004). The third narrative inquiry limitation is in accumulating knowledge, raising the question of how theory could be advanced without making it more real or losing the richness of the narrative (Josselson, 2006).

Counter to the above concerns or limitations, according to McMullen and Braithwaite (2013), should be the knowledge that comes from narratives of rich, local, and particular studies of life. They stated: “Narrative inquiry has significant scope to contribute to understandings of social (including organizational) life but it needs to be practiced in a manner that plays to its strengths rather than its limitations” (p. 102).
Considering the principles and potential limitations of narrative inquiry, researchers also need to keep in mind that narrative research analysis should be about the event, the experience, and/or the expression of the experience by the participant (Andrews, Squire, & Tamboukou, 2013). Thoughts and feelings are expressed regarding a particular event or experience which is the topic being researched. Stories are shared, which can be deeply personal and deal with the participants’ social and personal life (Wang & Geale, 2015). This could be collected in various ways and then organized to make sense of the data and be relevant to the object of the research. It must also make sense as a part of research. The narrative method can help the research become more relatable, real, and personal, depending on the participants’ similarities, differences, and experiences. Analyzing these similarities creates emerging themes, ultimately furthering the existence of the commonalities of the experience in an effort to enhance future connection positively. Within narrative inquiry, “the space between analysis and knowledge translation provided opportunities for seeing participants and data in new and different ways” (Bruce, Beuthin, Sheilds, Molzahn, & Schick-Makaroff, 2016, p. 4).

**Method of the Study**

My research delved into the lived or felt experiences of individuals when they learn they have inherited a mutation that significantly increases their risk of breast, ovarian, and related cancers. Through participants sharing their personal stories, my analysis, summary, and interpretation assists health professionals and others with more fully comprehending the potential psychological implications that may accompany this unique situation, and that have not been addressed in the current literature.

The steps in narrative inquiry methodology, according to Mills and Gay (2016), include identifying an issue, choosing participants, developing questions, determining how the research
will be conducted, developing data collection techniques, collaboration with research participants, and a final narrative. Below I briefly explain what each of these steps entails and outline how I addressed each in my research design.

**Purposeful sample.** I began by utilizing social media pages, which are only open to survivors and previvors, to solicit volunteers. Participants who met the following baseline requirements were invited to share their personal story with me for the purpose of the study: age—they had to be 18 years old or older; they had to have a family history of hereditary breast and ovarian cancer (HBOC); and they must have had positive results for BRCA1 or BRCA2 mutation, my goal was to obtain 12 to 15 participants (in the end, there were 14). The numbers of participants required depends on the richness and detail of the material in the stories and the point in which redundancy of content occurs.

The recruitment of volunteer participants occurred within a few days. There are many Facebook groups to support those who are BRCA positive. For example, five that I approached were Being BRCA (n.d.), BRCA Breast Cancer Gene (n.d.), BRCA Genetic Sisters Awareness (n.d.), BRCA Sisterhood (n.d.), and FORCE (n.d.). I reached out to the creators or owners of such pages to seek permission to post publicly in their group. I informed them that I was looking for volunteers to participate in a research study on previvors of BRAC+ (See Appendix C for the post I used). I sent requests on a Saturday to 20 account holders and heard back from seven. Of those, one directed me to a different organization, one page owner responded and said she wanted to participate, and the other five either posted the information on the wall, or gave me permission to post it on the wall.

**Participants.** The participants ranged in age from 27 to 72. They were mostly from the United States, including Pennsylvania, Indiana, Montana, Michigan, Ohio, Nevada, South
Carolina, California, Minnesota, Texas, New Jersey, and two from New York. There was one international participant from St. Thomas in the Virgin Islands.

All of them had a close relative who either died or was diagnosed with breast or ovarian cancer. In most cases, they were deeply affected by the loss that close loved one. Many had children of their own and feared passing the gene mutation on to their children.

Table 3.1

Participants’ Pseudonyms and Relevant Demographic Information

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Residence</th>
<th>Relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jen</td>
<td>27</td>
<td>PA</td>
<td>Grandmother died of ovarian when Jen was 6; mother discovered mutation when Jen was 13</td>
</tr>
<tr>
<td>Alexa</td>
<td>27</td>
<td>IN</td>
<td>Grandmother had breast cancer at age 33 and 60</td>
</tr>
<tr>
<td>Betsy</td>
<td>34</td>
<td>MT</td>
<td>Mother had breast cancer in her mid-30s and 57</td>
</tr>
<tr>
<td>Mary</td>
<td>37</td>
<td>NY</td>
<td>Sister and female cousin, both age 41, diagnosed with breast cancer</td>
</tr>
<tr>
<td>Sally</td>
<td>38</td>
<td>MI</td>
<td>Grandmother had breast cancer twice, died; aunt had breast cancer at age 32</td>
</tr>
<tr>
<td>Annie</td>
<td>40</td>
<td>OH</td>
<td>Grandmother, grandmother’s sisters and aunt all died of breast cancer; female cousin, Annie’s same age, died of breast cancer</td>
</tr>
<tr>
<td>Carol</td>
<td>42</td>
<td>NY</td>
<td>Mom survivor of ovarian cancer</td>
</tr>
<tr>
<td>Sophie</td>
<td>44</td>
<td>NV</td>
<td>Mother, father and aunt all died of cancers</td>
</tr>
<tr>
<td>Bessie</td>
<td>46</td>
<td>SC</td>
<td>Grandmother, aunt and female cousin all died of breast cancer; uncle died of pancreatic cancer; half-sister and aunt survived breast cancer</td>
</tr>
<tr>
<td>Marissa</td>
<td>47</td>
<td>CA</td>
<td>Mom died of ovarian cancer; oldest sister currently has breast and ovarian cancer</td>
</tr>
<tr>
<td>Pam</td>
<td>53</td>
<td>St. Thomas, Virgin Islands</td>
<td>Mother and female cousin died of ovarian cancer; sister survived breast cancer, but is now battling melanoma, groin and spine cancer</td>
</tr>
<tr>
<td>Alisha</td>
<td>62</td>
<td>MN</td>
<td>Half-sister died of ovarian cancer</td>
</tr>
<tr>
<td>Danielle</td>
<td>65</td>
<td>TX</td>
<td>Mother had breast cancer twice, died; female cousin died of breast cancer at age 27</td>
</tr>
<tr>
<td>Gigi</td>
<td>72</td>
<td>NJ</td>
<td>Grandmother died of breast cancer at age 35; mother had breast cancer at age 38 and then died of ovarian cancer at age 47</td>
</tr>
</tbody>
</table>
**Setting up the interviews.** Via email, participants were initially connected with me to schedule a time for their interview, which was conducted from the comfort of the participant’s home via telephone or video call, whichever the participant was more comfortable with while sharing their personal story. Participants were told that each interview would take an average of 45 minutes. In addition, they were also made aware of the purpose of the study, as well as my connection to HBOC, including previvor status and abridged family history. Participants were also informed that the interviews would be recorded for the purpose of reviewing their comments and making meaning.

Within minutes of the first post on Saturday afternoon, I had my first inquiry. Over the next 48 hours, almost 30 inquiries trickled in, and I responded with an email and consent form for them to sign (See Appendix D for my email response and the consent form). Although my post had mentioned that participants were required to be previvors, not cancer survivors, there were still a couple of cancer survivors who wanted to volunteer. I had to decline them. There were also several previvors who wanted to share their story, but the timeline of their genetic testing results was greater than five years; again, I had to decline them. After one woman inquired, I responded with the consent form, and she sent the signed form back immediately, and said she lived in the same town and wanted to do an in-person interview. I agreed and gave her several options for times for the interview. Then I did not hear from her for a week. When she finally reached back out to me, she apologized for not responding sooner, saying:

Hi Cammi, sorry it took me so long to get back to you; an unexpected development has occurred that might make me ineligible for your study. I was just diagnosed with breast cancer. Shocking, to say the least, considering I had a prophylactic mastectomy eight years ago. Let me know if you can still use my story. If not, I’m so sorry.

Unfortunately, this did leave her ineligible for the study.
Over the first few days or so, I received 15 signed consent forms, and scheduled 15 interviews, three were via video conference, the other 12 were over the phone. I spent the next two weeks conducting individual interviews that lasted between 25 to 50 minutes. It was revealed during the interview that one member of the group of participants was actually a cancer survivor, so the total number of participants for the study was 14.

**Interviewing.** The participants were advised of the topics ahead of time in regard to the following questions:

- Tell me the story about your family history with HBOC leading up to your story.
- Talk about your experience discovering your inheritance of a gene mutation that drastically increases your chances of breast, ovarian, and other cancers.
- Share with me your options and decisions about what to do with this information, and how and why you made the choices you made.
- Express to me the thing that surprised, shocked or concerned you the most about your genetic journey.

The questioning phase of the interview process followed the phases and rules narrative inquiry interviewing, according to Jovchelovitch and Bauer (2000):

1. Preparation. Exploring the field and formulating questions
2. Initiation. Formulating initial topic for narration and using visual aids
3. Main narration. No interruptions, only non-verbal encouragement to continue storytelling, and wait for the coda
4. Questioning phase. Only “What happened then,” no opinion and attitude questions, no arguing on contradictions, and no why-questions
(1) Concluding talk. Stop recording, why-questions allowed, and memory protocol immediately after interview

In addition, each interviewee had opportunity to add any further clarity or comments.

Viewed from this position, stories of their lived experience (data) were co-constructed and negotiated between myself and the participating interviewee, to help capture the participant’s authentic, complex, and multi-layered understandings of their personal HBOC story. I was involved in, listening to, reading the conversations of, and analyzing the conveyed stories of each participant. I compared each, without filling in any gaps in understanding, but instead, asking any further questions about how pieces of their story fit together.

I also conducted some meta-cognitive work by keeping notes in a journal immediately after the interviews reflect my observations, feelings, and thoughts during the interviews. This was an important piece of the reflexive analysis.

The following questions loosely guided the organic flow of the interviews:

(1) Tell me about family members who have had breast or ovarian cancer.

(2) How you first learned about genetic testing for HBOC?

(3) Tell me why and the process of making the decision to have genetic testing done.

(4) How did you feel when you got your positive results? What was the first thing that went through your mind?

(5) Talk to me about the connection with your physicians along your journey. Were you confident in their knowledge; and did you trust their experience—why or why not? Was there anything additional you would have liked from them?

(6) If you have children, how did you tell them about HBOC? Have they been tested? Why or why not?
(7) What, if any, risk-reducing measures did you decide to take and why?

(8) If you opted for a double mastectomy, talk to me about the emotional process that led you to your decision.

(9) Have you had any complications from your risk-reducing procedures, if so, what steps have you taken? What are your next steps?

(10) Share with me your greatest support system during this timeframe.

(11) Considering how long it has been since you first learned about HBOC, reflect on your journey and share with me how you feel about each of your decisions; and how you cope today.

Brief follow-up survey. Within the first few days following each participants’ interview, each received the following thank you email, inviting them to participate in an anonymous one-question survey (Appendix E). Of the 14 invited participants, 10 completed the anonymous survey which asked:

“After spending time reflecting on your HBOC journey during your interview, how emotionally beneficial or healing do you believe it was to share your personal story with someone?

1. Extremely beneficial
2. Somewhat beneficial
3. Indifferent
4. Not beneficial

Please share why you gave the above rating.”

(The answers and analysis of these will be revealed and discussed in the next section.)
Story Analysis

It is typical in narrative analysis of this sensitive nature that the researcher does the coding. This adds to the trustworthiness of the interpretation through the researcher’s reflexive voice and the provision of details from the interviews themselves to illustrate points of interpretation. In addition, given the aforementioned reflexivity, the importance of my personal connection offered the opportunity to move from emic to etic perspective.

Because I did not know what the stories would yet unfold, in the end, it was optimal for me to use a holistic-form-driven approach, which emphasized the complexity and coherence, feelings evoked by the story, and choice of metaphors and words, in addition to an analysis of the commonplaces of temporality, sociality and place.

As described earlier in this chapter, I applied three forms of analysis to the women’s stories: plot analysis, thematic analysis, and commonplaces. First, I engaged in a process of plot analysis by tracking the timeline of the story and gaining a sense of the full story from the discovery period to the reconciliation period. This offered a unique understanding of what an individual goes through at each stage of the discovery that they are carriers of such a genetic mutation, through their decisions, outcomes, and other critical points in their stories.

My second pass through each story sought out themes that were dominant in the stories. This analysis offered more texture to the fabric of the stories and provided the opportunity to highlight an emotional and metaphorical understanding of the phases of the journey. Not surprisingly, emotional content was striking throughout the stories as was the use of metaphor dramatizing the intensity of feeling. The metaphoric figures of speech through a word or phrase—as applied to an object or action to which it is not literally applicable—lends itself to the poetry of suggestion as representative or symbolic of something more abstract.
Finally, I considered these stories in terms of Clandinin and Connelly’s (2000) commonplaces. Through the consideration of the temporality, sociality, and place of all stories, I was able to create a connectedness or relationship between researcher and participant, as well as place and social interaction, allowing me to consider the complexity of the relational composition of people’s lived experiences.

Together, these three approaches added coherence, emotional texture, and the commonality of the women’s experience.

**My Reflexive Process**

Authentic stories also give others the power, including those in the healthcare field, to connect and understand the essence of the lived experience of HBOC. Berger (2015) researched both the benefits and challenges to reflexivity under three types of researcher’s positions: reflexivity when researcher shares the experience of study participants; reflexivity when researcher moves from the position of an outsider to the position of an insider in the course of the study; and reflexivity when researcher has no personal familiarity or experience with what is being studied.

I am confident that my reflexivity was a benefit to me in this narrative inquiry and plot analysis research. Daiute (2014) describes one of the benefits of using narrative inquiry referring to reflexivity and the fact that the researcher’s experiences may be shared with the participant of the study. There is an empathetic understanding of the participant’s experiences in the study and having an inside look at the subject. It shows human life and discusses social and personal experiences in depth. And, there is a shared human real world experiences.

With Daiute’s (2014) idea of these benefits in mind, my reasoning for choosing narrative inquiry as my methodology (how that knowledge may be gained) was twofold. The first is my
extensive background in storytelling. My career began as a journalist at a major metropolitan newspaper and progressed to founding and serving as associate publisher of content-driven magazines aimed at connecting, empowering, and inspiring through the stories of others. The second piece is relative to my own genetic condition of HBOC, as well as the personal experience of more than two dozen immediate family members with the same genetic condition. This first-hand experience has led me to write my own unpublished memoir, as well as the opportunities to speak at events where I could share my story, serve as a mentor to others in similar situations, and be an advocate for others.

In my reflection, the epistemology of storytelling, which understands the world as created, understood, and experienced by individuals or groups in their interactions with other people, helped aid the development of personal resilience and provide opportunities to celebrate survival through sharing stories of difficulty and adversity. Stories are fundamental ways our brain organizes our experience of the world and then processes and presents the complex information in manageable narrative forms so that we can understand events that have occurred. Using narrative to embrace illness, or chaos, in order to find some meaning in life’s events, helps pull us in to connect, learn, and potentially pass insight on to others to continue the healing process. Considering narrative is the human way of healing and working through hardships of a chaotic world, the stories we tell are almost like healing survival manuals, not bound by geographic location or culture identity, but connecting us all spiritually as humans.

One of the goals for my dissertation research was to use stories to create a world where individuals and families do not fear the threat of HBOC, and where a positive test for a BRCA mutation does not invoke a feeling of hopelessness but instead inspires the confidence that prevention and treatment are simple and effective. The idea of using narrative inquiry as my
methodology for my research is that stories are collected as a means of understanding experience as lived and told, connecting, and, ultimately, understanding.

**Ethical Considerations**

I upheld the privacy and respect of the participants and recognized the sensitivity and potential emotional upset that the research interview may have evoked. I also took precautions to protect confidentiality issues, given the impact of others not knowing the participants’ diagnosis and being able to identify them through the excerpts from the stories. Great effort was made to eliminate any identifying factors from the stories.

Within the Internal Review Board (IRB) process, I also noted that the volunteer participants are sought from a place where members go to seek support and share like experiences with others on similar journeys. I believe the possibility of exposure to harm is lessened or nonexistent, due to this fact. In addition, there has been significant time since their testing and risk-reducing procedures to mitigate any potential emotional turmoil in sharing their story in the interview. If there is a potential for risk of remembering any traumatizing emotions, this will be mitigated by the fact they are already part of a support system (like FORCE, BRCA Sisterhood, BRCA Strong, who specialize in this area) where the stories are told and retold, so I will have contact info for their prospective support group and or counseling information available for them should they need it. Also, I am familiar with the work of these support groups and a member of my dissertation committee is the Vice President of education for FORCE and has contacts that can be quickly identified to offer emotional or social support, if needed.” See Appendix F for full IRB. Finally, the anonymous follow-up survey had allowed them to inform me if the interview had been beneficial and not harmful.
Chapter IV: Sharing a Journey

I didn’t quite know the journey I was about to go on, but I knew it wasn’t going to be good.

–Betsy (one of the participants in this study)

In this chapter I will begin the presentation of the findings by providing brief vignettes to honor the women’s life events without deconstructing their experience. Each vignette includes a brief background of the woman, a relative summary of her story including how she found out about HBOC and genetic testing, what steps she had taken so far, including any prophylactic decisions made, actions taken, and her future plans for coping or perhaps, becoming a trailblazer and/or advocate. These stories were retold by me to highlight their psychological insights, personal values, and decision making processes that guided their actions and plans for the future.

I made natural connections within each participant’s story as an important way to guide readers as they weave in and out of the lives of the participants, their ups and downs, trials and tribulations, and the impact of their actions.

As you read each story be cognizant of their powerful words used to convey their experiences, including their fear, helplessness, hopelessness, anxiety, and, in some cases, a feeling of overcoming adversity—or a fight they did not want. The gripping words and meaningful metaphors they use to describe the overall feelings of each fork in the road from finding out they are carriers to deciding to take proactive measures, evoke similar emotions in the reader, along the participant’s journey.

As you might imagine, I was also deeply affected by their retelling of their experiences. With each interview, as the women shared their challenges, obstacles, and hurdles, I imagined myself in her shoes: How would I handle their situation? How did their situation resemble my own? Was their path of discovery and turning points similar to mine? I found myself silently
wondering if I agreed with their choices. I tried to understand what values or frameworks were
driving my own reactions. If I did not face a similar challenge yet, I considered how I might use
their story to prepare for what may lie ahead. Their sharing helped me to reflect on my own
situation, goals, values, plans and future.

The Stories

I have shared the essential elements of the women’s stories, including excerpts from each
interview to highlight their voices. The order of the participants is based on age, starting with the
youngest.

Jen: “I would much rather not have time bombs on my chest, than have cancer.” Jen is 27 and lives in Pennsylvania with her wife. When she was only 6, her grandmother died of
ovarian cancer, and when Jen was 13, her mother learned she inherited the BRCA2 gene
mutation.

On the day we spoke, Jen was sitting on the bed in her bedroom, leaning against her
headboard; her laptop was on her lap. She fidgeted throughout the interview, causing the soft light
lamp on the nightstand to her left, to dim and light her face, all at the same time.

Jen said:

I don’t remember a time when I didn’t know about the mutation, which is weird, because
I’m 27, and you’d think, well, maybe it wasn’t as well known or whatever. I guess it was
because my grandmother died when I was 6 that I knew about cancer right away. And I
just don’t remember not knowing that I probably had it.

In addition to her grandmother’s ovarian cancer, numerous maternal relatives died of
breast cancer.

And, although her mother did not have cancer, Jen was only 13 when she watched her
own mother undergo a prophylactic hysterectomy and double mastectomy, with a difficult
recovery including hemorrhaging and sudden menopause with no hormone replacement therapy.
Still, even though Jen knew since she was 13 that she could carry the mutation too, she put off her own genetic testing until last year.

I think part of it [waiting] was that I just felt I always knew I was positive. It’s obviously a 50/50, but I just didn’t want it to be real. Then I realized that with the knowledge I had, that it was silly of me, and not an intelligent decision, to keep putting it off as my risk grew every year. But it was hard.”

The day Jen learned the truth, she and her wife were sitting in their bedroom in a little apartment in Jackson, MI. Jen’s mother was listening on speaker on one cell phone and a representative from Color—a physician-supported access to genetic testing company—was on speaker on another cell phone.

Jen said:

The first thing that I remember is when she said you’re positive, I just felt almost a sense of nothingness, because it was just like, duh, yeah. Then, I immediately felt, a sense of relief because I knew a little bit about my options already. And now that I have the tangible evidence of what I’ve always kind of assumed, I can start taking action.

Jen said she and her wife came to the conclusion together that she would do as much prophylactic surgery as possible or as much as made sense.

She said:

We decided for now, we’re going to do screenings every six months because the real bottom line issue this brought up for me is the procreation issue. As much as I say, I was relieved when I found out that I had the mutation, there was this element of incredible frustration. My wife and I, we always talked about getting pregnant as a team. We each wanted to carry one child. So, then to get a diagnosis, and to be certain that I was positive, was kind of like a sledgehammer. It just made everything more complicated. But, I’m not going to do screenings forever. I would much rather not have time bombs on my chest, then have cancer and then get a bilateral mastectomy. I’m not interested in that.

For Jen, the journey has been an emotional one, but she felt the positive results have been more emotional for those closest to her.

My wife has dealt with this in her own way. I think it has been kind of a struggle that she never really contemplated having and she knew about it when we were dating. ... I struggled with some guilt about that, even though that’s not reasonable,” she said. “The first day that I really felt supported by her was a day when I don’t think that she felt she
was supporting me. She went to genetic counseling with me and we had had my results for maybe a month or two and she heard what it really meant; I think for the first time. And, she was weepy the rest of the day. We talked and we would go do something else, and then she’d get weepy again, we talked about it some more and that was really the first day that I felt she got it; and I was getting through to her and it wasn’t her fault, it’s just the hardest thing, I think because you can’t empathize.

Alexa: “I’ve grown up knowing that my grandma got breast cancer early (young) and so I have always had it in the back of my mind; this is my deadline.” Alexa, who lives in Indiana, was nearing 28 when we spoke. The only person she had ever known to have breast cancer was her grandmother, who had it once at age 33 and again at age 60. And, while that always frightened her, she said she did not know anything about hereditary breast cancer until college, where she had a friend who was studying to be a genetic counselor. Alexa confided in her friend about her grandmother’s breast cancer and her friend suggested she have genetic testing done. Alexa did not listen.

It was not until Alexa was 24, and had a health scare, that she decided maybe she should have genetic testing done. Alexa was shared her story via a phone call and from the comfort of her home. She was confident and matter-of-fact about her decisions and her long road ahead of her.

There was a point where I felt something in my breast and then that freaked me out, Everyone, even the other genetic counselor said I didn’t really have a strong history, but I definitely qualified (for genetic testing) because of the age that my grandmother had it and then the two instances. And, when I got the results back a couple of weeks later, and I was positive for BRCA2, that kind of shocked me.

Later she found out that her grandmother’s father died of pancreatic cancer, and her grandmother’s brother died of colon cancer. “Gathering the information was kind of hard, especially since I was the first one to be doing any of this, and in my family, some people are still not wanting to talk about it.”

Alexa, who had just turned 26 at the time of her genetic testing, was sitting at her home desk when the doctor called her to give her results of the genetic testing over the phone.
I didn’t know how I was going to react at all. I think I had it in my head it was nothing. It just didn’t get to me, so it caught me off guard. I had no idea what to expect. So, it was a hard day. I had a lot of choices to make, lots of decisions, but I knew what I wanted immediately.

Alexa wanted a prophylactic double mastectomy.

It kind of freaked some people out. It seems a lot less popular for younger women or at least no one’s talking about it. It has been hard to find people here my age because a lot of people have had kids and all of that. And people always kind of judge and they look at you differently when you make that decision.

Alexa said that even her physicians didn’t seem on board with it, and pushed the date out, bringing up things that surgery would take away from her, like the choice to breastfeed.

I was frustrated. I didn’t care. I don’t want that. I have made my decision. That really made me mad. So, if she’s (doctor) going to keep fighting me, I was about to get a new one [doctor]. I was ready to get rid of her. Even though she does a really good job, she is really amazing, and she does know her stuff too. I was mad about that for a while.

Alexa said that eventually her doctor supported her decision.

I’ve grown up knowing that my grandma got breast cancer early and so I have always had it in the back of my mind; this is my deadline. That was before I even knew about BRCA or anything. I remember when Angelina Jolie did that whole thing, she made it public. And I remember seeing the magazine headline at the grocery store and I was like, I would so do that. That was when I was a teenager, I think.

So, I’ve had that in my mind, like it's just been how I am. And, that’s why the decision. The decision was really easy for me and I think that made people uncomfortable because it is a big surgery. I mean, even though the decision was easy, it’s still a surgery and a loss and so I’ve had to go through that, and there were tough days where I was either really anxious or really sad or mad that I have to do this. Like this is my best option and other people don’t have to. I just kind of felt all of the gamut of emotions, like some days I’d be really excited and then some days I would feel really down about it, but ultimately, I knew that’s what I was going to do. And I was going to follow through with it.

So, I just kind of let all the emotions hit me because I knew that I had to just to get through it. The overall feeling is not one feeling. It’s a very weird right now, especially since I’m in the middle of reconstruction where I’m kind of day-by-day, like one day is like not great. And then the next day is okay. Yeah, but I think I feel more like myself. I feel that I don’t know, like I feel more brave than I’ve ever been. I feel a lot better about myself doing this. For me, it just put a lot of things in perspective, I think for me it’s been hard. It’s been hard because I feel like I’m the only one in my family. I’ve been the first one to do this. I feel like a pioneer and that’s not easy, but I’m proud of myself for doing it. So, it’s kind of a positive empowering thing.
Betsy: “I didn’t quite know the journey I was about to go on, but I knew it wasn’t going to be good.” Betsy is 34-year-old Ashkenazi Jew who lives in Montana. Her mother had breast cancer in her mid-30s. A year before we spoke, her mother was 57, and a routine mammogram showed another scare, which turned out to be a false scare. But the doctors decided to do genetic testing and the results showed that her mother is positive for a BRCA mutation. Betsy agreed to have genetic testing too, thinking all the while, she was not going to have the mutation.

“I thought I was invincible or I was like, whatever,” she said. But, much like tracking a package delivery online, Betsy could track the progress of her genetic testing. After waiting three or four weeks, she decided to check one day while at work.

I saw right there on the computer screen that said that I was positive. I couldn’t panic. I was at work. And so, I just walked away from my computer and went in the back room and just like started crying; then called my mom. I mean, my mom felt so guilty because she passed it on to me, and I’m like, Mom, you didn’t know. My mom is just such an incredible person, but she started crying. She was really sad. But I didn’t quite know the journey I was about to go on, but I knew it wasn’t going to be good.

She was advised that she could do surveillance or surgeries.

That scared me because there’s not very many good testing or screenings for ovarian cancer and sometimes when you find out it’s too late. Luckily, I don’t want kids and I never have. So that means this is a lot easier. So, they told me I had up to 87% chance of breast cancer by the age of 60 and then with that specific variant my ovarian cancer risk was obviously way higher than the normal population.

And so, my mom was a carrier and she had beat cancer. My grandpa was a carrier. He had beat cancer. I just felt like someone was telling me someday, you’re going to get cancer. I’m like, I know that. Maybe I don’t, but the odds were so staggering it I was like whoa. No, thank you. So, January of (20)18 I found out I was positive, In June of (20)18, I had my tubes and ovaries removed and in July of (20)18, I had my breasts removed. So, the plan was to do expanders, so I did the skin sparing so I don’t have my nipples, but they did skin sparing and were going to put in expanders and then do an exchange and I woke up with implants and I also have post mastectomy pain syndrome.

So, they damaged my nerves. So, I have been on opioids since my surgery and my quality of life is like, right now I’m sitting in bed. I’m in an incredible amount of chronic pain, she said. “I really can’t even put that into words. … Well, I’m going through menopause.
So that is shitty. I’m 34, and I’m on hormone replacement therapy, but it’s clearly not the right concoction because I’m always having hot flashes, it’s just a struggle. I was in so much pain every single day that I was put on suicide watch like it was just like I couldn’t even be in my own body. I was in so much pain and it never ever went away for one minute. It’s just like a bad dream. It’s called an iron bra. They damaged the nerves on my chest wall.

Before her surgery, Betsy went in for a baseline breast MRI. The woman doing her paperwork said that she was BRCA1 positive, and that when she discovered that information she planned to opt for surveillance every six months. But, in the first six months, she went from a clean scan to breast cancer.

“That hit me hard,” she said. “I just felt like my mind was already made up and then when she told me that, I was like, Oh, my gosh, no thank you.”

Mary: “I feel like it’s a journey that never ends, that you have to be prepared that it’s never going to go away.” Mary is 37, originally from Canada, and now lives in New York. About two years before we spoke, her sister, who lives in Poland, was diagnosed with breast cancer just before turning 41. At the same time, Mary also found out that her cousin, who was in her late 40s, was also diagnosed with breast cancer.

Mary’s sister and cousin both did genetic testing and learned they have a BRCA1 gene mutation. Subsequently, Mary did the testing too, and it also was positive. Until this point, there were few known cases of cancer in their family—at least not that they were away of just yet. They soon learned that their grandfather died of prostate cancer, a grandmother had melanoma, and three uncles had lung cancer.

Once my sister found that she was positive, I kind of started assuming that I probably will be too. I just had a feeling that that’s what it’s going to be 50-50 chance. I was really distressed. The first few weeks when I was waiting for the results that were very, very stressful, like to the point that I was just throwing up being so stressed out. And once I got my results, it was stressful too.

It took Mary more than a month to decide to have a bilateral mastectomy.
Having that surgery gave me some peace of mind. And now I had to go for the ovaries to be removed too. It was emotional, but, I’m also trying to be very rational. So, I look at the science, I look at the statistics and it was very hard for me to make that decision... but, I just wanted to do it and not get cancer too. I found that actually having my ovaries removed is more of a decision. That’s something that’s more emotional for me. So, I’m still kind of struggling with that. I have one child, so even though like I know that I probably will have one, in a way, that possibly, it’s kind of hard to make it so final because I’m 37 and even though I kind of decided we just want one (child), I don’t know, it’s always good to have an option. I don’t think that anybody can understand unless they go through that.

I’m definitely grateful that I managed to find out about the mutation, I guess. I mean nobody wants to find out about anything like that, but I feel like if I didn’t find out, maybe get cancer and I could take some steps right now. I feel like it’s a journey that never ends, that you have to be prepared that it’s never going to go away. I worry about my daughter as well, because she’s 5, so I will have to probably get her tested at some point. Yeah, really hoping she didn’t get it.

Sally: “It’s that possibility of the cancer showing up. And I guess in my mind, it was not a matter of ‘if,’ it was a matter of ‘when.’” Sally is a 38-year-old from Michigan, whose father’s mother (her grandmother) was diagnosed with breast cancer, went into remission, and then ended up with breast cancer again that spread to bone, brain and liver. She died soon after. In the 1980s, one of Sally’s father’s sisters was diagnosed with breast cancer at age 32. And in 2008, an uncle from that side also got cancer, and died of leukemia.

Knowing that there was a breast cancer history, I pushed on to the doctor and they said, not to be concerned about it, but there was never any kind of genetic testing or anything because typically it a mother’s side, but it was my father and my father’s side and it wasn’t like a direct female, so there wasn’t much of a concern. So, it took me probably about three years, and something inside just kept saying, just for peace of mind, you should get checked. Yeah, because cancer is so huge in the family. And so, I did, and that’s when they found that I was BRCA mutation positive, BRCA1. So, it can be passed on from dad’s side.

My husband and I went out to lunch. And, I’d gotten a phone call from the OBG, who had ordered the test. And she calls to let me know, ‘I’m sorry to tell you, but it came back for a mutation present.” It’s kind of one of those fears, too, because of the huge cancer history in the family and having three kids and I’m like, oh, my gosh, I felt like either I go ahead and go through these surgeries or not. And then, of course, it’s that possibility of the cancer showing up. And I guess in my mind, it was not a matter of “if,” it was a matter of “when.”
I think to have that control and power to say, I’m going to do this, but as opposed to allowing my body to do this to me anyway. But I think I knew from the start, even when I did the blood test. I already had my mind if it comes back positive, I’m just going to get some surgeries as a preventative. Almost as if you look at it like a vaccine; are you ever going to get measles or mumps? polio? Probably not, but I would do a vaccine to prevent that . . . I had my hysterectomy first. I had that in January of last year she did a full hysterectomy took everything out. And then it was February I started my breast procedures. So, it was really, really fast paced, very overwhelming. Sometimes you do have to sit back and go, man, I wonder, would I have done anything differently? No, and it really sucks. I just keep reminding myself life is better by preventing cancer. And again, had I not done this, eventually down the road, there is a possibility you would always be wondering.

I consider myself lucky. Sometimes it’s hard for a woman, I think, because that’s (breasts) what we define ourselves as . . . I feel kind of been that advocate, there’s a couple other cousins who didn’t get tested. And then once I got tested positive, I’m working with them. So, there’s a small, extra support because of our same diagnosis. I have a couple of cousins who are a couple years older than me, but they also tested positive and they've been pushing off the surgeries. I told them, don’t focus on the back-end part, but what you’re actually doing for you and your family.”

Sally’s oldest daughter is 15, middle son is 13, and youngest is 8.

**Annie: “I cried daily, it (prophylactic surgery) was awful. There are times I regretted it.”** Annie is 40 and lives in Ohio. All of her maternal grandmother’s sisters passed away from breast cancer when they were younger, and her grandmother was 85 when she died of breast cancer. When she was an infant, her mother’s oldest sister, who was 40, died of breast cancer. About 10 years ago, another maternal aunt was the first to have genetic testing done, tested positive and had a double mastectomy. When learning about her aunt’s genetic results, she says she remembers thinking, “Oh, that’s why we have so much breast cancer in the family,” but it didn’t really sink in that she could be affected too. About five years ago, her sister, who is only a year older, was tested and tested positive. At first, her sister was doing monitoring and after the first six months, she decided she could not do this every six months.

“We are really close. That was when I thought, oh my God, I might have it too.” Annie says her OBGYN was not helpful and uninformed about genetic testing.
I finally ended up getting tested when my boyfriend had hernia surgery and when we were in the office for his follow up, I went with him and the doctor had posters up about genetic testing and they were so knowledgeable about it. They are the ones that helped me get the testing. I don’t know why he even knew that much about it.

Annie said she hasn’t spoken to her mother in about 20 years but heard about a year ago that her mother had genetic testing too, but never told Annie and her sister that she was positive.

I was sitting there (at the doctor’s office) and they told me I have it, I had convinced myself that I didn’t have it. My boyfriend didn’t know why I was so upset. I knew, I knew, but I didn’t know. It’s hard to explain to somebody I know I didn’t know. When I had the first MRI, they thought they saw something, but then they couldn’t find it—so that was difficult. And at the same time, my cousin was dying of breast cancer and she’s only six months older than me, and has three little kids and they are about the same age as my kids. When I got the results back, I decided to do the surgery, preventative mastectomy, but it was still a really hard decision. You go through all the scenarios like this really good chance that I would never get breast cancer or if I did, I will be much older. But, then I had a 2 year old and my oldest was 14, and my cousin just died and her kids had to go to another family member to live. It basically came down to I want to be around for my kids and if I do get cancer, I don’t want them to go through watching me suffer through the treatment.

In 2016, she had the mastectomy and reconstruction “took forever” Annie said, adding that after four different staph infections, she had her latest surgery a year ago, and she stills feels they look terrible. “I cried daily, it was awful. There are times I regretted it.”

Annie’s oldest is now 19.

We’ve talked about it quite a bit, she had the doctor order the test for her, but she’s kind of on the fence. Last time I talked to her she wanted to wait until she’s done with college doesn’t want to stress. I had to explain to her that it is never going to be a time when you’re not stressed. If it’s not college, it’s going to be your job and then your kids and then yeah, but I don’t want to push her because it’s a very personal decision.

Carol: “If you see something than it’s too late. I don’t want that. You know, I wasn’t willing to wait for cancer.” Carol is 42 and lives in New York with her husband and 14-year-old son. Most of the women in her family lived until they were in their 90s. Her grandmother was 100 when she died. Carol had genetic testing because her mother was an ovarian cancer survivor. When Carol discovered she is a carrier, she was a little surprised.
It was just a bit of a shock. I heard about BRCA in an Angelina Jolie story, but I really never thought about it. I had a gut feeling that I was positive. I don’t know why. I just felt like it was going to happen. I was home when the genetic counselor called me to tell me. I got teary. And, even though I kind of expected it, it was overwhelming. I was really overwhelmed.

The doctors told her that they were going to monitor her, “four times more than the regular average person.” And, they told her that if they find something, they would catch it early.

Carol had already watched her mother go through chemotherapy. “I’m like, if you see something than it’s too late. I don’t want that. You know, I wasn’t willing to wait for cancer.” Since her mom had ovarian cancer, Carol opted to remove her ovaries. “I mean I have horrible hot flashes and no one wants to give me hormone replacement therapy which is fine, I’m dealing with it.” She also had a double mastectomy and reconstruction.

She said, although her son is a teenager, he doesn’t quite understand what his mother’s status could mean for him.

He’s a worry wart. So, I’m not going to tell him until he’s a lot older. When the time’s right, I’ll have the talk. ... For me, it was really difficult. I went to a therapist before the hysterectomy. I was a wreck,” she said. “Once in a while, I focus on my chest. Oh, my God, there are these silicon things in my chest, but I made my decisions and I feel lucky. I don’t have a horror story, so I was just so lucky.

**Sophie: “I’m very alone, no one in my family wants to know.”** Sophie, 44, who lives in Nevada, watched her mother die of pancreatic cancer and her father die of colon cancer and a rare type of bladder cancer, and her aunt die of ovarian cancer. And, when she was only 24, her doctor found what he thought was a lump in her breast. It was biopsied and considered a step below cancer.

In January of 2016, a pap smear revealed some suspicious, extremely aggressive pre-cancer cells. “He’d [the doctor] never seen anything as aggressive and, after he consulted with some other doctors, they said they don’t think they can control this and get my affairs in order,” she said. With, as she thought, nothing left to lose, Sophie decided to switch to a plant-based
diet. In May 2016, she had her hysterectomy, and the doctor said, he didn’t know what happened, but there was no cancer. “I told him I had given up meat and dairy, he said, don’t ever go back,” she said.

In June 2018, just before Sophie moved from Illinois to Reno, she had genetic testing done and tested positive. “I was completely taken off guard. But I mean, I’d only heard about BRCA, really,” she said. Sophie started the process of telling her family the news; her two brothers, cousins, nieces, nephews, anyone who would listen—but most didn’t want to listen. “I’m very alone, no one in my family wants to know,” she said.

Fortunately, her 19-year-old daughter did listen. Sophie recounted:

She’s in her second year of college and my daughter has decided to wait till after she’s out of college to be tested . . . This is an area that I really didn’t want to be a pioneer in. It is pretty hard for me emotionally, but I have joined a couple groups, it sucks that their online support groups. I always try to remind people that what works for me doesn’t work for them. We are different. When my dad was dying, my dad was asking how long do I have to live, and I remember the doctor just saying to him, believe it or not, your body’s not a perfect science, we just don’t have an answer, and I always take that with me. I’ve been very blessed, but I mean I’m scared. I’m scared for pancreatic. I’m scared for colon cancer. I’m scared, but my next steps are just to do the screening. I’m just trying to be as informed as I can, try to make good decisions that will be good for my body. I don’t know why that I feel like I want to educate people about it because maybe because I was never educated on it or it just wasn’t a big thing. So, when people ask, I always remind them about Angelina Jolie, she didn’t have cancer, but she had them (breasts) removed. That’s the biggest thing I think, the big hurdle for me talking to people is they don’t understand why I would do preventative surgery, and I try to explain to them that I came up with 95% to get breast cancer, even though it doesn’t run in my family. Why would I just wait to get cancer?

**Bessie: “When I found out, most doctors had no clue; and they are still a few and far between.”** Bessie, 46, lives in South Carolina. She remembers her grandmother always being sick. Her grandmother died of bone cancer.

So, when our cousin got breast cancer, and by this time our aunt had died from breast cancer, and our uncle died from pancreatic cancer, and my dad had a half-sister who had also been diagnosed with breast cancer, then we started thinking about this, and maybe we always kind of knew, that it had to be in our genes, but we thought it came from our grandmother. When our dad’s half-sister came up, it’s like, well, it can’t come from her
because that was our granddad’s daughter and come to find out he had had prostate cancer when we were all really young and it wasn’t really talked about.

Not until her 60-year-old cousin was diagnosed with breast cancer did the family discover through genetic testing, that a mutation ran in the family. After her cousin’s positive BRCA results, Bessie and sister decided to get genetic testing and both were positive.

I was actually on my way to a trip to the mountains for the week (when the doctor called her with her positive results) but I mean I already knew. I can say, I had already made the decision. I had two little boys. So, I’m just not going to do that to them. I will not have them go through that again.

Bessie said that her sons, who are 17 and 14 now, are well aware of the family history. People who say, “I don’t want my kids to be tested,” I don’t understand that. I just don’t. With the knowledge that’s out there, why would you not? We have some cousins that don’t want to be tested, and I don’t understand. I’m just baffled. To be honest, I don’t understand it. I don’t. I mean knowledge is power and you are sitting on that knowledge isn’t helping anybody. Once the BRCA came out, it was like I tell you what we could do something different. I know in 2010 when I found out, most doctors had no clue. And they are still a few and far between.

Marissa: “I’ve been frustrated with recovery and that process, but I just feel it’s better than chemo, as far as I know, because I watched my mom go through all that.”

Marissa is 47 and lives in California. Her mother was in her 50s when she was diagnosed with ovarian cancer and died at age 59. Her sister is currently battling both breast and ovarian cancer.

Marissa said:

We didn’t know any other family history at that time, it was a surprise of why she got it or she didn’t fit the profile that was available at that time for somebody who would have ovarian cancer. I have three older sisters, in 2017, one of my sisters was diagnosed with breast cancer, so because the test is now available, they did that and actually found out she was positive for the BRCA1 genetic mutation.

So, all three of us went and got tested, and I was the only other one that was positive. She obviously went through chemo first, and then she had a double mastectomy, and then she did a hysterectomy. And then when they tested her tissue, she had ovarian cancer also, but they caught it really, really early and they tested the surrounding tissue. They didn’t find any additional cancer growth but felt that it was isolated to the ovaries. It’s day-by-day and yeah, continuing to get monitored.
So, I found out December of 2017, and then the first thing I did with my ovaries and my hysterectomy, because of my mom. Well, the timing of my testing, was really kind of crazy. I had blood work and the week before Thanksgiving, I found out my sister was positive. I went to my doctor to have a test done. And I was pretty solid on what I was going to do. I told my doctor, if this comes back (positive) do whatever you have to my body. I have a 7-year-old to be around for. But honestly, I felt like I got the good diagnosis. You know, I wasn’t being told you have breast cancer. And now you have to decide, and I already knew my sister was going through chemo for breast cancer. Yeah, anytime I got to choose when I did it.

My decision was, obviously, to take the action that I did, and I felt like, why would I wait, like wait, and see when I get it. It didn’t seem like a great option. Because my son was so young, I didn’t want to wait 10 years, and then he’s in high school, and he’d have to watch me go through something like I went through when my mom died. I didn’t want that for him. I can honestly tell you, I have not cried about it, because I feel it was the right course of action for me. I’ve been frustrated with recovery and that process, but I just feel it’s better than chemo as far as I know, because I watched my mom go through all that. ... And so, I did it. I personally wasn’t sure I wanted to do reconstruction and, putting in implants. I’m not the kind of person who would have gone to get a boob job. ... I had a bye-bye boobies party. I used to refer to my boobs as the girls and so they were the strangers to have my first surgery and they think that they would now be that’s great.”

Pam: “It’s still hard to look at the mirror and we’re almost two years later, it’s so bizarre. It’s just a daily reminder.” Pam is 53, lives with her husband on a sailboat off the island of St. Thomas in the Virgin Islands. Her mother was diagnosed with ovarian cancer in April of 1988, when Pam was in her 20s. And, although the cancer was far along, her mother made it through chemotherapy and survived another three years before she died on Christmas day in 1991.

I watched her battle that disease and saw firsthand the effects of chemotherapy and what that did. She did get a lot of good time as a result of her decision to undergo treatment, but it definitely was a battle. So that was my first experience with someone close to me that had been diagnosed with cancer. About 10 years before that in the late 70s or the 80s my cousin was diagnosed with late stage breast cancer and lost the battle very quickly. She was late stage breast cancer and we lost her.

Around 2004, Pam’s sister, who is four years older than Pam, was diagnosed with breast cancer and she had a lumpectomy and she underwent radiation and chemotherapy. But in 2015, her sister was diagnosed with cancer again, this time melanoma, that eventually spread to her
groin and spine. Pam said: “At this point, it’s inoperable. So, she is out in Arizona battling that right now.”

Pam had her own medical scare in November of 2016, which led her to her doctor asking if she wanted to get tested for the BRCA mutation. “That’s the first time I heard the term, other than Angelina Jolie,” she said. In January of 2017, Pam got her positive results on her way to the airport to say goodbye to her sister.

It was a moment I’ll never forget, because it was just so scary for me and her having been through it all, if you could just imagine, we both were so emotional. Standing there in an airport, we just said goodbye. I got in the car, and I drove up with my husband when I got my phone call from my surgeon and got the message that he wanted me to get with the secretary and schedule the first available appointment. He called me back for a consult. With everything that happened with my mom and my sister, I wanted to do what I could to increase my chances of survival. So, I opted for the bilateral mastectomy.

Pam also had a complete hysterectomy and did a full body check and had any moles removed. She opted for no reconstruction.

I just felt this late in my life, it’s just not that important to me in my life. You know, it’s still hard to look at the mirror and we’re almost two years later, it’s so bizarre. It’s just a daily reminder, but I don’t regret my decision at all. I feel it’s changed how I look at life. It’s changed how I choose to spend my time, it’s changed what I worry about and what I don’t worry about, it kind of helps me move in a direction that is less focused on my career and my job and all of the pressures of life and more about making sure I take time to enjoy the experiences that I have right here in front of me every day and for me that’s the beach and the Caribbean and the ocean and just a lot of life. It’s my sanctuary and then my place of peace and comfort and trying to embrace that a lot more and the more of a high strong intend to workaholic kind of person to help them really hard, but I’m still fearful, I am fearful this thing could rear its ugly head again.

There’s not a day that goes by, even though I took every step that I took to prevent my chances of that. But, there’s a lot of mixed emotion and there’s definitely a lot of fear and anxiety, so I don’t sleep as well as I used to. There’s a lot of anxiety that comes with knowing that I don’t want to say, your days are numbered. But I’m finding my way through it but I guess I’m learning, learning how to be more peaceful and to set aside the time to reflect, so hopefully it’s helping me grow.

Alisha: “BRCA positive, is truly not for the faint of heart. It’s kind of a little cloud that is constantly there.” Alisha is 62 and lives in Minnesota. She has a half-sister who died in
2013 at age 66 from ovarian cancer. Within a few months, Alisha had genetic testing done and was told she was positive for a BRCA gene mutation. Coincidentally, the timing coincided with Angelina Jolie’s public announcement about her own genetic testing story.

Alisha said:

I did not want to hear it, because frankly, I didn’t give a rat’s ass about Angelina Jolie, and was right in the middle of my work day, and now I was going to die, just like Pam (sister). It kind of seems like a blur from after he (the doctor) told me and then I had to call a genetic counselor. And we did that, and I got into see her and that was a good thing because she kind of took the fear down a couple levels. She just explained, it ended up simply, and in a way, that wasn’t as scary as what I thought it was. I mean, I was still scared, but she took that initial fear down a few levels.

Alisha’s daughter was then testing, and also found out that she is positive.

She was very angry and upset with me. I actually don’t blame her because I kind of was, I felt the same thing. I was very sad. There was nothing I can do, it with this genetic thing. I’m not in control of that, especially since I didn’t really have a relationship with my father at all. That made it even worse. I mean, I listened to her, and I knew what she was feeling, exactly what she was feeling.

Alisha said it was years before her daughter would speak to her again.

I was totally devastated because I didn’t want her to have this. I would have done anything in the world for her not to have this. But it was out of my control, I was helpless, there was nothing I could do. I was literally helpless and powerless.”

Alisha opted for a hysterectomy and breast surveillance.

Surgical menopause, that was not fun. But I kind of just made up my mind that this is how my life was going to be, and I would just incorporate those every-six-months visits. Today, I just do what I’m supposed to do, and hope for the best. And it scares me to death. But you can’t let yourself go down that road. Because I mean, that would just be fatal to think about all the time.

So far, so good for me, and so far, so good for my daughter. So, it’s been a road that I definitely didn’t choose to go down. And, and I would do anything not to have to go down it. On one hand, I’m grateful that there was a genetic testing that at least to have an idea that I was a ticking time bomb for this. And that’s all I feel like a ticking time bomb. Like when am I going to get the bad news? When is it not going to be a good MRI or
mammogram? So, you just sit here waiting? And then, you’re always waiting. I mean, it’s not anything positive, that’s for sure. It’s kind of gloomy and doomy. I need to be based in reality. Because if you think it can happen, and it happens, then you’re a little closer to reality, then if you don’t think it can happen, and it happens. Being BRCA positive, is truly not for the faint of heart. It’s kind of a little cloud that is constantly there. And then sometimes, it rears its ugly head like, oh God, it’s time for another mammogram; I’m going to miss another half a day of work. And, then be afraid until you get the outcome.

Danielle: “I’m crying about her (daughter) experience because it was so much harder than mine and I felt so badly.” Danielle is 65 and lives in Texas. When she was about 10 years old, her 40-year-old mother went into the hospital and she didn’t understand why.

It was very scary, and we knew that all the neighbors are like showing pity on our family, they would invite me and my sister over to eat with them, that kind of thing. And your poor mother, but no one told us what happened to our mother. She had a radical mastectomy and she had radiation. After that and she never explained to us, but we would see her put that thing in her bra, and when she wears a bathing suit she had to have a very high one. And back then, which was long time ago, if you survived five years (after breast cancer), you were good and you were okay and you would live, and she did (dying at age 60), but both of her sisters also had the same thing.

But there was no doubt in my mind that I was going to get it. It’s like when is it going to be, how am I going to find it? I never thought I was going to die. I just thought, I’m going to get it.

When Danielle was about 27, her cousin, who was the same age and who she was very close with, was diagnosed with breast cancer.

My world fell apart. At 27 years old, she found a lump and they remove her breasts. But at that point I became very knowledgeable about it and all that kind of stuff. She ended up going to Johns Hopkins and she was in a research study with Dr. Mary Claire King and apparently, ours was the first Lithuanian family that was found to have to be BRCA1.

While Danielle’s sister tested negative, Danielle was positive. And, it turns out that all six of her mother’s siblings were also positive. “I knew it was going to happen. It didn’t surprise me,” she said. Danielle chose to have a hysterectomy and surveillance until a doctor said, “Honey, do you want to take one month out of your life now and have a double mastectomy, or do you want to take a year and have to have chemo. I said, well, when you put it that way, I’m ready.”
Danielle has two daughters, one with children who tested negative and a second, with no children, tested positive.

So, it stops there and I’m really glad. Although my younger one has had terrible trauma because she was very large-chested I mean that was always part of her self image. And when I had it done, I wanted to look like I looked and she did. She wanted nobody to know.

She also added that her daughter has had terrible difficulties with the surgeries and has had six surgeries so far.

She ended up having to have the back muscles fold around to the front to hold the expanders and actually she looks like Frankenstein with all the stitches. It was very hard. It is very hard. But she’s beautiful and she’s doing well and she feels she made the right decision.

Danielle’s tears brought her to a pause in her story.

“I’m crying about her experience because it was so much harder than mine and I felt so badly,” she said.

**Gigi: “Now I know why my mother died.”** Gigi is a 72-year-old living in New Jersey with her husband and cat named Frank. Her mother was 30 when she birthed Gigi and 38 when she found a lump in her right breast, which was breast cancer. It was 1954, her mother had a single mastectomy, and radiation, which Gigi says, made her “quite ill.” While she finished all her treatments, they had terrible lymphedema, and used to sleep in traction with her right arm elevated. When her mother turned 41, she had spent so much time in the hospital, and bonded with the nurses, that she decided to go to nursing school and become a nurse.

She used to tell us she was the oldest one in the class, but she finished at the top of her class. When she was 45, she became very sick again and her abdomen started to swell and that was the ovarian cancer and they knew it, but it was so metastasized that they couldn’t do anything. And she died in February of (19)64 when she was 47. She had turned 47 in September. Yeah, I was 17, it was a bitch.

Gigi sat in an older-styled home office, with paneling walls and a cork bulletin board behind her with miscellaneous pictures of her family member, drawings from her grandchildren,
coupons, and other random pieces of memorabilia that hold significance to her and her husband. Every now and then, her dark black cat would cross in front of the screen and Gigi, would gently nudge her from view.

Gigi’s grandmother (her mother’s mom), died of cancer at age 35. Gigi said: “When my mom started to get her belly on her at 45 . . . This is what my mother looked like too so we can only assume that she also had ovarian cancer.” Gigi also became a registered nurse, but she is retired now. From 1992 to 1997, she was in the breast cancer prevention trial through the University of Pittsburgh. She participated in a study she was either given a placebo or tamoxifen, which was known to prevent breast cancer in some women. In 1999, shortly after the discovery of the BRCA1 mutation, Gigi’s doctor suggested she have genetic testing. But it wasn’t until almost 17 years later that she was tested.

For some reason, in March of (20)16, when I went to my GYN, she said, ‘you really need to be tested. I said, “Oh, sure, what the hell, go ahead.” And, she called me and she said, “Are you sitting down?” As soon as she said that, I’m like, oh my God. And she said, “You’re positive. You’re BRCA1.” I said, “Oh my God.” And then in the same sentence, I said, “Thank you God.” And she said, ‘Why did you say that?’ I said, ‘Because now I know why my mother died. She didn’t just get breast cancer. You know, it made sense then so yeah, I told the doctor I felt a little better because now I knew 52 years later why my mom died of breast cancer.

Gigi said, while she was initially overwhelmed, she decided to talk to a genetic counselor. After that, she decided to opt for a double mastectomy, and no reconstruction. “My husband and I made this decision. They [her breasts] worked for three kids. I’m 69 years old. Why do I need boobs? I used to think, oh my God, everybody stares, but they don’t really look,” she said.

Gigi has three children, two boys and a girl, ages 50, 47 and 45. Her oldest son and her daughter tested negative. Her youngest son, who is currently in Taiwan, will be tested when he returns from overseas.

So, I was the lucky lottery winner. And my mother had four siblings. There were five of them and none of them died of cancer. Three of them had diabetes and eventually a stroke
and the fourth one was killed in a car accident so none of them had cancer, so she was a lucky lottery winner. I don’t know anything about her aunts or uncles on her mom’s side. I have talked to my husband obviously, he’s very important in my life, and for him to look over at me when I’m coming out of the shower or getting ready for bed or getting dressed and see no breast. How would you feel about that? And he kept saying, “we want you to be alive.”

Gigi said her mother’s death because of breast and ovarian cancer was not the only reason she opted for the risk-reducing surgeries.

It was also my best friend, Claire, who at 27 was a nurse came to me at my desk and she said come into the bathroom. When I went into the bathroom with her, she said, look at this. And she has a mushroom thing, honest to God, growing on her chest. I said, Claire, what the Hell is it?

It turned out to be breast cancer, and Claire died of it in 2008 at age 44.

I didn’t want reconstruction. So, going flat was really our option because we had seen what Claire went through, and the thoughts of chemo and radiation scare the shit out of me, and I don’t want any part of that. But I know that I have to keep up with myself and I do I don’t just take a shower and they go, I’m fine. You know, I’m always feeling (for breast cancer lumps).

Between the initial soliciting of volunteer participants, the emailing back and forth to obtain signed consent forms, answering and questions, scheduling the interviews and conducting the interviews, the timeframe stretched over a few weeks period. It was an intense time for me with each interview lasting between 30 to 60 minutes on an emotionally charged topic, many participants interviews included or concluded with tears.

**Summary and Reflection**

During this period, I took significant time to reflect on their journeys and how their stories were now intertwined with my own journey. I have devoted sections of Chapter VI to review this period of reflection and subsequent journaling more fully. But first, Chapter V will address my summary and analysis of these personal journeys of previvors and their experience from beginning of diagnosis to the time of the interview. Additionally, I provide findings of the post-interview survey questions.
Chapter V: Analysis

I feel like it’s a journey that never ends, that you have to be prepared that it’s never going to go away.”

–Mary (A participant in this study)

After the collection of data was finished, the end products consisted of the interviews, the follow-up survey comments and results, as well as my own personal reflection that followed each of the interviews. The analysis hinges on a holistic-driven approach to plot analysis with a thematic analysis overlay. The findings from these combined approaches emphasized the complexity and coherence of the stories, the feelings evoked, and the power of metaphors. Finally, I reflected on Clandinin and Connelly’s (2000) commonplaces of temporality, sociality and place as present in the telling of the stories.

The findings are organized in a way that walks you through the elements of the plot analysis and the related themes and subthemes. Quotes from the stories further illustrate elements of plot and underlying emergent themes. The analysis of emergent themes, with emphasis on emotional content and metaphors, are first presented in table format, then fully explained and elaborated on; I conclude with a visual representation of the combined analysis to help convey the fluidity of the complex information uncovered and to emphasize that these narratives may not always follow a linear path.

Purpose of Plot Analysis

Plot analysis allowed me to dissect the different elements of the previvors’ story lines from the moment of their first introduction to HBOC. “Plots are like lenses that guide perception, memory, and interpretation of the dramas of life . . . [the] narratives of life experience make sense in part because of plots” (Daiute, 2014, p. 114). Thus, plot analysis helps to take an overarching look at the process, to streamline these unique, yet similar, experiences, including
my own reflective actions, to ultimately, create a framework for healthcare professionals to better treat and understand the psychological implications for their own patients facing HBOC and related decisions.

Through the eight plot line elements—characters, setting, initiating action, complicating action, high point, resolution strategy(s), ending, and coda or reflection, which are all further defined below—the arc of the story lines revealed one continuous story that was consistent among previvors, but unique among individuals based on their life experience.

For example, the following excerpt from Alexa’s story reveals the plot elements of characters, initiating action, and complicating action. Alexa, aged 28, whose grandmother had breast cancer twice, first at age 33, then again at age 60, (the characters of the story introduced) had already resigned herself to her belief that she was destined to get breast cancer before she hit her early 30s (initiating action). So, when she learned there was something she could do to help steer the ship away from that iceberg, per say, she decided it was the best choice for her and her future. “I’ve grown up knowing that my grandma got breast cancer early and so I have always had it in the back of my mind; this is my deadline,” Alexa said. “That was before I even knew about BRCA or anything” (complicating action). Within this quote, it is easy to see that, based on Alexa’s lens of knowing that her grandmother battled breast cancer twice, and early on, in her story she believes this is her deadline too.

**Purpose of Thematic Analysis**

Thematic analysis revealed the topical themes that deepened the emotional understanding and sense-making with the previvors’ discovery of HBOC, and the psychological implications of living with that knowledge. A thematic map of their journeys helped to create a larger overall picture of what it is like to live with HBOC. The emergent themes revealed through emotional
content and metaphors the similar paths each woman took on her journey from HBOC discovery to resolution. The points along the way were:

1. The discovery of the knowledge of a genetic mutation in the family
2. Fear of possibly being positive for the mutation
3. Finding out that they were positive
4. Fear of getting cancer or, worse, possible cancer causing death
5. Decisions to take prophylactic action
6. Guilt and sorrow of unknowingly passing this deadly mutation on to their children
7. Uncovering self-empowerment
8. Realization of a never-ending journey to outrun a cancer that may never come

“I feel like it’s a journey that never ends, that you have to be prepared that it’s never going to go away,” said Mary, whose sister and female cousin were simultaneously diagnosed with breast cancer. After their genetic testing showed positive for a genetic mutation, Mary followed with testing and she was positive too. She now worries about her own daughter, who is only 5. This is an example of the realization theme, where one has come to the conclusion that this is something that cannot be ignored, it must be faced with knowledge to get through to the other side. It must be accepted and dealt with in order to move forward in the battle to outrun a cancer that may never come. And, the realization and acceptance must be recognized for what it is—a journey that does not end. It doesn’t end because it is passed on from generation to generation—to children, nieces, grandchildren and so on. It is also never ending because at any point in the journey the experience can revert back to prior feelings, complications, more battling and even, in worse case, cancer rears its ugly head.
Findings: Integration of Plot and Themes

The plot analysis revealed insights into the participant’s narration that made plot analysis “a systematic way to identify the deep structure of narrative meaning [or in other words,] the skeleton of meaning” (Daiute, 2014, pp. 123). Using Daiute’s (2014) model, the plot analysis was organized around the following elements:

1. Setting—place where the action physically happened
2. Characters—actors sharing their experience in narrative
3. Initiating action—a major action that served as the catalyst for the story
4. Complicating action—a “fork in the road” that requires additional action, related to the initiating action
5. High point—an important and pivotal conflict of the story
6. Resolution strategy(s)—an attempt to better the situation by resolving the main issue in the story
7. Ending—where the story is in the moment, as a result of attempting to resolve the issues in the story
8. Coda—how the person feels now as a result of the experience as a whole as they reflect on the story, often a transformation or discovery has occurred of moral or lesson learned.

The thematic analysis allowed me to point out the emerging themes, emphasize them using quotes, metaphors and emotional content. In Table 5.1, I display the elements, with a description of each element, and any topical themes and subthemes uncovered in the analytic process. I’ve organized these findings within a table format, expanded upon them in context format with quotes to illustrate plot, elements, themes, and subthemes. I share the findings by
telling you how the elements, themes and subthemes intertwine to create the journeys that can fork at any given moment.

Table 5.1

*Plot Elements, Topical Themes, and Subthemes*

<table>
<thead>
<tr>
<th>Element</th>
<th>Description</th>
<th>Topical Theme</th>
<th>Subtheme(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Setting</td>
<td>The original stories took place within the constructs of the previvors’ own lives, news was delivered at home, work and even in a car. Stories were retold by the previvor, from their own homes, via telephone or video conference call</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Characters</td>
<td>All participants were women, first-person narrators, had a family history of HBOC and had learned they were carriers of a genetic mutation that drastically increased their chances of breast, ovarian and other cancers, some up to 90%.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initiating Action</td>
<td>At least one immediate family member succumbed to breast or ovarian cancer, or an immediate family member was a survivor of breast or ovarian cancer, who learned they were a carrier of a genetic mutation.</td>
<td>Overwhelmed</td>
<td>Initial fear they could be carriers too; anger—why our family, why me; sadness for family members lost and/or who are carriers</td>
</tr>
<tr>
<td>Complicating Action</td>
<td>Genetic testing revealed they were carriers of a genetic mutation that drastically increased their chance of breast, ovarian and other cancers up to 90 percent</td>
<td>Reality sets in, greater fear that they could die</td>
<td>Guilt they could pass this on to their children; stress of making decisions to be proactive</td>
</tr>
<tr>
<td>Element</td>
<td>Description</td>
<td>Topical Theme</td>
<td>Subtheme(s)</td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------------------------------------------</td>
<td>--------------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>High Point</td>
<td>Decision of actions to prevent cancer</td>
<td>Anxious to make the “right” decision</td>
<td>Barbaric surgery vs surveillance; children vs infertile</td>
</tr>
<tr>
<td>Resolution</td>
<td>Action from their prophylactic decisions</td>
<td>Prophylactic procedures/recovery</td>
<td>Permanency, lifelong consequences</td>
</tr>
<tr>
<td>Strategy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ending</td>
<td>A settling of the main plot conflict that they are a carrier of a genetic mutation, without the need to resolve it</td>
<td>Living with this knowledge</td>
<td>Coping, advocacy</td>
</tr>
<tr>
<td>Coda</td>
<td>Their reflection on their entire experiences as narrative, the moral of their story, and/or transformation realized after becoming a carrier of a genetic mutation, and facing extreme difficult decisions</td>
<td>How they feel about themselves</td>
<td>Brave, empowered, proud, trailblazer</td>
</tr>
</tbody>
</table>

Note. Setting and Characters set the stage of the story and do not include thematic analysis.

**Character as the first plot element.** All women were first-person narrators, had a family history of HBOC, and had learned they were carriers of a genetic mutation that drastically increased their chances of breast, ovarian and other cancers. Most of the women had a grandmother and/or mother who had succumbed to breast or ovarian cancer, and in many of those cases, the previvor was the one main caregiver of that person. This first element establishes the common experience of all the women in the study. There is no thematic analysis for this element.

**Setting as the second plot element.** The initial setting of the original stories was within the constructs of the women’s lives. Parts of the stories were lived out at home, work, at a doctor’s office and even in vehicles. And, in most cases, different parts of the stories were set in multiple settings, with the only common denominator being the woman, herself, facing difficult decisions that will affect her life and her family’s lives.
Recounts of the stories were told to me for the purpose of this research, by the previvor, from their own homes, via telephone or video conference call. The day, time and place and medium was chosen by the participant to ensure they felt the most comfortable and at ease telling their story. This second element sets the stage for the retelling of the stories and is not thematically analyzed.

**Initiating action as the third plot element.** At least one immediate family member succumbed to breast or ovarian cancer, or was a survivor of breast or ovarian cancer, who learned they were a carrier of a genetic mutation.

**Topical theme: overwhelmed.** Inside many of the journeys of the participating previvors, the initial introduction to the world of HBOC was not a positive experience. Three were extremely young when they watched their loved ones die of breast or ovarian cancer, thus shaping the start of their lifelong battle with this disease. The participants were overwhelmed with sadness, fear, grief.

Jen was only 6 years old when her grandmother died of ovarian cancer, and 13 when her mother discovered she was a carrier of a gene mutation for HBOC. “I guess it was because my grandmother died when I was 6 that I knew about cancer right away,” said Jen, adding that although her mother did not have cancer, Jen was only 13 when she watched her mother undergo a prophylactic hysterectomy and double mastectomy, with a difficult recovery including hemorrhaging and sudden menopause with no hormone replacement therapy.

In this example, Jen knew from a very early age that her grandmother died of cancer. She witnessed her mother discovering she was a BRCA gene mutation carrier and watched as her mother underwent barbaric surgery in hopes to prevent her cancer fate. Jen was only 13. She categorized the situation as overwhelming because she mourned the death of her grandmother
who she barely had a chance to know in her few brief years with her. She was sad and
grief-stricken when her mother discovered she was a carrier and suffered through difficult
surgeries. And she was anxious, nervous and overwhelmed with negative emotion surrounding
her own potential fate as a carrier and fear of the unknown. Would she die like her grandmother?
Would she suffer like her mother?

Gigi was only 8 when her mother got breast cancer. Her mother was then diagnosed with
ovarian cancer when Gigi was 15. Her mother died two years later. It was 1954; her mother had a
single mastectomy, and radiation, which Gigi says, made her “quite ill.” While she finished all
her treatments, she had terrible lymphedema, and used to sleep in traction with her right arm
elevated.

When she was 45, she became very sick again and her abdomen started to swell and that
was the ovarian cancer and they knew it, but it was so metastasized that they couldn’t do
anything. And she died in February of ‘64 when she was 47. She had turned 47 in
September. Yeah, I was 17, it was a bitch.

Gigi’s maternal grandmother died of cancer at age 35. Gigi said: “When my mom started
to get her belly on her at 45, she said: ‘This is what my mother looked like too, so we can only
assume that she also had ovarian cancer.’”

Gigi is overwhelmed with grief that she lost her grandmother and mother to cancer at
such young ages. She’s angry that she didn’t get to share her life with her mother. And, she feels
overwhelmed with fear that history will repeat itself and she would die at an early age as well,
and not be there for her own children.

Underlying subthemes included sadness, grief and fear. Participants expressed their grief
for their loved ones and family members who had already succumbed to breast or ovarian, and
initial fear that they may someday die of cancer, as well (Table 5.1).
Sally experienced the pain of family members who succumbed to cancer, and she is fearful she will suffer the same fate and, like Gigi, Sally is overwhelmed with fear that she would not be around to support her children. She said:

It’s kind of one of those fears, too, because of the huge cancer history in the family and having three kids and I’m like, oh, my gosh, I felt like either I go ahead and go through these surgeries or not. And then, of course, it’s that possibility of the cancer showing up. And I guess in my mind, it was not a matter of “if,” it was a matter of “when.”

In addition to the overwhelming fear of death and not being around to be able to take care of her children, is the anxious feeling that cancer is going to show up and kill her no matter what she does.

Pam also experienced debilitating anxiety due to HBOC.

There’s a lot of mixed emotion and there’s definitely a lot of fear and anxiety, so I don’t sleep as well as I used to. There’s a lot of anxiety that comes with knowing that I don’t want to say, your days are numbered.

Pam’s fear and anxiety are physically affecting her health. Worry is keeping her awake and not allowing her to get adequate sleep. She is overwhelmed with the knowledge and believes that discovering that she is a carrier of a BRCA gene mutation is equivalent to telling her that she is certain to die of breast or ovarian cancer no matter what prophylactic measures she decides to take.

**Complicating action as the fourth plot element.** Genetic testing revealed they were carriers. As a direct result of the initiating action of either losing a loved one to breast or ovarian cancer or discovering that an immediate relative carried a genetic mutation that greatly increases their chance of breast, ovarian or other cancers, each of the participating women chose to have genetic testing done. Some opted for genetic testing as soon as they found out they had a 50/50 chance to be a carrier, while others waited years, and sometimes even decades, to undergo
genetic testing. In all situations, they came face-to-face with the knowledge and reality that what killed their loved ones, would most likely attempt to kill them as well.

**Topical theme: increased fear of cancer and death from cancer.** With the direct knowledge that they could be at risk for HBOC, the participating women expressed an increased fear that there was a very high probability that they would die of cancer.

Alisha’s half-sister, Pam, died of ovarian cancer. Within a few months, Alisha had genetic testing done and was told she was positive for a BRCA gene mutation. Coincidentally, the timing coincided with Angelina Jolie’s public announcement about her own genetic testing story. “I did not want to hear it because, frankly, I didn’t give a rat’s ass about Angelina Jolie, and was right in the middle of my work day, and now I was going to die, just like Pam,” she said.

The phrase “don’t give a rat’s ass” is a vulgar and angry way of expressing very minimum amount or degree of care or interest. Thus, Alisha redirects her anger to the coincidental announcement of Angelina Jolie’s BRCA genetic testing and positive result. The anger and blame stem from her amplified fear of death from cancer, just like her sister.

Annie, 40, has two children, and had just watched her female cousin, who was the same age and also had young children, die of breast cancer. She said:

I had a 2-year-old and my oldest was 14, and my cousin just died and her kids had to go to another family member to live. It basically came down to I want to be around for my kids and if I do get cancer, I don’t want them to go through watching me suffer through the treatment.

With the recent cancer-related death of her cousin, Annie found herself fearful that she too would be diagnosed with cancer that in her experience always leads to death. And, on top of the fear of death was the angst and anxiety of leaving behind her young children to live a life without their mother, just like Annie’s sister’s children were left behind.
As underlying subthemes, many participants expressed a feeling of guilt when they realized that that may have potentially passed this on to their children; in addition to the overwhelming stress—not just in passing on the mutation, but actually in all aspects of being a carrier (Table 5.1).

Mary is 37, originally from Canada, and now living in New York. About two years ago, her sister, who lives in Poland, was diagnosed with breast cancer just before turning 41. At the same time, Mary’s female cousin, who was in her late 40s, was also diagnosed with breast cancer. Mary’s sister and cousin had genetic testing done to discover they are both positive for a genetic mutation that greatly increasing their risk of some cancers. She stated:

Once my sister found that she was positive (for the genetic mutation), I kind of started assuming that I probably will be too. I just had a feeling that that’s what it’s going to be, 50-50 chance. I was really distressed. The first few weeks when I was waiting for the results, that was very, very stressful, like to the point that I was just throwing up (from) being so stressed out. And once I got my (positive) results, it was stressful too.

Mary’s distress began with her wait for the genetic testing results and was followed with the stress in decision making after the results evidenced the BRCA gene mutation. Her anxiety was so intense that it caused repeated vomiting.

**High point as the fifth plot element.** Genetic testing and learning the result of the genetic testing, are only the beginning stages of the difficult decisions that the participants faced. The next step was what to do with that knowledge. The prophylactic choices offered an opportunity to outrun a cancer that may never come. What actions should she take to lessen the percentage of risk for breast, ovarian and other cancers, and lead as close to a normal life as possible.

**Topical theme: anxious to make the “right” decision.** When each participating woman was faced with the knowledge that they are positive for a genetic mutation that greatly increases their risks for breast, ovarian, and other cancers, they have decisions to make in regard to
proactive measures that they can take to lessen that risk. Most of the women participating in this study opted for a double mastectomy, reconstruction and an oophorectomy, to remove their ovaries and fallopian tubes. They could have chosen other options including surveillance, or screenings, every six months via mammograms or MRIs, and then taking action if cancer appears. In most cases, the women were not interested in “waiting for cancer to show up.”

Jen, 27, even though she has not gone through the prophylactic surgeries just yet, plans to after she decides if she would like to give birth to children. “I’m not going to do screenings forever. I would much rather not have time bombs on my chest, then have cancer and then get a bilateral mastectomy. I’m not interested in that.”

Jen uses the metaphor that her breasts are like “ticking time bombs” to her. The phrase ticking time bomb refers to a person, thing or situation that at any moment can cause much havoc and result in a disastrous outcome, in this case particularly death. She is anxious because she knows that if she does not make the right choice, her chances of breast cancer (or ovarian cancer) are almost certain. And if she waits, that certainty of breast cancer could happen at any moment; in other words, she could wake up tomorrow with breast cancer. This is difficult waiting game as she balances the desire to have children and the dread that cancer will come, although when is unknown.

Alisha used the same wording when she found out that she too was positive for a genetic mutation for HBOC.

I was a ticking time bomb for this. And that’s all I felt like, a ticking time bomb. Like when am I going to get the bad news? When is it not going to be a good MRI or whatever? mammograms? So, you just sit here waiting? And then, you’re always waiting. I mean, it’s not anything positive, that’s for sure. It’s kind of gloomy and doomy.

In the same vein as Jen, Alisha also refers to herself as a ticking time bomb, wondering when she was going to be told that she has breast cancer or ovarian, or any of the other cancers
that come with being a carrier of the BRCA gene mutation. The sense is that she is always waiting for bad news, a cloud of gloom hangs over her. Her doom, a feeling that the situation is without any hope for a positive outcome, stays with her as she struggles to choose between two abhorrent choices.

This overarching feeling that life is bad and it could get worse at any minute leaves Jen and Alisha in a constant state of anxiety, particularly over making the right decisions to avoid the inevitable cancer.

Pam, 53, lives on a sailboat off the island of St. Thomas in the Virgin Islands. Her mother died of cancer in 1991 and Pam’s sister is currently battling cancer. Pam’s own positive genetic testing results pushed her to choose to have a double mastectomy. She opted not to have reconstruction. “You know, it’s still hard to look in the mirror, and we’re almost two years later, it’s so bizarre. It’s just a daily reminder.”

Pam says she wears padded bras or tank tops with built in padding because every time she sees herself—more so, sees her flat chest, where her breasts used to reside—it is a constant reminder of her situation, a situation which she categorizes as difficult, sad, and that makes her angry. She is sad that she lost her mother to breast cancer. She is angry that her sister is currently battling what seems like a losing breast cancer. And her physical appearance has changed because she opted for the double mastectomy and no reconstruction, as her choice to combat what seems like the inevitable—breast cancer. But, although she took such drastic measures to greatly lessen her increased chance of breast cancer, Pam still feels grief over the loss of her body parts—her breasts. She’s also anxious and concerned about whether or not she will ever really feel comfortable without breasts.
As underlying subthemes, such permanent and brutal surgery versus the anxiety-induced act of surveillance were top of the list, as well as the choice of bearing children or no children were on the participants’ minds (Table 5.1).

Gigi is 72. She too opted for no reconstruction but agrees it’s difficult to look in the mirror some days. “They worked for three kids. I [was] 69 years old. Why do I need boobs? I used to think, oh my God, everybody stares, but they don’t really look.” Like Pam, Gigi opted for no reconstruction, but, also like Pam, seeing herself in a mirror is a daily reminder of lost loved ones, close relatives currently battling cancer, her own mortality, and the choice she made to pursue a surgery that removed her breasts. She also raised concern regarding her own insecurities of how she looks without breasts.

For Jen,

The real bottom-line issue this brought up for me is the procreation issue. As much as I say, I was relieved when I found out that I had the mutation, there was this element of incredible frustration. My wife and I, we always talked about getting pregnant as a team. We each wanted to carry one child. So, then to get a diagnosis, and to be certain that I was positive, was kind of like a sledgehammer. It just made everything more complicated.

A sledgehammer is a large, powerful, heavy hammer with a long handle used for breaking up rocks and concrete. When people say, news hit them like a sledgehammer, it means they were so shocked by the news, that it figuratively destroyed them, like a sledgehammer destroys concrete, with no possibility for mending.

This is how Jen describes her emotions after learning the news of being a carrier for a BRCA gene mutation. She feels anxious, angry, sad all rolled under the umbrella that life is bad, and this news is devastating, devastating enough to destroy her mentally, and her body physically.

**Resolution strategies as the sixth plot element.** The action(s) of participating women discovering they were positive for the gene mutation that causes an increase in the risk of breast
and ovarian cancer, faced them with choices that they could make to reduce their risk to that of 
someone without the mutation. Most of the participating women chose a double mastectomy 
with reconstruction, and an oophorectomy, in some cases a hysterectomy. Two women chose not 
to have reconstruction after the mastectomy, and two chose surveillance, which means 
monitoring every six months. No matter their choice, these actions are body-altering physically, 
as well as altering the way a female body typically works, which is to use the ovaries to help 
create a child, and the breasts to feed the child.

*Topical theme: difficult procedures and recovery.* Marissa is 47 and lives in California.

I was pretty solid on what I was going to do. I told my doctor, if this comes back (positive) 
do whatever you have to my body. I have a 7 year old to be around for. I feel it was the 
right course of action for me, (but) I’ve been frustrated with recovery and that process, . . . 
I personally wasn’t sure I wanted to do reconstruction and putting in implants. I’m not the 
kind of person who would have gone to get a boob job. ... I used to refer to my boobs as 
“the girls” and so they were the girls and then they became the strangers after my first 
surgery.

While these difficult procedures drastically reduce the risk of breast and ovarian cancer, 
they are also brutal procedures that mutilate participants’ bodies, leaving them unrecognizable, 
which not only affects the women physically, but also emotionally and mentally, most often 
formulating negative self-images of oneself.

For Marissa, the reconstruction of her breasts left her feeling like she didn’t even 
recognize them as hers. This experience of disembodiment, the loss of breasts to call her own, 
the sadness for loss of “the girls,” stages these new breasts as not a part of her, hence, “the 
strangers.”

Betsy, a 34-year-old Ashkenazi Jew living in Montana, decided to have a double 
mastectomy and oophorectomy. After her mastectomy surgery, she woke with mastectomy pain 
syndrome.
They damaged my nerves. So, I have been on opioids since my surgery and my quality of life is like, right now I’m sitting in bed. I’m in an incredible amount of chronic pain . . . I really can’t even put that into words. I’m going through menopause. So that is shitty. I’m 34, and I’m on hormone replacement therapy, but it’s clearly not the right concoction because I’m always having hot flashes, it’s just a struggle. I was in so much pain every single day that I was put on suicide watch like it was just like I couldn’t even be in my own body. I was in so much pain and it never ever went away for one minute. It’s just like a bad dream. It’s called an iron bra. They damaged the nerves on my chest wall.

So for Betsy, her surgical double mastectomy procedure resulting in damaging the nerves of her chest wall. She is in constant excruciating pain, including side effects of weakness, tightness, or pain in the shoulder, muscle loss in the chest wall, muscle spasms, and trouble taking a deep breath, which is all compared to the sensation of wearing an “iron bra” the pain so severe that she was put on suicide watch. This is cry of desperation and despair. For her, the surgery she chose to reduce her risk of breast cancer resulted in a lifelong battle with pain. Her anguish that she traded one heart break for another, is palpable.

As underlying subthemes, lifelong consequences were at the top (see Table 5.1).

Alexa, 28, from Indiana, said:

It’s still a surgery and a loss and so I’ve had to go through that, and there were tough days where I was either really anxious or really sad or mad that I have to do this. Like this is my best option and other people don’t have to.

Alexa expresses that, overall, she had grief from her loss of her breasts, as well as anxiety, sadness and anger. Throughout her surgeries and recovery, she goes through the gamut of emotions, sometimes sad, sometimes grief-stricken, sometimes angry, and each day can bring a new layer of despair.

**The ending as the seventh plot element.** This is a settling of the main plot conflict without the need to resolve it. No matter what, the participating women had to come to the realization that they will live as a carrier for the rest of their lives. They need to understand their
risks, share their risks with family and cope with their decisions and consequences. This left them all trying to figure how to cope and advocate.

**Topical theme: living with this knowledge, and as underlying subthemes, coping and advocating.** Sally, 38, from Michigan, said:

Sometimes it’s hard for a woman, I think, because that’s (breasts) what we define ourselves as. ... I feel like I’ve kind of been that advocate, there’s a couple other cousins who didn’t get tested. And then once I tested positive, I’m working with them. So, there’s a small, extra support because of our same diagnosis. I have a couple of cousins who are a couple years older than me, but they also tested positive and they’ve been pushing off the surgeries. I told them, “don’t focus on the back end part, but what you’re actually doing for you and your family.”

Alexa was actually one of the pioneers in her family for genetic testing: “Gathering the information was kind of hard, especially since I was the first one to be doing any of this, and in my family, some people are still not wanting to talk about it,”

Obligation emerges late in the narratives of each of the participants. It was a sense of taking care of themselves first, and then the sense that this is hereditary, second. The obligation begins with self, then stretches to their children, then to the other biological family members who could be affected. Thus, living with the knowledge develops coping strategies, but also ways of advocating. And, after advocating for self, they are able to think beyond self, to other family members potentially affected by HBOC.

**The coda, or reflection, as the eighth plot element.** This is the reflection on the entire narrative, the moral of the story—or transformation realized—and what this journey as a whole has done for the individual, for the family and for others in similar life stories. Some of the participants said that through their realized transformation, they now felt a sense of bravery, pride, empowerment, and even like a self-described trailblazer, navigating the way for others, particularly as an advocate for family. In most of these cases, while the participants were not technically volunteer trailblazers, they did indeed feel proud and brave to be considered such.
And, although it did not improve or negate their own hereditary situation, it did give them reason to change the fate of their futures and their family’s futures, as well.

**Topical theme: how do they feel about themselves?** Alexa knows that her journey is not over, but she also knows she’s come a long way since finding out she is a carrier. She said:

> I feel more brave than I’ve ever been. I feel a lot better about myself doing this. For me, it just put a lot of things in perspective, I think for me it’s been hard. It’s been hard because I feel like I’m the only one in my family. I’ve been the first one to do this. I feel like a pioneer and that’s not easy, but I’m proud of myself for doing it. So, it’s kind of a positive empowering thing.

Within this eighth plot element, the coda, participants are beginning to feel uplifted and empowered, and like a pioneer or trailblazer for themselves and their family with new knowledge and important information that comes with a difficult journey. When they are first informed that they are carriers of the gene mutation, they are overwhelmed with desperation, depression, anxiety, loss, sadness, anger and more, but when they finally make it over, even a small hurdle, they almost feel a sense of pride and strength in themselves. In some cases, their confidence is boosted, as is the way they understood themselves and their viewpoint on life, along with a better understanding of the way they look at the importance of powerful life happenings.

**Summary of Analyses**

Figure 5.1 is a summary of the analyses presented as a mindmap, using a freeware application called Coggle (n.d.). It draws the paths from plot line elements, to topical themes, to underlying subthemes, that all spell out the depth of the psychological implications of participants affected by HBOC.
Figure 5.1. Coggle (mind map) of plot elements, themes, and subthemes derived from the stories.
This figure starts in the middle and arcs or moves in a circle, clockwise motion, but because of the stability of the center, participants can go back to the center at any time they are experiencing any other parts of the elements of their story, and continue to flow around the circle. As participants move from a state of overwhelmed to a sense of agency, the movement and the rhythm across help the narrative to flow, identifying the points, elements, offering descriptions, themes and metaphors that emerged. The beauty of this flow summary is that it actually summarizes the similar arcs of the stories by winding readers around the varied plot analysis themes, in addition, it suggests that things are not necessarily always linear.

One example is the woman who initially volunteered to be a participant in the study, but then reached back out to me to tell me that was just diagnosed with breast cancer, which now meant she was ineligible for the study. “Hi Cammi, sorry it took me so long to get back to you; an unexpected development has occurred that might make me ineligible for your study. I was just diagnosed with breast cancer. Shocking, to say the least, considering I had a prophylactic mastectomy eight years ago. Let me know if you can still use my story. If not, I’m so sorry” (Anonymous, personal communication, February 6, 2019).

I replicated the discoveries above by using metaphors, themes, and subthemes in a descriptive way, with each part taking on a very specific purpose. Begin with the first element, (the violet-colored rounded rectangle) that describes the characters as previvors, and they are all narrating their own experiences to tell their own story. They are all female, they all have a family history of HBOC, and they have all discovered, through genetic testing, that they are carriers of a genetic mutation that drastically increases their lifetime chance of breast, ovarian and other cancers. The second element concerns the setting in which the participants shared their experiences, which turned into their stories, which were all shared from the comfort of their own
homes, some via telephone, and others via video call.

The third element (yellow rounded rectangle, marked 3) participants move through highlighting their initiating action, which in this case, is that at least one immediate family member succumbed to breast or ovarian cancer, or are a survivor of breast or ovarian cancer and subsequently learned that they are a carrier of a genetic mutation that increases their chance of breast, ovarian and other cancers. This brings about an initial fear that they could be carriers too, immense sadness for family who has succumb to cancer, and/or those family members who are carriers, an overwhelming feeling, and a sense of anger, including about why them and why their family.

In the fourth element of the flow, participants delved into their complicating action, which in these cases was the fact that through genetic testing, it was revealed that they too are positive for being carriers of a genetic mutation that greatly increases their chances of breast, ovarian, or other cancers. This creates a sense of reality setting in, an increased fear of death, guilt that they could pass the mutation onto their children, and the emotional stress of making proactive decisions in an effort to save their lives.

The fifth element describes the high point or turning point which delves into the act of the decision of actions to prevent potential cancer. This includes the choice of a potentially barbaric surgery vs surveillance, intense anxiety to make the “right” decision, as well as a decision of children versus being unable to have children.

The sixth element describes the resolution strategy, which in these cases is prophylactic surgeries and recovery, and the permanency and lifelong journey when the participants discover they are carriers.
The seventh is the end result, which is learning to live with this knowledge, and the participants way of coping, as well as advocacy, for self, then children, then other family members who are potential carriers as well.

Lastly is coda reflection or transformation the realization about self, which in the cases of these participants includes bravery, a sense of being a trailblazer, self-pride and self-empowerment.

**Commonplaces**

During the interview the stories followed an organic reflexive process as the women retold their lived experiences. The use of plot and thematic analysis revealed significant meaning for the participating previvors and encouraged me to consider and study my own experience throughout the inquiry. The commonplaces approach, as described by Clandinin and Connelly (2000), provided a conceptual framework to understand the co-construction of meaning through their stories and my reflexive process, thus holding the unfolding meaning between previvors’ and me as a researcher and previvor. Clandinin & Connelly discussed using commonplaces of narrative inquiry as a way of understanding and inquiring into experience through “collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieu” (p. 20).

Through attending to the commonplaces of temporality, sociality, and place, I was able to study the complexity of the relational composition of each previvor’s lived experiences, both inside and outside of an inquiry, drawing correlations between the participants’ stories, conveying empathy of their experiences and imagining the future possibilities.

**Temporality.** “Events under study are in temporal transition” (Connelly & Clandinin, 2006, p. 479), using time and its association to experience. Temporality serves as the
commonplace holder of time in narrative inquiry. For the previvors telling their stories, at the time of the interview, the time is situated in the past, because that’s when the experience occurred. The previvors are telling their recollection of their past experience in the present, as well as predicting a potential future or outcome. Once they share their experience, it becomes their story.

The elements of the story, like characters and setting, all influence the previvors’ reflection, remembering, re-telling, which in turn affects the previvor, as well as the interviewer and even future readers.

Temporality reminds me of my own BRCA2 positive status, and the connection with the women of this study because my memories tend to be similarly structured around the overarching HBOC theme, with comparable transitions and stepping stones like loved ones succumbing to breast or ovarian cancer. I traveled down a similar path of decision making for myself, and my family members; I was being held up as a trailblazer, particularly within my family members. Listening to the participants’ stories, and the constant triggering of my own memories, left me feeling emotionally drained, that I needed to do more, but more how? —or what? And, because I was at another turning point in my journey, I wondered if the burden of being a previvor ever really ends. Or, as one participant commented, it’s a never-ending story. A few years ago, I decided to write a type of memoir of my experiences. I was never quite satisfied with the ending, and I couldn’t quite understand why. Although it was a powerful ending, in the true essence of the word, it wasn’t the end. There have been so many additional chapters to add that since my initial writing yet they are not the ending—indeed it is a never-ending story.

**Sociality.** Narrative inquirers attend to both personal conditions and, simultaneously, to social conditions. By personal conditions, “we mean the feelings, hopes, desires, aesthetic
reactions and moral dispositions” (Connelly & Clandinin, 2006, p. 480) of the inquirer and participants.

As for social condition, which is the situation one has in society because of their income, occupation, or education, there were no commonalities. Even the one commonality of being of Ashkenazi Jewish descent (which drastically increases the chance of carrying one of three BRCA founder mutations), was not prevalent across the board with all participants.

When considering sociality within narrative inquiry, each previvor has similar feelings and hopes and desires as they consider their future. They are in a situation by no fault of their own, as they inherited this mutation, yet they find themselves taking drastic measures to change their almost certain fate. They struggle with their own mortality, they suffer with the overwhelming guilt of potentially passing this gene onto their children. Yet the social arena in which they lived was similar among all the participants in the fact of living in a social arena where, when they discovered they inherited a BRCA gene mutation, they had all already experienced the loss of members of the family who had succumbed to breast or ovarian cancer. And, because of this particular commonality, their decisions were critical and, in most cases, directly related to their understanding of choices they made.

My own sociality is similar. I’ve lost my maternal grandmother, maternal aunts, and a maternal male cousin. In addition, my own mother, who lives with me and is my dependent, was diagnosed with breast cancer—fortunately, she won her battle. And, I also feel a tremendous amount of guilt for unknowingly passing on a gene mutation to my own daughter that increases her chances of having to battle breast cancer.

**Place.** Connelly and Clandinin (2006) define place as “the specific concrete, physical and topological boundaries of place or sequences of places where the inquiry and events take place”
(p. 480). The key to this commonplace is recognizing that “all events take place some place” (p. 481).

The original setting of the participants’ stories was in varied places from their homes, to their place of work, to the doctor’s office and more. And, in most cases, the different experiences from discovery to decisions that made up their stories took place in different settings, often with different people. For example, the moment that Jen learned the truth about being an HBOC carrier, she and her wife were sitting in their bedroom in a little apartment in Jackson, Michigan. Jen’s mother was listening on speaker on one cell phone, and a representative from Color, a physician-supported access to genetic testing company, was on speaker on another cell phone.

The first thing that I remember is when she said, “you’re positive,” I just felt almost a sense of nothingness, because it was just like, duh, yeah. Then, I immediately felt a sense of relief because I knew a little bit about my options already. And now that I have the tangible evidence of what I’ve always kind of assumed, I can start taking action.

The participants’ retelling of their experiences, predominantly took place over the phone although there were two that took place on video chats. This physical state of being able to see the person via video created a connection that heightened the interview experience. I could see the expression on their faces, the inflection in their voices, and their body language, as well as their surroundings. And, of course, vice versa, they could see me, hear me, and capture my surroundings. I was conscious of creating what I hoped was a welcoming, calm, safe place to share their story, further enhancing the experience for both of us.

On my end, the interviews took place in one of two places, either in a quiet conference room at Florida Atlantic University, or from my home office. Both settings are free from interruption and create an environment that allows me to devote undivided attention to the participant.
I remember that participant Jen sat on her bed while we chatted via video conference, and her laptop was on her lap. The lighting was a bit dim, with soft light from lamp on the nightstand to the left of her. As she shifted positions, leaning forward or backward, her long brown hair would often fall to and from the side of her face, making way for the soft lamp light to shine on her cheek. She was a confident-speaking young woman who knew what she wanted, but also acknowledged the obstacles life put in the way to getting there, using her head and heart to find a way.

Settings like this allowed the retelling of their story to come alive with emotion and finding commonality in the fact that all stories happen in “some place.” And, finding the right place for a story to happen, as well as the retelling of their story, can often make a difference in every aspect of the outcome from the reaction, the lens, the memory, and much more.

Jen brought me into her personal story by opening up her setting to me as she retold her story—which spanned more than 20 years, starting with her grandmother’s breast cancer diagnosis when Jen was only 6 years old.

I found myself reflecting on parallel aspects of our lives, including the heartbreak and grief of losing someone we loved, the stubbornness to be proactive, the self-driven mission to be an advocate, and the worry for the future, my own and the future of my family, legacy, and the hope to lead the change for a world where HBOC is no longer a death sentence filled with drama, emotion, and pain, but, instead it’s curable, or at least much more manageable.

**Checking on the Retelling Experience**

Through the participants’ anonymous responses to the inclusion of their experience of interviewing and telling their story, I was able to open up dialogue and give them the opportunity
to inform me if the interview had been beneficial and harmful. It was unanimous that they found the process either extremely beneficial or somewhat beneficial.

For those who described the experience to extremely beneficial, they further elaborated in the following comments:

• Feels good to say it aloud. I think that I am so accustomed to my reality just living day-to-day that it’s easy to forget the magnitude of all I have been through. Telling someone else was a reminder to me that I have been through a lot and to not be so hard on myself.

• It is cathartic and always beneficial to process by conversing.

• I believe sharing my experience is healing for myself and others.

• Sometimes it’s easy to focus on the things you can see instead of the things you can’t see. I see the deformities on my chest, I feel the discomforts of my new body parts but I don’t see how I have changed my future. I have to keep the correct focus on why I made those choices. By sharing my story, I feel I am able to remind myself of the importance of prevention and educating those that may not know. My experiences have helped others determine if they should be tested and if a positive test comes back, what those suggested surgeries mean. It feels good to know that I have impacted others’ lives in a positive manner, and to take ownership of one’s own health. Knowledge is power and I think sharing my story and the knowledge I know, can help make differences in the future of not only myself but others. Thanks for listening to my story!

• I have found that telling my story has been a great coping skill for me throughout this process.
• For those participants who described the experience as somewhat beneficial, they further emphasized this with the following comments:

• I will always share my story if it means I can help others.

• I hope it will be helpful.

• I have shared my story many times. I really do like the idea of helping others through similar journeys. But perhaps, since I have told this story many times before, it feels slightly less beneficial than when it was fresher for me.

• It makes me feel good to help others and if by sharing my experience someone else can benefit then it’s a win-win.

• I have found that telling my story has been a great coping skill for me throughout this process.

Comments like these hit home with the message that telling one’s story has a profound healing effect and brings full circle the founding aspects of narrative medicine. And, sharing experiences can help find meaning even in the most painful events and gain a greater sense of purpose and direction. Often, many survivors of trauma or violence become active in movements focused on prevention and helping others who have had similar experiences. This is often a key part of their healing process. Similarly, many former alcoholics and addicts become sponsors in Alcoholics Anonymous or substance abuse counselors and use their own past to help others avoid similar fates.

Also, sometimes you learn things about yourself from the act of writing or storytelling that helps to clarify the things (and people) that matter most to you. People who have found their voice shared their story and reaffirmed their values often find a sense of peace and a hopefulness that they did not have before.
Chapter VI: Discussion

I’ve grown up knowing that my grandma got breast cancer early (young) and so I have always had it in the back of my mind; this is my deadline.

–Alexa (2019)

Connelly and Clandinin (2000) encourage narrative inquirers to understand and to learn from differing epistemological and ontological assumptions to help strengthen the future of narrative research. Through engaging with participants, narrative inquirers are able to use the participants’ stories to more clearly define and change practices by looking at stories through the participants’ lens and ultimately understanding new ways and greater possibilities of connection and social change. By using narrative inquiry, I was able to enter the lives of each previvor interviewed, drawing attention to the importance of acknowledging the essence of the ongoing experience as expressed in story. Through the interview, previvors shared their lived experiences, offering a heartfelt vision of the HBOC journey and revealing the powerful psychological effects of living with HBOC. As noted in Chapter II, there is a paucity of literature on the psychological effects HBOC, thus reducing the opportunity to compare the key findings of this study to specifically relevant research studies. Nonetheless, this study was undertaken primarily to advise practitioners and healthcare professionals of the felt experience of living with HBOC and to consider these findings in light of medical and educational practices currently employed. This chapter will focus on the implications for leadership and practice and examine key findings to available literature in the field.

Discussion of Key Findings

Through the narrative inquiry of the previvor participants, I discovered several key findings that include: the importance of studying the arc of the previvors story to uncover pertinent, telling information regarding their journey and their healthcare needs; the greater the
family history of breast and/or ovarian cancer, the more proactive in the decision making process; the immense sense of guilt when passing gene mutation on to children; the powerful and psychological impact that accompanies losing one’s breasts; the ambivalence and conflicting reactions to reconstructive surgery based on the stage in life; the value of the story-sharing experience; and the sense of empowerment and advocacy.

**Previvors’ story arc.** The arc of previvors’ stories has never been studied. This research serves as a vital study to uncover pertinent, telling information regarding their journey and their healthcare needs to better care for their emotional and psychological needs, instead of just their physical treatment.

**Proactive decision-making.** If someone has a close relative like a mother or sister who succumbs to breast and/or ovarian cancer, it is more likely they are to be proactive in their decision-making process, ultimately taking drastic risk-reducing steps to prevent cancer. For example, Alexa was adamant about being prophylactic because she had watched her grandmother battle breast cancer. “I’ve grown up knowing that my grandma got breast cancer early (young) and so I have always had it in the back of my mind; this is my deadline.”

It appears the fear of the same thing happening to them, drives previvors to make the critical decision to change their fate. This feeds their “knowledge is power” mindset. With the knowledge of what happened to family members, coupled with the knowledge that they too are carriers of the genetic mutation, they now have control to change their risk of breast, ovarian and other cancers. Ultimately, this moves them from a sense of powerless, to empowered.

**Guilt.** There was overwhelming guilt parents felt about passing along the mutation to their own children. Although it is no fault of their own, along with the fear of succumbing to cancer, the greatest amount of emotion was expressed in the realization that their children may
have to go through the same trauma if they carried the gene. Not only would she be succumbing to cancer, the mother would not be around to take care of her children. For example, in Danielle’s interview, she paused to cry as she told me that her daughter is positive and the struggles her daughter has gone through with her risk-reducing prophylactic decisions. “I’m crying about her experience because it was so much harder than mine and I felt so badly,” she said.

In contrast, Alisha’s daughter was so angry when she tested positive for the mutation that she wouldn’t speak to her mother for years. “She was very angry and upset with me. I actually don’t blame her because I kind of was, I felt the same thing,” Alisha said.

I was very sad. There was nothing I could do, it was this genetic thing. I’m not in control of that, especially since I didn’t really have a relationship with my (own biological) father at all. That made it even worse. I mean, I listened to her, and I knew what she was feeling, exactly what she was feeling.

And, even before Marissa’s genetic testing results came back positive, she told her doctor, “if this comes back [positive] do whatever you have to do to my body. I have a 7-year-old to be around for.”

It appears that the mindset of knowing that they are responsible for passing this hereditary gene mutation on to their children—although not done with malice or intent—gives mutation carriers a great and overwhelming sense of anxiety and guilt. There is the conflict between motherly instinct to protect their children from any harm and the fact that they are the reason their child has such a mutation that could ultimately be the cause of her death.

**Losing one’s breasts.** The participants conveyed powerful narrative, including extreme metaphors and descriptive psychological impact when sharing their experience and feelings surrounding the loss of their breasts, and, in some cases, their regard for their “new” breasts, that they felt separate from or a sense of disembodiment. For example, Marissa said:
I personally wasn’t sure I wanted to do reconstruction and putting in implants. I’m not the kind of person who would have gone to get a boob job. ... I used to refer to my boobs as the girls and so they were the girls and then they became the strangers after my first surgery.

And, for Pam—she opted not to have reconstruction, and still feels grief over the loss of her breasts. The decision was difficult, she says, and it still haunts her some days, and she wonders if she will ever really feel comfortable without breasts.

I just felt this late in my life, it’s just not that important to me in my life. You know, it’s still hard to look at the mirror and we’re almost two years later, it’s so bizarre. It’s just a daily reminder.

Pam says she wears padded bras, or tank tops with built in padding because every time she sees herself—more so, sees her flat chest, where her breasts used to reside—it’s a constant reminder of her situation.

**Reconstruction ambivalence.** To reconstruct or not reconstruct, that is the question. And, not all answers or reactions were equal when it came to reconstruction. There were conflicting reactions, beliefs or feelings toward reconstructive surgery based on the participant’s stage in life.

Gigi, who is now 72 years old but was 69 when facing the reconstruction decision, said she felt like her breasts had served their purpose in her life. So, after consulting with her husband, she decided against reconstruction. “My husband and I made this decision,” she said. “They worked for three kids. I’m 69 years old. Why do I need boobs?”

**Value of retelling.** In addition to the interview, participants were asked to take part in an anonymous one-question Likert-type scale survey (Appendix E) in which 10 participated. Five rated the experience extremely beneficial, and five rated it somewhat beneficial.
The results supported the benefits of the story-sharing experience. While their stories take us down different paths, with a variety of characters and settings, they all have one thing in common, and these previvors have found strength and purpose by sharing their experiences.

In addition, more often than not, sharing our experiences with others is also empowering and can help light the way for those who are walking a similar path, as well as those who are helping others on a parallel journey to heal and move on to a positive moral, ending, or coda. Nonetheless, sharing our stories also takes a tremendous amount of courage. It means letting go of the carefully crafted image of the person you believe you should be, in exchange for the unedited version. And, it means opening up yourself, your decisions and actions, and all that you’ve learned—mostly learned the hard way—to the potential judging of the ways and whys of your personal experiences.

**Empowerment.** Although most participants agreed this is an ongoing battle, another key finding was a sense of bravery, empowerment, and pride from within, knowing they acquired the knowledge and were proactive in doing something aggressive about potentially turning around their own handed-down fate. The feeling that they took matters into their own hands, led to self-described words such as brave, empowered, proud, trailblazer. For example, Alexa said:

> I feel more brave than I’ve ever been. I feel a lot better about myself doing this. For me, it just put a lot of things in perspective, I think for me it’s been hard. It’s been hard because I feel like I’m the only one in my family. I’ve been the first one to do this. I feel like a pioneer and that’s not easy, but I’m proud of myself for doing it. So, it’s kind of a positive empowering thing.

It appears that being a previvor is a complex matter that empathizes the trials and tribulations one had undergone knowing that they are mutation carrier. On the other side, it is also viewed as an accomplishment, in the sense of proactive measures, with previvors knowing they took steps to get ahead of a cancer diagnosis or reducing it altogether. Previvors also
considered themselves trailblazers, especially among their own family members, and their actions may have saved them from a cancer diagnosis.

Comparing Findings to Literature

As previously discussed, there are seven substantial findings gathered from the participants’ shared experiences in this study that corroborate with the literature, and offer more information to healthcare professionals, support groups, and previvors.

First, I have established that little is known about women’s views of the psychological outcomes of a BPM, a controversial cancer prevention strategy for women at high-risk of familial breast cancer, and studies to date have often been carried out on small (and, therefore, possible unrepresentative) samples (Hopwood et al., 2000). For example, in a single case report, Hopwood et al. (2000) reported that the patient revealed that her BPM surgery resulted in a loss of femininity and sexuality with considerable pain over a long recovery period. Hopwood et al. suggested that, while the one report is not enough to draw conclusions, the findings are disturbing.

The lack of knowledge of women’s views of being a HBOC carrier is due part to their story arc not being studied. This research serves as a vital study to uncover pertinent, telling information regarding their journey, and their healthcare needs to better care for their emotional and psychological needs, instead of just their physical needs.

In addition, in a qualitative discovery-orientated study Lloyd et al. (2000) interviewed 10 women who had undergone a prophylactic mastectomy, along with eight of their partners, with the aim of exploring the personal experiences of surgery, factors associated with psychological adjustment and the impact on the family. Information was transcribed and systematically analyzed using grounded theory. As mentioned in Chapter II, themes that represented women’s key experiences emerged like deciding, telling, experiencing surgery and recovering.
maintaining womanliness, processing the loss, moving on, and isolation and being supported (Lloyd et al., 2000).

Such literature validates the findings in my study regarding uncovering that, the more that women have a family history of breast and/or ovarian cancer, the more proactive they are in the decision-making process. The literature also supports my finding that previvors experience a tremendous amount of guilt when they unknowingly pass the gene mutation on to their own children.

In addition, psychological response may also be determined by how much the individual believes they had a choice in the decision-making process. The psychosocial ramifications may be different for women who felt they had a ‘forced choice’ as a result of genetic testing than those acting on the basis of greater uncertainty (Lloyd et al., 2000). But, this study helped bridge the gap in research and more fully explore the lived experiences of the psychosocial ramifications. For example, this work uncovered that most previvors feel a sense of advocacy after HBOC discovery, and a sense of empowerment when they take proactive steps to fight breast and or ovarian cancer before it arrives.

In another study that focused specifically on high-risk pre-menopausal women who had undergone prophylactic bilateral oophorectomy to manage their inherited risk of ovarian cancer, Hallowell (2000) discovered that “although the benefit of risk reduction was perceived as outweighing the costs of surgery, many women reported that they would have liked more information about the physical and emotional after-effects of oophorectomy prior to and following surgery” (p. 486). This qualitative study did in-depth interviews with 23 high-risk women following surgery and identified five types of information needed by women making surgical decisions: comprising information about ovarian function and menopause, hormone
replacement therapy (HRT), surgical procedures, convalescence, and the risk of inheriting a genetic mutation and developing cancer.

However, Hallowell (2000) did not address any potential psychosocial implication, as my findings uncovered that there are powerful psychological emotions that accompany losing one’s breasts. One participant in my study talked in detail about the terrible pain that she had after her surgical procedures and the long-time consequences. My research also highlighted the ambivalence and conflicting reactions to reconstructive surgery based on the stage in life, as well as the value of the story-sharing experience.

Summary

While few studies exist, the literature corroborates the findings of this study. These findings offer a road map for healthcare professionals to understand more fully and therefore better care for patients. Specifically, findings that are corroborated include: that the closer an affected relative, the more proactive the participant’s decisions; that there is overwhelming guilt over passing on to children; that there is a coming into a sense of bravery, empowerment, and pride with realization; and that there are invaluable benefits of the story-sharing experience.

In addition, this research added to the literature by using the arc of the story and the detailing of the emotion at different points in the story to uncover vital parts of their healthcare needs and their emotional and the psychological implications of discovering they are genetic mutation carriers. This information allows professionals and previvors to be prepared for the points of decision-making and the emotional turmoil.

Limitations of the Study

Stories are essentially individual recollections of human experience and have limitations of objectivity and representation. This study asked 14 women to tell their story of being a
previvor. There were a small number of stories gathered therefore calling into question the representation of these women’s experiences to others’ experiences. However, to strengthen the trustworthiness of the findings the stories were analyzed using three approaches to narrative inquiry-plotline analysis, thematic analysis and commonplaces thus ameliorating McMullen and Braithwaite’s (2013) concern that research labeled as narrative might be without any systematic narrative inquiry. Further, taking an analytical rather than a celebratory stance, as advised by Atkinson and Delamont (2006), McMullen and Braithwaite charged that “narratives are collected and celebrated in uncritical and analyzed fashion. Common weaknesses are researchers assuming that informants’ accounts ‘speak for themselves’ and also failing to acknowledge the social and cultural context of accounts given” (p. 166). In response to the latter failing of narrative, this study fully embraced the social and cultural context of the stories through the analysis of temporality, sociality, and place (Clandinin & Connelly, 2006).

A further possible limitation concerns the differing capacity and interest by people in relation to storytelling. There is an argument that not everyone may share the compulsion to weave their lives into a coherent study (Strawson, 2004). But in this study, there was considerable evidence that many women respond immediately to the call to share their story, and once interviewed, offered rich detail and accompanying emotion to describe their unique related experiences.

The third narrative inquiry limitation concerns accumulating knowledge, raising the question of how theory could be advanced without making it more real or losing the richness of the narrative (Josselson, 2006).

Counter to the above concerns or limitations, according to McMullen and Braithwaite (2013), is the knowledge that comes from narratives of rich, local, and particular studies of life.
They stated: “Narrative inquiry has significant scope to contribute to understandings of social (including organizational) life but it needs to be practiced in a manner that plays to its strengths rather than its limitations,” (p. 102). In this study, by using the previvors’ untold stories, I have maximized the richness of narrative inquiry for the purpose of this study.

There are significant limitations of this study given the inclusion criteria. Findings only relate to previvors, and not survivors, meaning they have never had cancer. Further study could include survivors extending knowledge to women who have had cancer as a result of BRAC+ gene and survived. In addition, there are also multiple genetic mutations that cause HBOC, but this study required that participants have a BRCA1 or 2 mutation, which are the most common, but not exclusive. Further study could include those with rarer genetic mutations and if their story differs or adds knowledge of these different diagnosis. Finally, the criteria I used also limit how recent or long ago a participant discovered they were a carrier. Future studies could include participants who discovered they were carriers greater than three years ago, and research if time affects their recollections of experiences.

**Implications for Leadership and Change**

Implications for leadership and change in this field are wide. There is great need for family clinicians to design and implement innovative research and treatment protocols to address the holistic experience of hereditary disease (McDaniel, 2005; Sobel & Cowan, 2003). This study offers an opportunity to link research and practice, highlighting the potential of the work to inform and improve healthcare practice available for an individual facing HBOC and their caregivers.

A rising number of people discovering they are genetic mutation carriers, are confronted with difficult decisions about management of risks that might include aggressive screening,
treatment regimens, and prophylactic surgery. The emotional challenges not only exist for the person with the genetic mutation, but also for that person’s children, significant other, and family members. It is vital that healthcare professionals are aware of the complex and special needs of this increasing population. Doing this means they must find out as much information about their past as possible, as this group includes people who carry a hereditary mutation, a family history of cancer, or some other predisposing factor. The term specifically applies to the portion of that community that has its own unique needs and concerns separate from the general population, but different from those already diagnosed with cancer.

With the increase in public awareness, healthcare professionals are also attending to a greater number of individuals, currently without cancer, who are considering cancer genetic testing, or have questions about results or options; therefore, they must be prepared to meet the mental health needs of this new population. Psychological challenges can occur throughout the process of genetic testing for cancer risk, from the beginning stages of discussions about referrals for testing, to medical decisions based on results.

The health care infrastructure also has its limits, given the severe shortage of qualified cancer genetic counselors and general practitioners who are unprepared to address genetics, creating a demand for creative approaches to service delivery. The combination of individual salience, low health literacy, the consumer movement, and important policy problems, then makes genomics the perfect information seeking research problem. (Johnson et al., 2005, p. 323)

This study played a role in advocating for the importance for narrative medicine to play a deeper understanding for healthcare professionals. This includes the need for part of the medical education to be concerned with the conditions under which medical residents engage in reflecting on their own clinical practice, which further deepens their understandings of the psychological implications of their patients living with HBOC.

Medical literature has demonstrated the effectiveness of narrative writing in enhancing self-reflection and empathy, which opens the door for deeper understanding of patients’
experiences of illness. Similarly, it promotes practitioner well-being. Therefore, it is no surprise that narrative writing finds a new home in medical education (Johna, Woodward, & Patel, 2014, p. 92).

Another implication for leadership and change is the recognition for healthcare professionals to implement such narrative medicine into their own clinical practice, allowing it to become an integral part of the of the treatment process. My research suggests that calling forth stories, as suggested by Charon (2006), results in a powerful transformation for patients, in this study particularly HBOC carriers. This is a crucial element that strengthens the connections and overall healing process. Narrative medicine is increasingly popular as a powerful tool that helps connect and create like bonds and supportive networks. Charon, the founder and executive director of the program in narrative medicine at Columbia University, said: “If sickness calls forth stories, then healing calls forth a benevolent willingness to be subject to them, subjects of them, and subjected to their transformative power” (p. 216).

Since stories convey values and emotions, and can reveal similarities between people’s experiences, sharing those experiences can help form bonds and supportive networks, which can help build resilience, particularly health-related. Charon (2006) posited that narrative medicine fortifies clinical practice with the knowledge of what to do with stories and how to be moved by them enough to act, both creatively and receptively. This medical approach can utilize people’s narratives in clinical practice, research, and education, stating that using narrative requires the ability to recognize, absorb, interpret, and act on the stories and plights of others.

In addition, the findings in this study identified additional examples that healthcare professionals and others can learn from, specifically related to the arc of the BRCA positive patient. The implications of these findings would require that the caregiver or medical professional would first need to know certain things about a patient, particularly their history related to HBOC. These are important findings because knowing the emotion that emerges at
various stages of the process will help healthcare professionals and support group leaders to anticipate the psychological needs of individuals based on the previvor’s point in the unfolding of events. One example of this is Pam,

There’s not a day that goes by, even though I took every step that I took to prevent my chances of that. But, there’s a lot of mixed emotion and there’s definitely a lot of fear and anxiety, so I don’t sleep as well as I used to. There’s a lot of anxiety that comes with knowing that I don’t want to say, your days are numbered. But I’m finding my way through it but I guess I’m learning, learning how to be more peaceful and to set aside the time to reflect, so hopefully it’s helping me grow.

In addition, one of the key findings here uncovered that the greater the family history, particularly if a patient has a close relative who has been affected by cancer or worst case scenario, in some cases they’ve succumbed to cancer, then the implication is that this patient is much more likely to be proactive in their care and decisions in regard to prophylactic surgeries versus surveillance. Nonetheless, women who test positive for BRCA1 or BRCA2 are also often met with resistance, shock, and other negative emotions from family members (Kenan, Arden-Jones, & Eeles, 2004). So, while the genetic testing may give women the knowledge they need to save their lives, this knowledge also comes with potential risks for other biological family members, causing additional stress on the carrier, as well as the family members.

In a study by Werner-Lin (2007), families frequently relied on multi-generational stories to make sense of the inherent ambiguity as they face medical decisions and navigate life’s journeys in relation women who carry a BRCA mutation. The findings revealed that beliefs about risk are more firmly grounded in family experiences with cancer than in biomedical research. Pervasive meanings included: the presence of “danger zones”—specific ages at which cancer risk was believed to increase dramatically—and the experience of “the wait and the worry,” in which participants felt increased urgency to achieve family development goals (e.g.,
child bearing) and limited control over relational factors influencing when these goals could be met (e.g., meeting a life partner).

The American Society of Clinical Oncology (2015) has said beyond the decision of whether or not to get genetic testing and to consider prophylactic steps to reduce risk, there are emotional implications throughout the entire process, including potential depression, anxiety, guilt, an increase sense of considering yourself sick, family tension, high cost, discrimination, privacy, unclear results, and more. For example, the carrier feels obligated to tell family members about test results, which could complicate family dynamics or they feel a sense of guilt if their own children inherit the mutation as well. In that realm, healthcare professionals should also be concerned with whether or not the patient has biological children. This study found the implication of passing the genetic mutation on to a child is a sense of overwhelming guilt—even though logically the hereditary gene cannot purposely be passed on to a child.

Participants also conveyed a powerful and psychologically emotional heartbreak, grief and loss over losing their breasts. Healthcare professionals should be aware of the potential feeling of disembodiment, particularly from the potentially newly reconstructed breast, or in some cases to the lack of breast or flat, deflated empty chest. In a similar vein, according to this research, patients will show ambivalence and conflicting reactions to reconstructive surgery based on the stage in life. The implications range from those who welcome reconstruction, although still struggle with the loss of their own breasts, to those who may opt for no reconstruction, maybe because of their age.

Overwhelming guilt also is an important risk factor for future distress include being the first member of the family to obtain genetic testing and having children (Meiser, 2005; Schlich-Bakker et al. 2007; van Oostrom et al., 2006). And, studies also show that managing and
acknowledging emotions surrounding a patient’s BRCA-related health decisions is in the top three advices offered to newly diagnosed previvors, from previously diagnosed previvors, (Rauscher & Dean, 2017). Additional advice from Rauscher and Dean (2017) included the importance of engaging in two-way dialogue with partners or spouses across the life span of the partnership and seeking information on new technologies and information regarding family-planning and genetic-cancer-prevention decision-making, as well as recognizing where to go for different support needs. This means that discovering one is a carrier is not the end of the conversation. There are decisions to be made throughout life. For example, if one finds out before child-bearing years, that there are choices in deciding not to have children or wait and have surgery after children. And, more often than not, if reconstruction of the breasts is involved, this may lead to multiple surgeries over a span of many years. Many health-related and lifestyle related choices exist at various ages throughout life that could be affected by this knowledge.

Also, uncovered through the process of sharing the experiences in this study, was that telling their stories held benefits that gave participants a sense of bravery, empowerment, and pride, particularly when the decision making was over, and the patient settled in with the realization of the permanency of their connection to HBOC. While this was intermittent, the implication gives the healthcare professional great hope to encourage the overall well-being of the patient.

Related to psychosocial genetics, there is great need for family clinicians to design and implement innovative research and treatment protocols to address the holistic experience of hereditary disease (McDaniel, 2005; Sobel & Cowan, 2003). Part of that holistic experience can include paying closer attention to an individual’s experience or their story of grief and loss of expectation. According to van Oostrom et al. (2006), their story is important because it may
affect the accuracy of their risk, perception, or outlook. Again, the study of the previvors’ story arc is vital in detailing the emotion at different points in the story to uncover important parts of their healthcare needs and the emotional and the psychological implications after discovering they are genetic mutation carriers.

Lastly, healthcare professionals also need to be aware of the implications of their patients receiving negative genetic testing results, as this may cause difficult emotions too. For example, some people may experience guilt if they do not have a gene mutation that other family members have. A negative result—which just means a specific genetic mutation is not present—may also give a false sense of security because people with negative results may still develop cancer. The negative result only means the person’s risk is average—which is still one out of eight for breast cancer.

In addition, an underlying theme running throughout each woman’s story here, was the complete helplessness of passing a life-altering mutation on to their children. For example, Alisha said:

When I was told about my test outcome I was devastated! It was honestly one of the worst days of my life. The second worst day was when my daughter told me she was BRCA positive . . . She blamed me.

This particular psychological implication needs to be further researched and to be a critical part of the healing process, where relevant.

It is important to note how prophylactic measures and reconstruction options have changed with time. Just as one example, in the brief five years since I have been identified as a carrier of HBOC, the Food and Drug Administration (FDA) identified an association between breast implants and the development of breast-implant associated anaplastic large cell lymphoma (BIA-ALCL), an uncommon cancer of the immune system (Center for Devices and Radiological Health U.S. Food and Drug Administration, 2011) The FDA believes that women with breast
implants that have textured surfaces have an increased risk of developing BIA-ALCL. I will
delve more into thus in my final reflexive comments.

While this research supports the fact that an effective practice of healthcare requires the
ability to recognize, interpret, and act on the stories and plights of others, it also enhances our
understanding of the role of narrative medicine, practiced with competence, as an important
aspect of humane and effective medical practice. Storytelling is an interdisciplinary field that
brings powerful narrative skills of radical listening and creativity from the humanities and the
arts. By doing so, it also addresses the needs of patients and caregivers to give them a venue
where they can voice their experiences, feel like they are being heard and valued. All of this
helps acknowledge and support the power of narrative to change the way care is given and
received.

This research is positioned to lead narrative efforts—particularly relative to the
psychological implications of those living with HBOC— in, for example, medical schools.
Programs that teach narrative medicine can help further develop, implement, and evaluate the
greatest impact of these programs on clinical practice and quality of care. In turn, healthcare
leaders early in their training will be equipped with skills to generate their own narrative work,
help to lead other practitioners and set and promote standards for all relative research work.

Narrative medicine, as a developing field, needs support from leaders in medical training
to equip upcoming healthcare professionals with powerful narrative tools to help patients
understand their own story of illness, healing, and recovery. Ultimately these leaders can change
the meaning of quality care and the role of all healthcare providers in the significance of story in
humane, individualized, and meaningful care.
Conclusions

In conclusion, my study shows the importance of the previvors’ story arc in providing the healthcare professionals with the vital details of the emotion at different points in their story. This vital information assists healthcare professionals in recognizing the emotional needs and the psychological implications of their patients after their patients discover they are genetic mutation carriers for HBOC.

Related to psychosocial genetics, there is great need for family clinicians to design and implement innovative research and treatment protocols to address the holistic experience of hereditary disease (McDaniel, 2005; Sobel & Cowan, 2003). Part of that holistic experience can include paying closer attention to an individual’s experience or their story of grief and loss of expectation. According to van Oostrom et al. (2006), their story is important because it may affect the accuracy of their risk, perception, or outlook.

Final Reflexive Comments

This section includes my closing reflections on my experience with the process, what was learned from this research, how this research changed me as a person, a scholar-practitioner, and as a professional working as a leader to encourage positive change.

For several days after I posted my solicitation for participants, my inbox flooded with tidbits of stories from women interested in being a part of the study. As I read their emailed inquiries, I could sense their ache to share their story, to express their pain over lost loved ones, family members, and the worry for the fate of their own future, and their children’s future. Below are some excerpts from those emails:

“My mother died in 2008 from pancreatic cancer at age 64.”
“My father died in 2013 from a rare bladder cancer but also had colon cancer (removed in surgery).”

“My aunt passed away from ovarian cancer in 2017.”

“In June 2018, I was diagnosed with BRCA1 and CHEK2 mutated genes. I had an oophorectomy a week later.”

“Both my mother (age 47 at death) and her mother (age 35 at death) died of breast and ovarian cancer.”

My half-sister passed away from ovarian cancer seven years ago.”

Over the next few days or so, I was able to schedule the interviews spread out over several weeks. In interview after interview, I sat and listened as women poured their hearts out, shared how they learned about HBOC, how it affected their lives, what compelled them to make their own personal decisions about genetic testing and possible risk-reducing surgeries, and how their support—or lack of support—affect ed them, their children, and their outlook on life today.

I conducted many of the interviews from the inside of my conference room at work. And, while this created a quiet, private setting for the interviews, it became somewhat of a challenge for me to switch on and off. In other words, I would walk into the conference room with my head in work mode, listen to their difficult stories and empathize with the reality of their experiences, then walk back out to the conference room to work. It was doable, but I am noting that at times, it was a struggle.

Reflexivity helped offer me the opportunity to examine how my history, upbringing, clinical experiences, and values affected and even transformed the interpretations of the participants’ stories. For the purposes of this study, this occurred primarily as introspective and intersubjective reflexive journaling (Finlay, 2002). Through personal introspection, I continually
drew on my own personal experiences to help make sense of the stories I was hearing, while being aware of the intrusion of my biases and opinions. I examined my experiences and reactions to the stories told, how they affected me, what the information or experiences mean, and what opened up within me as a result.

Finlay (2002) commented that, “Reflections are assumed to provide data regarding the social/emotional world of participants” (p. 214), thereby contributing to the greater analysis. Intersubjective reflexivity was a dynamic way of examining my relationship to other. This gave consideration to the unconscious interactions or processes that were likely to occur between the participant and myself as researcher. In understanding my own motivations and behaviors, I overlaid them onto the relationship and began to understand the other.

These are the types of reflections I was engaged in throughout the process of this dissertation, which acted as advancements to broader interpretations and insights.

This also explains that even the initial emails and proceeding interviews left me reflecting on my own journey, my own lost loved ones, and family members affected by the hereditary mutation. Especially poignant was the story from the woman who initially wanted to be a part of the research, but only a few days later, learned she had breast cancer, rendering her ineligible for the study. “I was just diagnosed with breast cancer,” she wrote. “Shocking, to say the least, considering I had a prophylactic mastectomy eight years ago.”

As her email left me wondering if everything we were doing to attempt to stop a cancer that may never come, was all for naught, I got a phone call from my cousin, Patty who is 32. She previously fought her own battle with breast cancer at age 27, followed by a double mastectomy. Her grandmother (my aunt) died of breast cancer at age 31. And, just a few months ago, doctors
told my cousin that the cancer was back—with a vengeance. The cancer was in her breast area and a few other places, as well.

That night on the phone, she cried. She got angry. She feared who would take care of her two young daughters. She worried if they might endure the same fate one day. She pleaded for more time. I listened. I offered few words, but Patty knew it was a safe place to share. In the end, she thanked me for listening to her and allowing her to unload her worries, concerns, anger, sadness, and more, saying it gave her a sense of freedom from the outrunning of cancer, to share her story.

As my mind raced through the countless experiences told to me by the women in my research, I couldn’t help but be even more moved with Patty’s story. I almost wanted to say it was the icing on the cake but icing and cake are sweet and this is anything but sweet. In that moment, I recognized the value I wanted my research to add to the world. What makes the story so important is, its authenticity. Real loved ones, with heart-wrenching dilemmas, in need of humanity, in need of a voice.

Coincidentally, the last three months while doing interviews and continuing to do research, I stumbled across an article that claimed the Food and Drug Administration (FDA) recently identified an association between breast implants and the development of breast-implant associated anaplastic large cell lymphoma (BIA-ALCL), an uncommon cancer of the immune system (Center for Devices and Radiological Health U.S. Food and Drug Administration, 2011). The FDA believes that women with breast implants that have textured surfaces have an increased risk of developing BIA-ALCL. ALCL is an uncommon cancer that can develop in any part of the body, most commonly the lymph nodes and skin. Research suggests that BIA-ALCL is usually found near the breast implant within the surrounding scar tissue, not the breast itself. Several
recent publications have estimated the risk of developing BIA-ALCL in individuals with textured breast implants. Current literature reported various estimates that BIA-ALCL may develop in 1 in between 3,817 to 30,000 women with textured breast implants based on confirmed cases, which is on the rise, and textured implant sales data over the past two decades (Clemens et al., 2017; de Boer et al., 2018; Loch-Wilkinson et al., 2017). Treatment involves surgical removal of the implants and the cancer.

Ironically, I was already struggling with some issues from the implants, including pain and capsular contracture, a common complication of breast implant surgery. In light of the new information and ongoing issues, my doctor suggested having the implants removed, and replaced naturally by transferring parts of my body. I found myself thrust into the same predicament—remove my breasts again, to outrun a cancer that may never come.

I agreed to go through with the surgery, and had my implants removed in the last week, of March 2019. I know it was only a week after that I wrote this, but there is not a day that has gone by that I haven’t cried when I look in the mirror. I realize they are swollen and grossly misshapen right now, but I can’t stop thinking, “What have I done?”

What I’ve done is made a knowledgeable decision for me—I made the decision to get in front of any potential cancer to the best of my ability. I made a decision for me to do everything within my power to be here for my children as long as I possibly can. And, it’s ok that it’s a never-ending story, because my plan is to be here to live it.
References


Association for Molecular Pathology et al. v. Myriad Genetics, Inc. et al., 569 U.S. 576 (2013)


Appendix A:

National Comprehensive Cancer Network Guidelines for Genetics Referrals
While the BRCA 1 and BRCA 2 genes are naturally found in every person, the National Comprehensive Cancer Network (NCCN) sets guidelines for referrals to a genetics expert for evaluation of genetic testing for a mutation if certain criteria are met (2018). The criteria are extensive and include the following:

- Anyone with a family history of a blood relative with (a) a known mutation in a gene that increases cancer risk; (b) a blood relative with two or more primary breast cancers; (c) two or more relatives with breast cancer on the same side of the family with at least one diagnosed before age 50; (d) blood relative with ovarian cancer; (e) a close blood relative with breast cancer before age 45; (f) a blood relative with male breast cancer.
- Anyone of Ashkenazi Jewish ancestry with breast, ovarian, or pancreatic cancer at any age.
- Anyone with a cancer diagnosis and (a) a blood relative with a known mutation in a gene that increases cancer risk; (b) breast cancer at or before the age of 50; (c) triple-negative breast cancer at or before the age of 60; (d) ovarian, fallopian tube, or primary peritoneal cancer at any age; (e) male breast cancer at any age.
- Anyone with breast cancer at any age and (a) a blood relative with a known mutation in a gene that increases cancer risk; (b) an Ashkenazi Jewish ancestor; (c) a close blood relative with breast cancer before age 50; (d) a close blood relative with ovarian cancer; (e) second primary breast cancer; (f) two close blood relatives with breast cancer or prostate cancer (Gleason score of 7 or higher), and/or pancreatic cancer at any age; (g) personal history of pancreatic cancer.
- Two or more close blood relatives with breast cancer with at least one diagnosed before age 50.
- Anyone with a personal or family history of three or more of the following cancers, especially if any of the cases diagnosed before age 50: Pancreatic, prostate, melanoma, sarcoma, adrenal, brain tumors, leukemia, uterine, thyroid, kidney, diffuse gastric, or colon.
- Anyone with metastatic prostate cancer.
- Anyone with BRCA mutations detected by tumor testing.
- Anyone with ovarian cancer.
Appendix B:

Hereditary Cancer-Related Syndromes
Cancer.Net names the following hereditary conditions, which raise affected families’ cancer risk for specific types of cancer:

Ataxia-Telangiectasia  
Attenuated Familial Adenomatous Polyposis  
Beckwith-Wiedemann Syndrome  
Birt-Hogg-Dubé Syndrome  
Carney Complex  
Cowden Syndrome  
Familial Adenomatous Polyposis  
Familial GIST  
Familial Malignant Melanoma  
Familial Non-von Hippel Lindau Clear Cell Renal Cell Carcinoma  
Familial Pancreatic Cancer  
Gardner Syndrome  
Hereditary Breast and Ovarian Cancer  
Hereditary Diffuse Gastric Cancer  
Hereditary Leiomyomatosis and Renal Cell Cancer  
Hereditary Mixed Polyposis Syndrome  
Hereditary Pancreatitis  
Hereditary Papillary Renal Carcinoma  
Juvenile Polyposis Syndrome  
Li-Fraumeni Syndrome  
Lynch Syndrome  
Muir-Torre Syndrome  
Multiple Endocrine Neoplasia Type 1  
Multiple Endocrine Neoplasia Type 2  
MYH-Associated Polyposis  
Neurofibromatosis Type 1  
Neurofibromatosis Type 2  
Nevoid Basal Cell Carcinoma Syndrome  
Peutz-Jeghers Syndrome  
Tuberous Sclerosis Syndrome  
Von Hippel-Lindau Syndrome  
Werner Syndrome  
Xeroderma Pigmentosa
Appendix C:

Notice of Opportunity to Participate
Opportunity

Invitation
You are invited to participate in a research study by Cammi Clark, Antioch University, by sharing your story.

What
This research delves into the lived or felt experiences of individuals when they learn they have inherited a mutation that significantly increases their risk of breast, ovarian, and related cancers.

Why
The purpose of this study is to assist health professionals and others with more fully comprehending the potential psychological implications that may accompany this unique situation.

Who
About 12 to 15 participants needed, must be 18 years or older, with a family history of hereditary breast and ovarian cancer (HBOC) and positive results for a BRCA1 or BRCA2 mutation.

When
Two to three interviews will be conducted over the next few weeks, the others will be spaced over the next three to six months.

Where and How
From the comfort of your home, the researcher will interview you for about 30 minutes via video call, or via voice call, or, if within a short driving distance to Boca Raton, Fla., in-person. Note: The interview will be recorded, but only for the purpose of the researcher reviewing the answers.

Discussion Topics
You’ll be asked to share the story of your (a) family history with HBOC leading up to your story, (b) experience discovering you inherited a gene mutation that drastically increases your chances of breast, ovarian, and other cancers, and (c) options and decisions about what to do with this information, and how and why you made the choices you made.

About the Researcher
Cammi is BRCA2+, previvor, writer, with a strong family history of breast cancer, including family members who succumbed to the disease, a mother who is a survivor, and about two dozen family members who are also BRCA2+, which includes her teen daughter. She is also a Ph.D. student.

Next Step
Let Cammi know you are interested in being a participant by emailing her at Cclark7@antioch.edu

CAMMI CLARK
Appendix D:

Email in Response to Interested Participants Including Consent Form
Hello “Participant,”

Thank you for reaching out to me regarding participating in this important research titled “When Bad Genes Ruin a Perfectly Good Outlook: Psychological Implications of Hereditary Breast & Ovarian Cancer (HBOC) via Narrative Inquiry Methodology.”

The purpose of this project is to use narrative inquiry methodology to investigate and analyze the authentic lived or felt experiences of individuals who learn that they have inherited a mutation that significantly increases their risk of breast, ovarian and related cancers, and their choices that directly affect their effort to outrun a cancer that may never come.

Participant interviews will be scheduled throughout the next few weeks. From the comfort of your home, I will interview you for about 45-75 minutes via video call, voice call, or, if within a short driving distance to Southeast Florida, in-person—whichever way you feel most comfortable. Note: The interview will be recorded, but only for the purpose of the researcher reviewing the answers.

During the interview, you will be asked to share your personal story to questions similar to (a) family history with HBOC leading up to your story, (b) experience discovering you inherited a gene mutation that drastically increases your chances of breast, ovarian, and other cancers, and (c) options and decisions about what to do with this information, and how and why you made the choices you made.

I’ve attached a consent form for your review. Please sign and email back to me, along with your availability for an interview over the next week or two.

If you have any questions, you may contact me at —

Sincerely,

Cammi
Consent Form

What
This consent form is for community, agency and academic informants and stakeholders who we are inviting to participate in a project titled “When Bad Genes Ruin a Perfectly Good Outlook: Psychological Implications of Hereditary Breast & Ovarian Cancer (HBOC) via Narrative Inquiry Methodology”

Investigator
Cammi Clark, Antioch University, PhD in Leadership and Change Program (Also, BRCA2+, previvor, writer, family history of HBOC including some who died, a mother who survived, and about two dozen others who are BRCA2+, including her teen daughter)

Project Information
With the discovery of the genetic condition called Hereditary Breast and Ovarian Cancer (HBOC), a rapidly rising number of healthy people (never had breast/ovarian cancer) who are also carriers, are flooding healthcare providers seeking options to reduce their elevated risk. Those prophylactic measures are invasive, permanent and can cause physical – and emotional – scarring. As a newer medical phenomenon, there are few studies that address the potential psychological implications, which include depression, anxiety, guilt, an increase sense of considering yourself sick, family tension, discrimination, and more.

Project Purpose
The purpose of this project is to use narrative inquiry methodology to investigate and analyze the authentic lived or felt experiences of individuals who learn that they have inherited a mutation that significantly increases their risk of breast, ovarian and related cancers, and their choices that directly affect their effort to outrun a cancer that may never come.

Invited Participants
About 12 to 15 participants with a family history of hereditary breast and ovarian cancer (HBOC) and positive results for a BRCA1 or BRCA2 mutation.

When
Interviews will be scheduled throughout the next month. From the comfort of the participant’s home, the investigator will interview the participant for about 45-75 minutes via video call, voice call, or, if within a short driving distance to Boca Raton, Fla., in-person - whichever way the participant is more comfortable. Note: the interview will be recorded, but only for the purpose of the researcher reviewing the answers.

Interview Process
During the interview, participant’s will be asked to share their personal story to questions similar to (a) family history with HBOC leading up to your story, (b) experience discovering you inherited a gene mutation that drastically increases your chances of breast, ovarian, and other cancers, and (c) options and decisions about what to do with this information, and how and why you made the choices you made.

Voluntary Participation
Your participation in this project is completely voluntary. You may choose not to participate. You may withdraw from this project at any time. You will not be penalized for your decision not to participate or for anything of your contributions during the project. You may withdraw from this study at any time. If an interview has already taken place, you may request that the information you provided not be used in this research.

Risks
I do not anticipate that you will be harmed or distressed as a result of participating in this project. You may stop being in the project at any time if you become uncomfortable.
You will not be provided any monetary incentive to take part in this research project.

There will be no direct benefit to you, but your participation will help others and healthcare professionals more fully comprehend the psychological implications of HBOC.

All information will be de-identified, so that it cannot be connected back to you. Your real name will be replaced with a pseudonym in the write-up of this project. I will be the only person with access to the list connecting your name to the pseudonym. This list, along with any recordings will be kept in a secure, locked location.

Please note, while your identity will be kept private for the sake of this study, there laws that require action if a person is at risk for self-harm or harming another or if a child or adult is being abused. In these cases, the investigator cannot keep things private (confidential): (a) The researcher finds out that a child or vulnerable adult has been abused (b) The researcher finds out that a person plans to hurt him or herself, such as commit suicide (c) The researcher finds out that a person plans to hurt someone else.

Please ask any questions you may have about this issue before agreeing to be in the study. It is important that you do not feel betrayed if it turns out that the researcher cannot keep some things private.

If you have any questions, you may contact Cammi Clark at [redacted]

If you have any ethical concerns about this study, contact Elizabeth Holloway, PhD, Committee Chair at [redacted]
or

Lisa Kreeger, Ph.D., Chair of the Institutional Review Board for the Graduate School of Leadership and Change at [redacted]
Certificate of Consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to participate in this project.

Print Name of Participant:
_____________________________________________________________________

Signature of Participant:  __________________________________________ Date
_____________________________________________________________________

Consent to being audiotaped as part of this project

I voluntarily agree to let the researcher audiotape me for this project. I agree to allow the use of my recordings as described in this form.

Print Name of Participant:
_____________________________________________________________________

Signature of Participant:  __________________________________________ Date
_____________________________________________________________________

To be filled out by the Researcher

I confirm that the participant was given an opportunity to ask questions about the project and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily. A copy of this Informed Consent Form has been provided to the participant.

Print Name of Researcher:
_____________________________________________________________________

Signature of Researcher:  __________________________________________ Date
_____________________________________________________________________

Page 3 of 3
Appendix E:

Survey Approach and Question
Thank you for your participation in the interview portion of my doctoral dissertation research titled, titled “When Bad Genes Ruin a Perfectly Good Outlook: Psychological Implications of Hereditary Breast & Ovarian Cancer (HBOC) via Narrative Inquiry Methodology.”

As mentioned at the end of your interview I am sending you an anonymous one-question survey to follow up on your interview experience.

This is a survey about your personal experience and will give you an opportunity to reflect.

There are minimal, if any, risks from participating. Your identity will be anonymous and confidential. You will not be asked for your name and all demographic data being collected will be reported as aggregated information. No personally identifiable information will be associated with your responses to any reports of these data. The survey will take only a few minutes to complete.

This survey is part of my dissertation research at Antioch University in the PhD in Leadership and Change Program. The study results may be included in future presentations and publications.

Your participation is voluntary and you may elect to discontinue your participation at any time. This project has been approved by the Institutional Review Board at Antioch University. If you have any questions about your rights as a research participant, please contact:

Dr. Lisa Kreeger, Chair, Institutional Review Board [cc-placeholder]
PhD in Leadership and Change, Antioch University

If you have any questions about the survey or the research study, please contact me at [cc-placeholder]
I have read and understood the above information. By clicking "Next" below, I am indicating that I have read and understood this consent form and agree to participate in this research study.

Please print a copy of this page for your records. Thank you for your participation!

Survey

After spending time reflecting on your HBOC journey during your interview, how emotionally beneficial or healing do you believe it was to share your personal story with someone?

a. Extremely beneficial
b. Somewhat beneficial
c. Indifferent
d. Not beneficial

Please share why you gave the above rating.