

8-2018

# I Cut Off My... Voice: An Autoethnography of an Artist and Art Educator with a BRCA Genetic Mutation

Nicki Lynn Hornbaker

Stephen F Austin State University, nickilynn109@gmail.com

Follow this and additional works at: <https://scholarworks.sfasu.edu/etds>



Part of the [Art Education Commons](#), and the [Fine Arts Commons](#)

Tell us how this article helped you.

---

## Repository Citation

Hornbaker, Nicki Lynn, "I Cut Off My... Voice: An Autoethnography of an Artist and Art Educator with a BRCA Genetic Mutation" (2018). *Electronic Theses and Dissertations*. 203.

<https://scholarworks.sfasu.edu/etds/203>

---

# I Cut Off My... Voice: An Autoethnography of an Artist and Art Educator with a BRCA Genetic Mutation

## **Creative Commons License**



This work is licensed under a [Creative Commons Attribution-Noncommercial-No Derivative Works 4.0 License](https://creativecommons.org/licenses/by-nc-nd/4.0/).

I Cut Off My... Voice:  
An Autoethnography of an Artist and Art Educator with a BRCA Genetic Mutation

By

NICKI LYNN HORNBAKER, Bachelor of Arts

Presented to the Faculty of the Graduate School of  
Stephen F. Austin State University  
In Partial Fulfillment  
Of the Requirements

For the Degree of  
Master of Art in Art Education

STEPHEN F. AUSTIN STATE UNIVERSITY

August 2018

I Cut Off My... Voice:

An Autoethnography of an Artist and Art Educator with a BRCA Genetic Mutation

By

NICKI LYNN HORNBAKER, Bachelor of Arts

APPROVED:

---

Dr. William Nieberding, Thesis Director

---

Dr. Cala Coats, Committee Member

---

Dr. Heather Olson-Beal, Committee Member

---

Dr. Jill Carrington, Committee Member

---

Pauline M. Sampson, Ph.D.  
Dean of Research and Graduate Studies

## **Abstract**

The effects of BRCA genetic mutations on artists and art educators had not been known. Autoethnography is a qualitative method for writing about personal experiences through a cultural lens. I used my personal experiences within a BRCA positive community to understand shared experiences among artists and art educators with this genetic mutation. This study aimed to explore the commonalities that are occurring within this subgroup. Anxiety and emotional stress played a role in most of the respondents' lives, affecting them in numerous ways. Most of the respondents underwent salpingectomy, oophorectomy, and mastectomy surgeries which led to further emotional and physical stressors. All respondents voiced that they were determined to take control over their lives, whether that was through surgeries or continued preventative testing. The arts can empower many with a BRCA genetic mutation to share their stories and let their voices be heard.

Keywords: autoethnography, BRCA, genetic mutation, artist, art educator, salpingectomy, oophorectomy, mastectomy, emotional, physical, empowerment, art.

## **Acknowledgments**

I would first like to thank Dr. William Nieberding at Stephen F. Austin State University, your encouragement and gentle nudging allowed me to start the process of writing about myself and sharing my story. Anytime I felt like I could not continue in the sometimes emotionally painful process of writing an autoethnography, you were there in my corner cheering me on. I appreciated your kind heart and listening ear when I needed to talk about my BRCA journey or verbally bounce ideas off of someone. I truly believe that I could not or would not have been able to write this thesis without you as my advisor; I cannot begin to thank you enough.

I am also grateful to the following university faculty: Dr. Jill Carrington, Dr. Cala Coats, and Dr. Heather Olson-Beal for serving on my thesis committee and their support and assistance with the writing process. I appreciated all the feedback along the way.

I would also like to express my gratitude for all the women with a BRCA genetic mutation who responded to my surveys. They took the time to write honestly and openly about personal aspects of their lives and shared their stories with me.

Special thanks to my sister, Gwen, whose strength amazes me every day. Her fight with breast cancer led to the discovery of our familial BRCA mutation and ultimately gave me options of prevention.

Thanks to all my family members for their support and understanding as I wrote this paper.

Last but definitely not least, an extreme gratitude to my daughter, Jasmine, who has been with me throughout the process: physical impairments, sleepless nights, and emotional ups and downs. I love you with all my heart!

## Table of Contents

<b>Abstract</b> .....	<b>i</b>
<b>Acknowledgments</b> .....	<b>ii</b>
<b>Table of Contents</b> .....	<b>iv</b>
<b>List of Figures</b> .....	<b>vi</b>
<b>Chapter 1: Introduction</b> .....	<b>1</b>
<b>Chapter 2: Background</b> .....	<b>3</b>
<i>Testing</i> .....	3
<i>Family History</i> .....	3
<i>Personal Thoughts</i> .....	5
<i>Doctors Do Not Have All the Information</i> .....	6
<i>Waiting</i> .....	7
<b>Chapter 3: Literature Review</b> .....	<b>9</b>
<i>What is BRCA</i> .....	9
<i>Psychological Effects</i> .....	11
<i>BRCA is Not the Same as Cancer</i> .....	13
<i>Autoethnography</i> .....	14
<i>Art Education</i> .....	16
<b>Chapter 4: Data Collection and Analysis Procedures</b> .....	<b>19</b>
<i>Instrumentation/ Data Collection</i> .....	19
<i>Data Treatment Procedures</i> .....	24
<i>Analysis</i> .....	27
<b>Chapter 5: A BRCA Journey</b> .....	<b>33</b>



<i>Power and Control</i> .....	35
<i>Decisions</i> .....	35
<i>Testing</i> .....	36
<i>Future Plans</i> .....	37
<i>Surgeries</i> .....	38
<i>BRCA is Not the Same as Cancer</i> .....	42
<i>After Surgeries</i> .....	43
<i>Limitations</i> .....	45
<i>Physical Movement</i> .....	45
<i>Emotional Experiences</i> .....	47
<b>Chapter 6: Effects on Career</b> .....	<b>56</b>
<i>Graduate Student</i> .....	56
<i>Teacher</i> .....	59
<i>Artist</i> .....	64
<i>Implications for Art Education</i> .....	67
<b>Chapter 7: Conclusion</b> .....	<b>77</b>
<b>References</b> .....	<b>83</b>
<b>Appendix A</b> .....	<b>89</b>
<b>Appendix B</b> .....	<b>91</b>
<b>Appendix C</b> .....	<b>95</b>
<b>Appendix D</b> .....	<b>97</b>
<b>VITA</b> .....	<b>102</b>

## List of Figures

Figure 1 .....	30
Figure 2 .....	31
Figure 3 .....	74

## **Chapter 1**

### **Introduction**

I am an artist and art educator living with a BRCA genetic mutation. BRCA is a genetic mutation that is linked to a significant increase of breast and ovarian cancer risks. This autoethnography explores my struggles and triumphs throughout this experience and examines them against shared experiences from other artists and art educators who also have a BRCA genetic mutation. I faced many questions and dilemmas within my BRCA journey and longed to know if others were sharing my thoughts and feelings as I had felt entirely alone in the world at the beginning of my discovery. I wondered if my thoughts were strictly a unique opinion or if there were people out there who were or are going through the same things. I wanted to share my BRCA story and the BRCA stories of other women in hopes of helping others better understand their journey.

Hearing that genetic test results show that someone is positive for a BRCA genetic mutation can have a significant impact on a life, but what does that mean? Does it have a significant impact on lives as an artist or educator? What impact is made? The most significant impact on my life from being BRCA2 positive has not been the physical appearance and struggles, but an inability to voice or share my opinions and feelings openly and freely. As I continue on my journey, it is becoming harder to stay silent about my feelings.

I have blended analytical and evocative autoethnographical work and used Interpretive Phenomenological Analysis (Smith, Flowers, & Larkin, 2009) and Wilber's All Quadrants All Levels (Neale, 2013) products to help assess my reflections and the thoughts and feelings of others with a BRCA genetic mutation. I have chosen in the writing of my thesis not to be tied down to one subtype of a framework; I wanted it to be more organic with regards to writing about scientific procedures and creating text that also told my story in a compelling way.

In Chapter Two, I discuss background information on what brought this research into my life: testing, my family, and my feelings and thoughts throughout the process. Chapter 3 will discuss the literature reviewed on BRCA, associated risks, psychological aspects, autoethnography, and art education implications. Chapter 4 shows the data collection and analysis procedures used in the writing of this research. Chapter 5 is a combination of autoethnographical writing and shared experiences of physical and emotional topics on our BRCA journey. Chapter 6 discusses effects on career, as a teacher and an artist, finding my voice and the implication for art education. Conclusions on ideas from research and suggestions for additional research emerge in Chapter 7.

## **Chapter 2**

### **Background**

In March of 2014, my sister was diagnosed with breast cancer just a few days after her 37th birthday. Within a week it was determined that she had ten masses in her breast and cancer was also in two lymph nodes; this was quite a bit more than the two lumps she had felt when she initially went in to see her doctor. The original diagnosis was Invasive Ductal Carcinoma stage 2B breast cancer that was estrogen fed but was shortly discovered actually to be stage IV.

### **Testing**

After meeting with her oncologist, he stated that he would like to do full genetic testing to determine if genetic markers were visible for cancer, as this information can be used as a predictor for results with different cancer treatments. It was determined by that test that she was BRCA2 positive, meaning that she had a genetic mutation of the BRCA2 gene. My sister then met with a genetic counselor to discuss what it meant to be BRCA2.

### **Family History**

BRCA2 is a hereditary gene that can be passed down on the maternal or the paternal side of our family and is linked to an increased risk of primary breast and ovarian cancers but can also be linked to melanoma, pancreatic and colon cancers (“BRCA1 and BRCA2 Gene Mutations”, n.d.; Mersch et al., 2015).

With this discovery my sister was told that any siblings of hers would have a 50% chance of inheriting the same genetic mutation, depending on whether they got that gene from their mother or their father. My mother was tested after my sister's BRCA2 discovery due to a high rate of cancers on her side of the family, but she was revealed to be negative for any BRCA genetic mutation. It was then determined by process of elimination that it had come from our paternal side. My father's side shows signs of linking our BRCA2 mutation with his maternal side, but we cannot know for sure as both his parents had passed before our family's genetic testing.

My paternal grandmother had ovarian cancer that was diagnosed at 69 years old and later also had separate uterine cancer. According to my aunt, who is the eldest on my paternal side, my grandmother's sister's daughter had issues that caused "treatments and a lumpectomy." My aunt also informed me that my grandmother's mother had "treatments and cobalt radiation linked to either ovarian or cervical cancer," and her mother had "cancer all over" in her abdominal area when it was discovered in the 1950s. My paternal grandmother's father had treatments for colon cancer. These could have all been BRCA2 related issues, so we cannot determine further back than my grandmother what side of the family had the genetic mutation.

When they discovered that my sister had the BRCA2 genetic mutation I started my research into the BRCA gene; what it is, what it causes, how it affects her cancer treatment, and what can be done about it (see Appendix D). I read

about genetic testing and who should have it done and the effects of surgeries and radiation. I also read about the effects of surgeries and testing for those who are positive for a BRCA genetic mutation before any cancer has been found. Mostly these were medical studies on what to expect physically with each, but I did not see much on the emotional aspects. Granted, I was not particularly looking for them at that time as it did not occur to me to do so.

### **Personal Thoughts**

My family's focus at that time was on my sister's health and doing whatever we could to make it the best situation for her. I did not even consider the risks for myself at that time. After the first three months of her chemotherapy, things had finally settled enough for me to begin thinking about what her genetic testing could mean for me.

I spent the next few months praying, researching, and considering what I would do if I had the same genetic mutation. I wanted to have a clear understanding of what this could mean before I ever went in to get the blood test done. I wanted to make sure that I knew my next steps in whichever way the test came out.

Before I ever went in for the genetic testing, I was consumed by thoughts of having a BRCA genetic mutation versus not having it. Since my chances were 50/50 on whether I would get the mutated gene from my father or the normal gene from my mother, I remember thinking that it would be great if I did not have the genetic mutation but then how would my sister feel? Would she feel unlucky?

Would she be happy for me? Would she wonder all the time why only she got the bad gene? But if I was positive for BRCA2, then she would not be alone in her journey, and she would not have to feel distanced by her DNA. All these things aided in creating stress that I felt physically and it created a level of anxiety I've never felt before.

### **Doctors Do Not Have All the Information**

Getting testing done for the BRCA genetic mutations requires intensive knowledge of your family's medical history and associated cancers. The use of BRCA testing has risen, but a study on the awareness and utilization of these tests by primary care physicians has found that "many physicians may not recognize the increased-risk family history patterns" (Bellcross et al., 2011), which leads to misinformation being given to patients.

The availability of genetic testing now is allowing more men and women to be tested for hereditary genetic markers that contribute to an increased risk of cancer than ever before. Even with the testing opening up to allow others outside of the clinical trials to be tested, many patients have still personally denied genetic testing due to lack of knowledge about the risks involved with the tests (Cho, Sanker, Wolpe, & Godmilow, 1999). Knowledge of genetic testing among medical staff is still limited for those outside of genetic counselors.

In early October of 2014, I went to my doctor to discuss how I could be tested for the BRCA2 genetic mutation; he was reluctant as he stated that it was NOT hereditary and he didn't think I had it (personal communication, October 9,



2014). I knew that it was hereditary from my research into what it meant to be BRCA positive for my sister and what the genetic counselor had told my sister. I also knew that there was no way for him to determine if I did or did not carry the gene without the genetic test being done, as there is no outward appearance of the mutation. After a very lengthy discussion, I was able to get a referral for testing based on my sister's positive test result for the BRCA2 genetic mutation and our family's history of cancer, and because I insisted that I be tested.

On October 16, 2014, at age 33 I had genetic testing done; my blood was drawn and sent to Quest Diagnostics Inc. for analysis.

I cried and read the Lord's Prayer as the nurse drew the blood from my arm to be sent off for testing. I never felt this way about a single test in my entire life, and now it was the rest of my life being sent away in a small vial. I knew deep down that I was positive for this same genetic mutation that was actively trying to kill my sister and it was all too much to handle at the moment. (personal journal)

## **Waiting**

Waiting for test results of any kind can stir up mixed emotions, and genetic testing is no different. Waiting for test results increases anxiety and builds as more tests are needed to be performed (Pineault, 2007).

In my generation, it often takes a self-cancer diagnosis or a cancer diagnosis of a parent still living to know that a genetic mutation exists in the family. In our children's generation, I am hopeful that enough people are being

tested now that we will only have to discuss preventative options and not cancer diagnosis options with regards to BRCA genetic mutations.

## **Chapter 3**

### **Literature Review**

This study is about the effects having a BRCA mutation has on your emotional and physical well-being and how it affects the career of an artist and art educator. I wanted to learn if others had the same experiences I did with regards to feelings about body issues and job-related issues, such as, how the physical and emotional challenges became a part of my “new normal.”

#### **What is BRCA**

BRCA is the name of “either of two tumor suppressor genes, BRCA1 and BRCA2, that in mutated form tends to be associated with an increased risk of certain cancers and especially breast and ovarian cancers” (BRCA, 2017). It stands for BREast CAncer and is usually pronounced as “Bra-Ca” in BRCA community settings but is said scientifically as each letter “B-R-C-A.”

Genes are the parts of the body that pass hereditary traits down through families (“BRCA1 and BRCA2 Gene Mutations”, n.d.). Every human has two copies of the BRCA1 and BRCA2 gene; they receive one from each parent. The BRCA genes are known as tumor-suppressor genes and usually work to keep off cancer cells from forming. “When functioning normally, these genes help keep breast, ovarian, and other types of cells from growing and dividing too rapidly or in an uncontrolled way” (“BRCA1 and BRCA2 Gene Mutations”, n.d.). BRCA genes “help repair DNA breaks that can lead to cancer and the uncontrolled

growth of tumors” and usually “help to prevent breast cancer” (“BRCA: The Breast Cancer Gene,” n.d.).

**BRCA genetic mutations.** In the case of a BRCA genetic mutation, the gene is missing or damaged, and it allows cancer cells to form and multiply without resistance. A person who has been found to have a genetic mutation of the BRCA gene is often referred to as “BRCA1 positive” or “BRCA2 positive”. Only a small percentage of people in the world have been determined to have either a BRCA1 or BRCA2 genetic mutation. About one in every 400 people in the world carry a BRCA1 or BRCA2 genetic mutation (“BRCA: The Breast Cancer Gene”, n.d.), while the odds lower only slightly for women in the United States of America to about one in every 500 (“BRCA1 and BRCA2 Gene Mutations”, n.d.). Other mutations have been associated with breast and ovarian cancers, but the majority of hereditary breast cancers are caused by the BRCA1 and BRCA2 mutations (“BRCA1 and BRCA2 Gene Mutations”, n.d.).

**BRCA mutation risks.** One in eight women, or approximately 12%, will be diagnosed with breast cancer in her lifetime. “People with a BRCA genetic mutation are more likely to develop breast cancer, and more likely to develop cancer at a younger age” (“BRCA: The Breast Cancer Gene”, n.d.). Having a BRCA genetic mutation increases the risk of breast, ovarian, and pancreatic cancers as well as melanoma. About 55-65% of women with the BRCA1 genetic mutation and about 45% of women with a BRCA2 genetic mutation will develop breast cancer before age 70” (“BRCA: The Breast Cancer Gene”, n.d.). “BRCA1

and BRCA2 mutations confer a 40-66% lifetime risk of developing breast cancer and a 13-46% risk of ovarian cancer” (O’Neill et al., 2010).

Speaking with a genetic counselor will cover the following topics: risk assessment based on family history, cancer risks associated with BRCA1 and BRCA2 mutations, the process of BRCA1 and BRCA2 testing, the implications of a positive or a negative test result, options for cancer prevention and surveillance, psychological risks and benefits of genetic test results and the risk of passing a mutation to children (O’Neill et al., 2010; "BRCA1 & BRCA2: Cancer Risk & Genetic Testing", 2015). Most doctors will refer a patient to a genetic counselor prior to testing.

### **Psychological Effects**

The psychological wellbeing of BRCA positive women is often addressed by genetic counselors but seldom sufficient, in my opinion. They try, but genetic counselors prepare women for issues that have not come up yet in the patients’ lives. So when they are discussing broad topics that one might feel anxious or get depressed about going through testing and surgeries, the women do not fully grasp the significance as they have not experienced those things.

Researchers have looked at the emotional distress levels-anxiety and uncertainty- associated with genetic testing and have reported an increase during the process (Bjornslett, Dahl, Sorebo, & Dorum, 2015; Dorval et al. 2008; Cella et al. 2002). The stressors associated with BRCA genetic mutations can vary

depending on the reason for testing, significant physical changes, family roles, and psychological effects;

For mutation carriers, the immediate months after test receipt often involve decisions about prophylactic options and communication of results to family and friends; these activities, accompanied by one's own emotional and cognitive processing of the result, may explain the heightened distress observed during this period. (Beran, et al. 2008, pp. 114)

The women who choose to consider risk-reducing surgeries had a more significant conflict in decision making which increased distress among them (Rini et al. 2009). Increased anxiety was also found in BRCA positive women who chose to have cancer surveillance instead of performing risk-reducing surgeries (Stan et al. 2013). Studies also showed the decrease of anxiety over a year's time after discovering that the participants had tested positive for a genetic mutation and once a preventative surgery was performed their anxiety decreased significantly (Beran et al. 2008; Frost et al. 2000). "A major psychological benefit of prophylactic surgery was a reduction in the fear of developing cancer" (van Oostrom, et al. 2003). Refer to Appendix D for additional information on genetic testing and decisions on non-surgical and surgical options.

Although negative impacts of having surgical decisions after the discovery of a genetic mutation were shown in a multitude of studies, these studies also showed that the benefit of surgical procedures produced favorable outcomes that exceeded the psychological distress (Tiller et al., 2002).

Emotional support needs to be sought when having testing done as “concerns about personal and family vulnerability were elevated among participants who test positively” (Cella et al. 2002).

### **BRCA is Not the Same as Cancer**

There are many studies showing connections between cancer patients and psychological distress (Burgess et al. 2005; Vahdaninia, Omidvari, & Montazeri, 2009) and fewer studies showing the connection of a person with a BRCA genetic mutation and psychological distress with an overall picture of their life. I do not wish to address specific similarities and commonalities of cancer patients and BRCA positive persons within this paper, but just to note that there is available research that shows these correlations.

In Diane Price Herndl’s research, “Virtual Cancer: BRCA and Posthuman Narratives of Deleterious Mutation” (2014), she compares and contrasts the narrative accounts of Jessica Queller’s book *Pretty Is What Changes: Impossible Choices, The Breast Cancer Gene, and How I Defied My Destiny*, Marsha Gessen’s book *Blood Matters: From Inherited Illness to Designer Babies, How the World and I Found Ourselves in the Future of the Gene*, and Joanna Rudnick’s film *In the Family*. Each tells her own story of having been told she had a BRCA genetic mutation and her different views on it.

Price Herndl notes that these authors at some point have to compare themselves to and identify themselves like cancer patients; whether due to doctor’s notes for insurance to pay for testing, they must go to the same cancer

centers for doctor visits, or have the same procedures as those who already have *detectable* cancer. “A BRCA positive test result, without any evidence of manifest disease, may result in the loss of both breasts and both ovaries” (Price Herndl, 2014).

### **Autoethnography**

“Qualitative research focuses on human intentions, motivations, emotions, and actions, rather than generating demographic information and general descriptions of interaction” (Adams, Holman Jones, & Ellis, 2015). The purpose of this study was to record the views of others in a shared situation encapsulated by my experience. Within this context, I wanted to determine how testing positive for a BRCA genetic mutation can change one’s view on health and their body; more specifically, how does it have an impact on the life of an artist and art educator?

The audience for this research is other artists and art educators who are going through their own BRCA genetic mutation discovery and their loved ones who will help them along the way. I chose to write an autoethnography instead of an ethnography, as it allows me to speak about my own experiences and not just the experiences of those I “observed or interacted with” (“Ethnography,” 2017).

Putting my experiences in the foreground and not hidden in the background of this study I am able to show that a single person can be a significant contributor to research. This allows the information from my experience and the experiences of others with a BRCA genetic mutation to give



specific knowledge about our lives for others who are going through similar situations to come to terms with their realities and identities.

The word autoethnography means “*self* (auto), *culture* (ethno), and *writing* (graphy)” (Adams, Holman Jones, & Ellis, 2015). Autoethnographical research is mostly written in creative formats, although some researchers use formal research writing within their work. The author can include their own experiences retroactively by finding the significance of each moment upon reflection and it can make the research more emotionally led (Bochner & Ellis, 2016; Adams, Holman Jones, & Ellis, 2015). Autoethnography combines autobiography and ethnography creatively to analyze and explain the data. In this study, I wrote in a manner that helps bridge the information between my accounts and those of the respondents, “to weave” the formal and informal parts of this paper (Lather, P. 1997). I did not insert personal accounts next to the main research for a break, as Lather did, but wrote in a way that I felt made the most sense for both the reader and me.

Autoethnography is both a process and a product of research in that it describes a personal experience within a shared experience, by finding a way to include individual stories of others in order to give voices to those who are going through similar experiences and to make the research more evocative (Ellis, Adams, & Bochner, 2011; Henderson, E. 2017).

## **Art Education**

“Art making is conducive to healing because it is a whole-body experience, one that adds to the complexity of the individual through its involvement of the body, mind, and emotions” (Nolan, 2014).

**Giving a voice.** Art can give a voice to those often unheard by which “art is an indirect means for exposing dominant narratives and empowering change, as well as illuminating possible channels of influence” (Nolan, 2014). Danielle Livoti said that art could and should “be able to uplift each other, help each other, speak up for each other” (as cited in Anderson, 2017), to give a voice to those who are silenced in one way or another.

**Narratives.** We can learn more about a person through their stories, so we need to find alternative ways to get those stories told when they are not able to share with their voices:

Everyone has a voice they want to be heard. Listening to the voices of others is one very important way in which we learn. We connect with, teach, and learn from others by sharing our experiences through narratives that take many forms. (Lawton, 2010)

**Community-based art programs.** Personal stories can be shared through artwork, such as PhotoVoice, and in community-based art programs that can empower many involved by giving them all a voice. PhotoVoice is a collaborative project that uses photos to bring awareness to different cultures, backgrounds, and social issues (PhotoVoice, n.d.). It is a place where everyone

has a story to tell and he or she can tell those stories through a universal visual language. “With social transformation, personal empowerment is key to emancipatory learning and eventually societal transformation” (Lawton, 2010). Experiences may be different, but they can be combined into one art project or shared experience to bring individual voices together for a powerful statement.

“Programs that educate or memorialize also empower” (Ulbricht, 2005, pg. 10). Art programs can have many benefits, both intrinsic and extrinsic; internal rewards of accomplishing something for one’s self as well as being able to express yourself in a fulfilling way by stimulating “creative expression, vital for psychological well-being and aesthetic, social, physical, intellectual, and emotional development” stated by Lowenfeld (as cited in Holt, 2012), and the external rewards are the impact of social awareness and visible changes within one’s community.

**Social change.** Participants involved in an art education program or project that focuses on a social change issue can be empowered to seek further knowledge on the issue. “Although not all contemporary art is political or critical in nature there are many artists that do create work about social issues with many diverse approaches” (O'Connor, 2014).

Anderson said social justice practice in art education centers “on art forms, visual artifacts, performances, and educational activities that encourage social equity and the opportunity for all people to achieve their vocational, professional, personal, social, and economic goals in the world” (as cited in Holt,

2012). Anderson stated, “Art education for social justice is action-oriented, taking place in the social arena toward the social ends of tolerance, equity, fairness, and decency, which make for respect and justice between one human being and another” (as cited in Holt, 2012). The making of an artwork or collaboration on an art project has the ability to give a voice to those affected by the subject matter and can enhance knowledge and understanding for the viewer.

## Chapter 4

### Data Collection and Analysis Procedures

#### Instrumentation/ Data Collection

**Personal narrative.** I am using my journal that I wrote in during my BRCA journey, as well as postings I created within private BRCA Facebook groups. I used them to guide my reflections and recall emotions during the time of my decisions, surgeries, and recoveries. I also have emails that I sent to my professors that are shared as personal communications to show my emotional and physical state at the time of each writing as it pertains to BRCA related issues.

Reading and reflecting on my previous writings in chronological order helped me to put my mind back into each moment to accurately depict my emotions during each experience for this study.

**Literature reviews.** I looked at previously documented studies to further examine commonalities among these women and use them to guide my own journey of discovery. It was important for me to include pieces of what I have learned throughout this experience and seek knowledge from others in the same situation. Although no one study provided all the physical and emotional aspects for artists and art educators, their separate information was useful in exploring my feelings on each of these issues.

Art projects delve into combining art with their voices for those in the BRCA communities to create a more meaningful dialogue about BRCA. I examined many art sources, as well as educational sources, to further examine the role that art plays in the lives of those affected by a BRCA genetic mutation.

**Surveys.** I used surveys instead of personal interviews as the participants were from anywhere in the world. I asked for personal interviews, but no participants accepted, although I was later able to email back and forth with one respondent about an artwork created about them.

The honesty that exists in the private BRCA Facebook groups allowed them to open up to me in an authentic and meaningful way from the beginning. A survey also allowed the respondents to have adequate time to process each question for a deeper reflection before answering it online.

I created two Google Form surveys to establish a good line of communication in which to receive the research. Qualifying questions were asked of respondents before they were allowed to continue with the survey; for the first survey each respondent must be positive for a BRCA genetic mutation and be an artist and art educator. The second survey was open to all women who tested positive for a BRCA genetic mutation and focused on women's empowerment through various sources.

**First online survey.** The questions about medical history that I asked in the background information of the survey were used to know where the respondent was coming from in regards to their BRCA status and their feelings

toward the testing process. I asked 2-point Likert scaling questions (Agree or Disagree) to better understand their emotions before genetic testing and after they learned the results of genetic testing. The Likert scaling questions gave information that can be applied to research more easily than an open-ended question and can produce useful information for comparisons. I feel that it worked effectively in gathering quick responses. I know that 2-point questions can be limiting with a breadth of choices still not discussed, but I felt that it was needed to set the stage for focusing on their emotions before then asking open-ended questions about the same subject.

Open-ended questions were incorporated to further gain insight into their feelings and attitudes towards particular subjects and their overall experiences. I felt that the most insightful information came from these types of questions as they got to the root of how they felt during a particular section of their journey.

Questions about surgeries and recovery times were asked to better establish reasons for answers in other questions such as, if someone were to answer that she had to be off work for 6 months following her mastectomy, it would be relevant for me to know that she also had many complications that lengthened the original time off needed.

***Second online survey.*** Most of the questions on this survey were open-ended questions based on thoughts and feelings that had come up after the first survey had been completed. I asked questions around a definition of women's empowerment:

The fostering of a woman's sense of self-worth, her decision-making power, her access to opportunities and resources, her power and control over her own life inside and outside the home, and her ability to affect change.” (“Global Issues,” n.d.)

The questions asked were about self-worth, control of emotions, control of the physical body, resources available to them, and how they could use their BRCA knowledge to help others and effect change. Scaling questions and answers were also asked; yes, no, or sometimes, when they felt empowered in the process of testing, surgeries and recovery.

The use of art and art therapy were also asked about in this survey from all respondents. I chose to ask in the second survey, not just from artists or art educators in the first survey, as participants in these programs may have other professions and backgrounds.

**Sampling size.** The information that was gathered is qualitative with a small sampling of art educators and artists working in various media for the first survey. Since BRCA positive persons make up less than three percent of the world population, the artists and art educators among that group was much smaller. Moreover, that small percentage of artists and art educators in the same BRCA Facebook groups is a tiny group but having them also see the post and answer my survey was an even smaller group (n=6). In the second survey, the group numbers widened as it was open to all women within the BRCA Facebook groups which resulted in a larger number of respondents (n=35).



**Informed consent.** Informed Consent Form was used as the first page with the online survey (see Appendix A). They were required to “Accept” in the consent form before continuing to survey. If they did not accept, it closed the window, and they were not allowed to proceed to survey.

Online surveys were used for respondents to answer questions that were posted in private BRCA groups on Facebook. Facebook groups were used to better reach those across the country and the world who are affected by a BRCA genetic mutation and other high-risk familial genes. A brief description of the research and a link to the online Google Form survey were posted in private BRCA groups on Facebook for those who wished to participate. Posting the research survey allowed the artists and art educators to take the time to answer honestly and as thoroughly as possible. Most BRCA positive people in the Facebook groups were women and the majority are there to advocate and help each other out.

**Limitations.** Limitations of having an online survey instead of personal interviews are that the researcher is unable to hear and see the emotions and connotations that come with each answer. This study asked respondents for a phone call or skype interviews, but they all declined. Finding a way to gather information in a face to face setting would be beneficial to developing more themes from the participants in future research, although I would still have them answer the survey first as it gives them a chance to be honest in a more

anonymous way. Writing down your true feelings and exposing hidden issues is easier than speaking the same words outloud.

### **Data Treatment Procedures**

The anonymity of each respondent is safeguarded as each respondent was asked to “provide a first name for use in research results, you may provide ANY first name as it does not have to be your own.” No additional coding of participants was needed as they could have chosen ANY name to go by for the use of this research. I will refer to respondents by only the first name given throughout this paper.

Information gained was used in comparison to other respondents to further develop emerging themes in experiences and shared perceptions as a continued path of discovery.

**Respondents.** The link created for access to the Google Forms survey was shared in eight private BRCA related Facebook groups of which I am a member. I asked among private Facebook groups that I belong to for participation in a survey of artists and art educators (See Appendix B - Artists and Art Educators BRCA Survey) for the first survey and only women in the second survey (See Appendix C). I also sent personal invitations to participate in the first survey to those who have identified themselves as artists or art educators in the private BRCA Facebook groups to gain more respondents.

Facebook groups were the best way to approach many of these people since I only knew them through Facebook group conversations before this

research. The private BRCA groups have been a great resource in my journey through getting tested, decisions and emotions after getting positive results for genetic mutation, and through surgeries and recoveries. These private BRCA groups allow people to have open and honest conversations about what is happening to them, give advice, and ask for help in a safe and secure environment. I know that when I had a question about something related to my testing and procedures, I could search a keyword in these groups or post a question and be given an honest answer almost immediately. We are all unique, and yet we immediately have this intense bond that brings us closer together than many of our friends in our physical world. It is a connection like no other that is hard to explain to those who have not experienced it. We become part of a “club” that we did not ask to be a part of, and now we would not want to be without the other members.

I included as many people as were willing to participate with no limit on size since those who are positive for a BRCA genetic mutation make up such a small portion of the population. Six respondents answered the Artists and Art Educators survey online and four of those responded to follow-up questions. Thirty-five women responded to the women’s empowerment survey.

***First online survey.*** This survey only had BRCA positive artists and art educators. I answered the questions myself in addition to the others as I fall into the category of being BRCA2 positive. There were no respondents who were male, BRCA1 positive or considered “high risk only” without a genetic mutation.

All respondents were female and listed themselves as being BRCA2 positive with ages ranging from 23-48 years. The respondents wrote openly about their experiences and gave detailed information about their physical and emotional triumphs and struggles.

**Second online survey.** Thirty-five BRCA1 and BRCA2 women, ages 24-67, responded to the second survey focusing on women's empowerment. These respondents were any woman from the same private BRCA Facebook groups but not limited to just artists and art educators.

**Interpretive phenomenological analysis.** Interpretive Phenomenological Analysis (IPA) is an investigative method used to understand individual experiences from a particular perspective within a context. In the book *Interpretative Phenomenological Analysis: Theory, Method, and Research*, IPA was used for examining phenomena through a "lived-experience" ("Division of Counselling Psychology"; Smith, Flowers, & Larkin, 2012). These experiences are looked at usually from an outsider point of view and examined from within the group without being a full participant. "The researcher is trying to make sense of the participant trying to make sense of what is happening to them" (Smith, Flowers, & Larkin, 2012).

There has not been any research on artists and art educators who have a BRCA mutation and the specific set of choices and experiences that they are given. An "outsider" to this unique group of individuals would not have the same way of seeing the research as someone who is also experiencing it.

IPA often uses a smaller sampling size of detailed experiences given by each of the participants and data is received through structured interviews, although surveys can also be used to gather useful information with an autoethnographical study (Cook, 2014). The surveys used in the research for this study allowed respondents to give their insights without the involvement or bias of an interviewer. Moreover, I believe I was able to gain honest reflections from each response.

I looked into many theories for the framework for this research and kept circling back around to autoethnography. Although Interpretive Phenomenological Analysis (IPA) allowed me to study the respondents' words and pull out the central themes while keeping the integrity of their meaning, it would have restricted my own words and personal experiences to be shared as part of the research. Many chapters that I wrote and printed out are collecting dust on my desk as they never seemed quite to tell the story the way I intended. All other frameworks only fit up to a point, and then it had to be forced. I felt that this research is too important to be just placed into another frame.

## **Analysis**

**Interpretive phenomenological analysis.** I used Interpretive Phenomenological Analysis (IPA) tools within my research to help understand the experiences and “personal perceptions” of the respondents in a more analytical way, specifically “the content and complexity of meaning in respondents' experience” (Chan, Fung, & Chien. 2013).

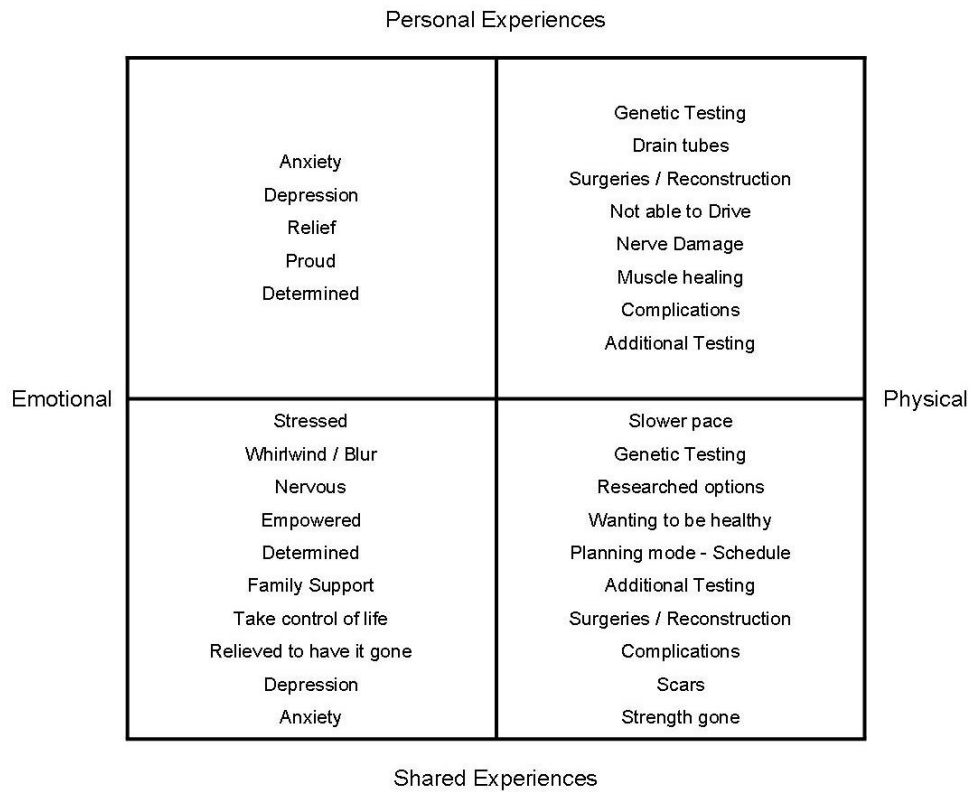
IPA works well for a smaller sampling size of quality respondents which is suitable for this research as getting contributions from other artists, or art educators who are also BRCA positive, can be challenging. IPA seeks to collect meaningful data from those involved and allows for open-ended questions to be answered without asking leading questions.

I used “exploratory commenting” as a tool to help me get the most from the data I received (Smith, Flowers, & Larkin, 2012). I printed out each page of questions and answers from the respondents to help analyze the data. I wrote notes on the papers about my thoughts, feelings, and questions while reading through it all, I then used the left side margin to highlight central themes that emerged. Some parts allowed for more thoughts and others only required one-word responses from me. I used *descriptive*, *linguistic*, and *conceptual* comments to analyze what was being told to me by the respondents (Smith, Flowers, & Larkin, 2012). Analyzing them in this way allowed me to focus on each part separately; detailed comments on *what* was said, linguistic comments on *how* it was said, and conceptual comments on *why* it was said.

**All quadrants all levels.** I then looked at the original data from the first online survey without any of my previous notes and completed two four-quadrant structures to analyze the data further and allow for a validity check. The quadrants structure I used as a tool for analysis came after looking at Wilber’s All Quadrants All Levels (AQAL) lens and his way of looking at the four areas as; “outside me, inside me, outside us, inside us” (Neale, 2013). I used this to

reflect and interpret information from the physical (outside) and the emotional (inside) aspects of myself (me) and others (us). The rest of his Integral Theory did not fit into the research or how I wanted to write it, but the tool became very useful in organizing the data to make better sense of how it all fits together.

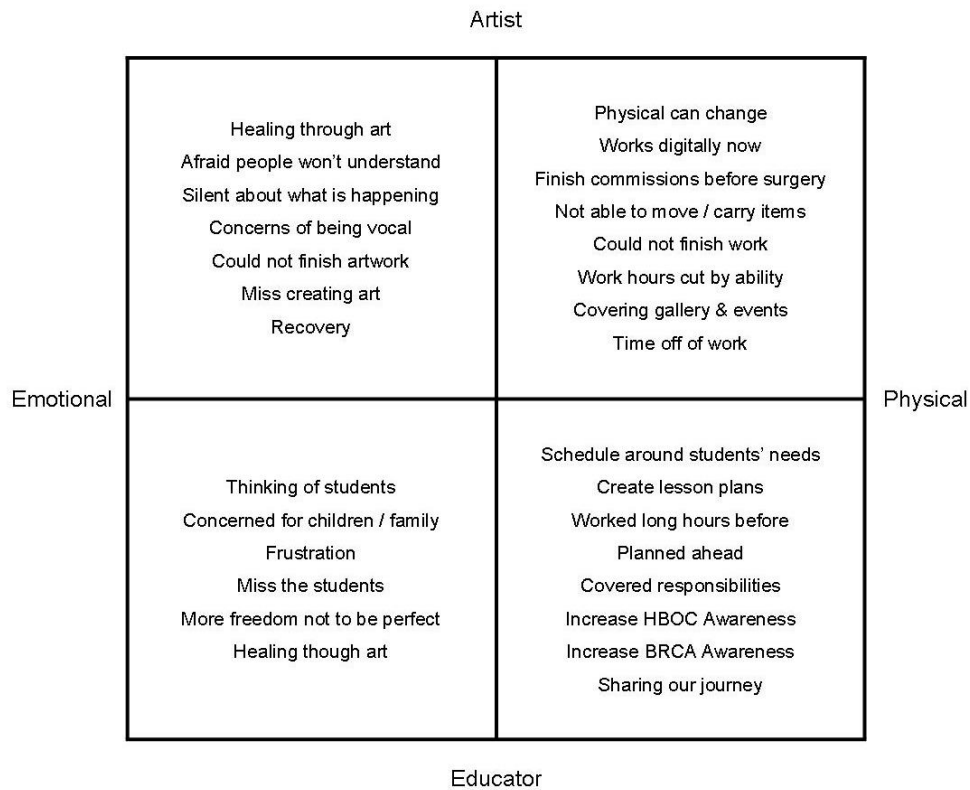
The first four-quadrant structure focused on my personal experiences, and the BRCA community of Artists and Educators shared experiences, as well as the Emotional versus the Physical aspects of having a BRCA genetic mutation. I printed out a new copy of the research survey results and used them in identifying keywords and ideas that emerged through reading over the results. I then looked at each word and idea and saw where it fit into the quadrant structure. I was then able to identify the broader concepts that showed up through the structure (see Figure 1). The structure helps to identify each focal area and determine if it was only an effect for me or for the BRCA community I studied.



**Figure 1. Emotional and physical aspects within personal and shared experiences.**

Emotional stress showed throughout the study but also included a determination to make the best of a situation and take control of one's life. The physical side of the quadrant can be broken down as before and after surgeries, as once surgery has occurred, the emotional and physical effects significantly increase.





**Figure 2. Emotional and physical aspects within the roles of an artist or educator.**

After completing the first four-quadrant structure, I was able to create a second four-quadrant structure focusing on Artists and Educators and the Emotional versus the Physical aspects of having a BRCA genetic mutation (see Figure 2). The focus on this structure was to break the key connections down further and see where they applied to the life of an artist or life as an educator.

Concerns for other people in work, business, and personal life is a cause of emotional stress. The physical and emotional play more of a connecting role within each context of an artist or an educator's life. For example, healing

through art was often a tool that one would use before BRCA positive status but during, it became an item of despair as they could not produce art the way they once could before surgeries. Recovery periods gave them more time to complete art but not the ability to do so. It became a different kind of healing process that had to come much later when they could become more independent in moving, lifting, and caring for themselves again.

All respondents to the surveys showed an increased desire to become more vocal about their journeys and help others to become more aware of BRCA mutations and HBOC (Hereditary Breast and Ovarian Cancer). With this autoethnography, I am able to become more vocal about my BRCA journey.

## Chapter 5

### A BRCA Journey

Both formal and informal writing structures are used within this autoethnography as the physical and emotional effects and choices for each respondent are serious and should be represented as such. I also feel that my personal experiences can be written in a more descriptive format to explain my point of view better.

When one has a diagnosed breast cancer, it has a specific location and shape, but when one is discovered to be BRCA positive, cancer is not just a potential; it becomes a part of identity. It is, literally, in one's genes and has (re)written one's life story. (Price Herndl, 2014)

On December 22, 2014, I was in Iowa helping my sister after her mastectomy and through her recovery and away from my doctors back home in Texas. When I got the phone call that my test results were in, I requested that they just tell me over the phone instead of having to wait longer for my results. The nurse confirmed that I was indeed BRCA2 positive, the same as my sister.

I received my lab report when I met back with my doctor on January 7, 2015:

MUTATION DETECTED: This individual is positive for one copy of the c.7976G>A (p.Arg2659Lys) mutation in exon 17 of the BRCA2 gene. The c.7976G>A mutation (also known as 8204G>A and R2659K) interferes

with BRCA2 mRNA splicing (as cited in J Med Genet (2003) 40:e23) and was reported as being deleterious in a study based on family history, co-occurrence, and co-segregation data (as cited in Am J Hum Genet (2007) 81:873-83). Therefore, this patient is at increased risk of developing breast cancer, ovarian cancer, and other BRCA-related cancers. Genetic counseling for this patient and testing for at-risk family members are recommended. (medical chart, December 18, 2014)

After my test results came back positive, my entire life changed; I was focused on researching and finding out everything I could do to not to let my body work against me. I now had a document of specifics and a new place to start with more research.

My doctor never mentioned whether he was shocked by the result or if he was sorry for trying to convince me not to have the testing done since he first insisted that I did not have a genetic mutation. He instead told me he could do a hysterectomy and mastectomy at one time “during my(his) lunch break.” In shock and disbelief, I couldn’t believe what I was hearing, yet again, from a doctor that I had respected for many years and had trusted with my healthcare. I’m not looking for a drive-through service of having my ovaries and uterus taken out while you lop off my breasts and send me on my way. No, thank you! I quickly left his office and have never returned.

## **Power and Control**

Once I was able to get a referral to the high-risk breast cancer center at MD Anderson in Houston, Texas from my regular doctor, I had doctors that knew more about what it meant to be BRCA positive. With these doctors, I was able to formulate a plan that would best benefit me and show what I needed to do to protect my health.

Once a woman is told of certain positive status for a BRCA genetic mutation, she can begin making the hard decisions among her options and take control over her life. The pros of having a risk-reducing surgery outweigh the cons when faced with a high-risk of cancer (O'Neill et al., 2010).

Feelings of determination were shown by all respondents of first survey (n=6) after receiving positive results from genetic testing. Jane stated, "and I immediately went into planning mode, I think my exact words were probably something like, okay. What kinds of tests will I need, how often, and can we schedule them?" and I knew immediately that I would be having a mastectomy. Feelings of being empowered (n=5) and satisfied (n=4) were experienced as well. Half of the respondents stated they also felt sad (n=3) as they received the results. Emily stated, "I assured my family it was good news, but I began to obsess over the results and experience anxiety like I hadn't felt before."

## **Decisions**

"Unlike the situation for breast and other cancer patients, few supportive care services for mutation carriers exist" (White et al., 2012). Each woman had

to determine the best treatment option on her own. Often women with a BRCA genetic mutation do not receive guidance on which option is best for them and are compelled to make these hard decisions based on their own preferences (O'Neill et al., 2010). Hard choices come to those who test positive for a BRCA genetic mutation,

Not surprisingly, the decision to remove apparently healthy body parts, especially those as culturally associated with femininity as breasts and ovaries, is an agonizing and relatively unprecedented one. Many women with diagnosed breast cancer find the loss of one breast a horrifying situation; women with only a predisposition to illness have an even harder time. (Price Herndl, 2014)

Since BRCA mutations are hereditary, sometimes the woman deciding has the views and thoughts of other family members swirling around her head, but often she is alone in her decisions. Most of the time, she can even picture those family members before her who were diagnosed with breast and/or ovarian cancer fighting for their lives and often losing the battle in the end. She can choose to have risk-reducing surgeries and have her breast and ovaries removed, or she can choose to not do any surgeries “since doing nothing is in fact a decision itself, and an action” (Price Herndl, 2014).

### **Testing**

Being told of having a BRCA genetic mutation is just the beginning of information, screening tests, and further results. All six respondents of the first

survey underwent additional tests for breast and ovarian screening (n=6); five had tests after receiving news of being positive for BRCA genetic mutation, and one had tests when diagnosed with breast cancer but received testing for ovarian cancer after BRCA positive status was confirmed. The CA 125 blood test, a transvaginal ultrasound, and a breast MRI were performed on all respondents (n=6) of this survey, and breast ultrasound (n=4), a mammography (n=3), and a LEEP Test (n=1) were also documented.

Preventative testing requires more time spent away from their jobs and careers due to an increased number of doctor appointments. More tests every six months or once a year also increase the anxiety of waiting on test results again.

### **Future Plans**

Two respondents, Emily and Jane, are under age 30 and have both stated that they are involved with further preventative screening and tests. “Annual MRIs, biannual physical breast exams, annual CA 125 tests, annual transvaginal ultrasounds, annual pelvic exams, and once I reach 30-35 I’ll begin mammograms”, Emily wrote, while Jane will participate in “yearly breast MRIs and ultrasounds, and an ovarian ultrasound and CA 125.”

Jane is planning on having a nipple-sparing bilateral mastectomy, salpingectomy, and an oophorectomy with the possibility of a full hysterectomy; “I’m going to wait until I’m at a more appropriate age so that I can breastfeed my

children, delay menopause, and protect my bones and heart from the effects of early menopause.” Emily “will consider it more in depth” in the future:

I feel that I am too young to make a decision for such drastic surgery. I am hopeful because medicine has advanced so much in a short amount of time with researching BRCA that in 5-10 years when I may feel ready that I will have more options as far as prevention and better recovery. I feel most nervous about a PBM because it is external and most noticeable and difficult recovery in comparison to removing ovaries and tubes.

It is clear that these two women have educated themselves well on the procedures and surgical options that they may or may not have in the future. Their apprehension to have surgeries now is well informed and thought-out.

### **Surgeries**

Heather Rocha, a woman with the BRCA1 genetic mutation, said on deciding about having a risk-reducing oophorectomy in an online article about her own BRCA story:

I talked with my mom, and she told me femininity is a state of mind and has nothing to do with the organs in your body. It has to do with getting dressed up, being happy and being a good mother... if you want to do those things, the surgery is how you give yourself the best shot. (Connor, 2013)

Four respondents from the first survey said that they had surgery(ies) related to genetic mutation and two said that they did not. Age may have played a



significant factor in the decision process of considering the surgical options as the four who did have surgery were over the age of 30, and the two who did not have any surgery are under the age of 30.

"It's empowering and scary at the same time," said Rocha. "Part of you is grateful that you have a wonderful opportunity to have these tests since they weren't around 30 years ago, and another part is scared since so few people actually get the surgery done" (Connor, 2013). Having your ovaries removed has also shown to reduce the chance of having breast cancer. The link between the two could very likely be caused by the fact that both the "breast and ovary are estrogen responsive tissues" (Livingston & Scully, 2000).

I was fortunate enough to be included in the first-in-the-nation clinical trial done at MD Anderson in Houston, Texas using a salpingectomy, the removal of both fallopian tubes, to reduce the risk for BRCA patients. This research was led by Dr. Denise Nebgen and focused on providing an alternative for pre-menopausal women who did not want to have an oophorectomy, the removal of both ovaries, due to the severe menopausal symptoms, further increased risk for developing cardiovascular disease, and osteoporosis before an appropriate menopausal age (Wendler, 2015; O'Neill et al., 2010).

I scheduled my salpingectomy to be done on March 31, 2015, my Prophylactic Bilateral Mastectomy with expanders to be done on April 20, 2015, and my breast reconstruction with implants to be done on September 4, 2015.

During the first survey, four respondents said they had surgery(ies) related to their genetic mutation and two did not have any surgery. Age may have played a significant factor in the decision-making process of surgical options as the four who did have surgery were over the age of 30, and the two who did not have any type of surgery were under the age of 30.

Four respondents chose to have surgeries (n=4) after receiving positive results for a genetic mutation; of the surgeries performed, five different kinds of surgeries were preventative, and three kinds of surgeries were done after a cancer diagnosis. All respondents had a bilateral mastectomy with breast reconstruction (n=4); three were prophylactic, and one was after a cancer diagnosis. A risk-reducing prophylactic salpingectomy was performed on three of the respondents, and an oophorectomy was performed on two respondents. Two hysterectomies were performed, one preventatively and one after a cancer diagnosis.

Gwen and Jessica were over the age of 38 when they each underwent an oophorectomy and a hysterectomy. These results suggest that an ordinary, natural menopausal age was an essential factor in determining which surgical procedures would be performed. Waiting until they were closer to that natural menopausal age would reduce effects from surgical-induced menopause and reduce the risk of cardiovascular disease and osteoporosis.

Two respondents under the age of 40 at the time of the survey did not have ovaries removed; the respondent over age 35 had a salpingectomy, and the

under age 35 respondent had no surgeries related to ovarian cancer prevention. Again these results suggest that age is a determining factor when it comes to continuing or ending reproduction abilities.

Reasons for many BRCA positive women to make the decision to have a mastectomy were genetic test results, family history or breast cancer, availability of reconstruction, age at the time discovered to be high risk, and stress related to screening (Rezende, 2016). Most women who end up having a mastectomy are satisfied with their decision (Rezende, 2016).

Other women are still reluctant to have a prophylactic bilateral mastectomy “due to concerns about body image, sexuality, quality of life, the irreversibility of the procedure, and the aggressive nature of removing healthy breasts (O’Neill et al., 2010). Concerns influential for women not to have a life-saving mastectomy include: look and feel of the body after mastectomy, loss of sensation in the breast, recovery time after reconstruction, recovery time after mastectomy, and surgical complications (Rezende, 2016).

And the prophylactic mastectomy experience within the BRCA community is a different approach to life than those who have had breast cancer.

I recorded in my dairy:

Fall of 2017:

I *choose* to have my “healthy” breasts removed without the immediate threat to my life, but I did so to preserve my health. As a single

mother, I wanted to be there to see my daughter grow up and I feared that I might not have that chance later on as my body was plotting against me.

I am trapped inside a body that is working against my life; my DNA is literally trying to kill me each and every day. I have done preventative measures to help contradict its behaviors, but those are still not a guarantee that I have done enough.

When asking respondents “Does your perception of the human body change after surgeries?” in the survey, all replied with a “yes.” I stated that “perfection is no longer an option,” because my body will never be what is shown as the ideal by normal standards. Gwen and Mary Catherine responded by saying, “I’m not the same as I was before,” and “the human body is amazing how it can recover after such trauma... I put my body through hell.” Their words speak of the significant physical impact that these types of surgeries have on each individual. Jessica focused on the emotional aspect and how it has changed her own views of other people’s bodies, they also experienced an “increased sense of compassion for the hidden physical wounds and pain people carry,”

### **BRCA is Not the Same as Cancer**

Mary Catherine stated, “most people ask if it’s cancer and you have to say there is undeveloped spot but it’s not cancer,” this statement connects for me literally being a card-carrying member of a cancer center. It’s not cancer, but yet we go through a lot of the same treatments. Some people act like we shouldn’t have any trouble with surgery and recovery because we didn’t have cancer. But

a mastectomy is still an intensive surgery with or without having cancer. That is not to say that it is the same as cancer. We chose these surgeries to NOT go through what we watched family members go through with cancer. I am just saying that I wish others would not be so dismissive of our struggle.

### **After Surgeries**

Taking off time for surgeries can be a difficult thing to manage within your regular routines and when lengthy recoveries are expected. Respondents who had surgeries related to ovarian cancer prevention: including a salpingectomy, an oophorectomy, or a hysterectomy, took from three to four weeks off of regular activities for recovery.

After four respondents had a bilateral mastectomy and breast reconstruction, they took from six weeks to five months off of regular activities for recovery; two respondents took six weeks, one respondent three months, and one respondent took five months. The extended times of three to five months were due to complications from nerve pain and breast cancer treatments.

Of the four respondents that had surgeries, all chose to have a bilateral mastectomy with breast reconstruction. The breast reconstruction was done as a direct to implants surgery (n=2) and expanders to implants surgery (n=2).

Direct to implants surgery requires only one surgery and uses one's own body tissue from elsewhere on the body, usually the back. Expanders to implants surgery requires multiple surgeries: the first one is the insertion of expanders that are filled with saline in intervals to slowly expand the skin where

the new implant will be placed and then surgery can be done to remove expanders and insert saline or silicone implants.

One respondent had a breast reduction prior to bilateral mastectomy, and one respondent had fat grafting done along with implants surgery to help with appearance and reduce pain.

Complications that come with having a bilateral mastectomy can be long-lasting. Respondents experienced, “several visits with specialists due to 3 years of unexplained chronic pain”, “nerve damage that required painkillers and a nerve blocker,” and an open wound that “took three months to heal.”

I wrote in my journal:

July 13, 2015:

I am almost three months post-PBM (prophylactic bilateral mastectomy) with tissue expanders. I have been mostly inactive due to drain tubes in for 4.5 weeks and severe nerve pain. They have now put me on a nerve blocker two weeks ago which has helped tremendously. I am still having pain from tissue expanders that feels like it is pulling on my ribs on left side. I am still having to sleep in the recliner, and now I cannot even recline it without pain because the expanders then pull on the middle of my chest when I lay back. It keeps me from sleeping, and I'm exhausted. I have until September 4th for exchange surgery. (personal journal)

Another of the respondents had another six-week recovery period after corrective surgery was needed after breast reconstruction.

### **Limitations**

Limitations on the physical abilities of the respondents after surgeries included: inability to lift anything or drive, inability to move with drains in, limited physical impact, and inability to work out or continue in exercises that were done before surgeries.

Continued limitations on physical abilities after surgery have affected all of the surgical respondents (n=4). I also responded by stating, “can not push or pull straight out from my body. ” Gwen wrote that she “still can’t move right arm as much as I could before, and no push ups ever!” and Jessica said that she has “major limitations on upper body movement and lifting... resulting pain has negatively impacted daily life.” The physical abilities, or lack thereof, have effects that continue long after the surgery.

### **Physical Movement**

Exercising in a low impact class that uses isometrics and dynamic movements to work out has helped Mary Catherine with pain management and regaining mobility after surgeries; “I just been able to start running again... I switched from weightlifting to Barre3 before my first surgery and this has been amazing. I used Barre3 as my rehab and to stay in shape. I can finally lift my arms again over my head.”

I have personally struggled with being able to exercise after surgeries and have gained weight with the inability to perform moves and strengths that I once did. This has affected me on a physical and emotional level that has not helped to improve self-esteem. Before my first surgery on this journey, I was participating in 5 a.m. bootcamp workouts three times a week, which included kickboxing, lifting weights and running on my elliptical three days a week with only one rest day in between. I was able to back squat 195 lbs. consistently throughout a workout and with the first surgery, I was unable to lift more than 5 lbs. at a time during recovery. Due to complications after mastectomy I was not allowed to do the things that made me feel better at all, and this compounded a depressed state.

I have only recently begun to get back into doing cardio at home on a regular basis with the hopes of starting back up in lifting weights and kickboxing. Paige Previvor wrote in her article “Exactly What I Did To Heal My Body & Mind After A Double Mastectomy”;

After my surgery, I was bedridden for weeks. I could barely move my arms or get out of bed on my own, and it was one of the most difficult experiences of my life. I was just lying there all day, every day, in pain and lost in my thoughts. I had made the biggest decision of my life. Typically when I had something this major or heavy on my mind, I would burn it off at the gym or lose myself in a cycling class. But with this, I just had to lie



there thinking about what I had just gone through. It made me anxious and depressed for the first time in my life. (2018)

## **Emotional Experiences**

**Anxiety.** The day before my salpingectomy, I wrote in my journal while sitting at home:

March 30, 2015:

Anxiety comes and goes; it is caused by other factors; work, who will drive my daughter to school, will I be able to get housework done, how are my students doing? I have peace with the surgery itself, a little nervous with the anesthesia but it's because it is something new.

Other people's doubts have crept up on me during this past week, but I know I am doing the right steps for me and my family (daughter). I have faith that God has led me to these decisions, and He encourages me daily.

The uncertainty in many areas of my life was combining into one significant stressor, I knew what I had to do, but it did not make it less scary for me.

BRCA Facebook groups are where I found others in the same situation, and I found comfort in their words, knowledge, and encouragements. That same day I also wrote my first post on a private BRCA Facebook group:

March 30, 2015:

This is my first post, but I have been supported by all of your wisdom on here as I made my decision towards surgery. Today I say

goodbye to my Fallopian tubes. My ovaries will be hanging around a while longer since I'm 33. I am excited to reduce part of my risk and at the same time become a part of a clinical study that could help future generations in the detection and fight against ovarian cancer. All prayers for peace and healing are appreciated.

It was clear that I was not ready to make my journey known to friends on Facebook, but I found it comforting to post within a group of people like myself, people I have never met before. It was a strange sense of familiarity within these groups of strangers. It was their understanding that allowed me to have someone to talk to who understood what I was going through.

Physical and emotional categories of the BRCA community studied mirrored what I personally had dealt with and been through on a physical and an emotional level. Anxiety was a key word that showed up on many occasions in the survey results as well as my own experiences. Meditation, therapy, medications, and an understanding support system are some of the ways that the respondents and myself were able to keep anxiety away.

Lengthy recovery processes have also impacted the emotional well-being of the respondents. Many spoke about having depression and anxiety (n=3). Anxiety is due to being unable to communicate effectively with others on what is happening to you with regards to recovery because it can change daily. A concern of the "lasting effect" of anxiety has created a cycle of worry that has yet to decrease for some.

Anxieties can lead to unprecedented emotional breakdowns when individuals are faced with the physical limitations caused by surgeries. The emotional well-being of the respondents was impacted due to surgeries. Gwen said she “worry(ied) if I will have any last(ing) effects,” while Jessica stated that a lack of estrogen has “increased daily irritations” and that she has “been taking antidepressants, anti-anxiety and pain medication for 4 years. Major body image issues have increased depression and decreased my social interactions.” I also wrote about depression caused during this process of surgeries and recovery, “I did go into a depression about not being able to do things around my house or anywhere. I still struggle with anxiety that I did not have before.”

I began having anxiety attacks during my wait for genetic testing results to be returned; I had chalked it up to worrying about my sister’s health from across the country but I failed to realize at the time how much not knowing was weighing on me.

May 24, 2015, at 7:10 a.m.:

God made me strong, beautiful and perfectly imperfect!! I’m a BRCA Previvor!!”

A Previvor is “a survivor of a predisposition (or increased risk) for a disease such as cancer” (Bates, 2016).

This was true, but it was not the whole story; it was a façade that I was putting on trying to hide what was really happening to me. It was not until I

began this research that I honestly sat down and reflected on my experience as a whole and could see when and where I began to pull away from others.

Anxieties had become part of my everyday recovery process after reconstruction, as I did not have anxiety during the decisions or with surgeries but rather during the healing process. I guess I finally had time to think about what had all occurred and how it now affects my entire life and the life of my family.

**Family Burden.** I was determined to have my testing and surgeries done in order to use preventive measures and not wait until I had a cancer diagnosis to do something about my health. Unfortunately, I was not thinking of the ramifications that it would have on others. After determining our own BRCA2 status, we inevitably open up our families and children to the uncertainty of their future. My daughter now has increased awareness of health and the issues that she could face if it is determined that she also carries the genetic mutation.

The National Comprehensive Cancer Network (NCCN) “Guidelines for Risk Management for Women with BRCA Mutations,” indicates that medical screening tests begin after age 25 (NCCN, 2017). Emily stated that she had undergone genetic counseling at age 20 but was “too afraid to know my results” she decided to wait and get tested at age 25 instead.

Testing for children is allowed by parents in other countries throughout the world but not for children in the United States of America. It is recommended that a person be a legal adult, at eighteen years of age, to make the decision. I

feel that this is a good reason as many adults with a family member identified as having a genetic mutation still choose not to be tested due to the emotional toll and burden it places on people.

I now can educate my family on our risks associated with the BRCA2 genetic mutation and possibly save a life as well. My daughter, who is not allowed to be tested yet due to her age, will now have the option to be tested. That will allow her to make her own decisions about testing and preventative measures if necessary.

Difficulty in tracing a family's history of cancer results in difficulty with getting genetic tests performed. Genetic testing has been around for only 21 years, and the absence of testing in previous generations to track familial cancer genes affects future generations.

Before finding out the results of her genetic testing, Jane wrote that; in a way [I] wanted to be BRCA positive because I felt that it would help my mom come to terms with her own diagnosis. If she has to die from this disease at least, she would have the knowledge that I would be able to prevent myself from developing cancer.

The thoughts of reassuring other family members who have already been diagnosed with cancer and tested positive for a BRCA genetic mutation is comforting to the ill relative to know that they could be *dying* in order to save loved ones rather than just having them *taken by cancer*.

Family's thoughts and reactions to finding out that the respondent was positive for a BRCA genetic mutation ranged from "shock" to "not surprised," with most discussion over how it affects everyone in the family; "it wasn't good news for anyone" and caused "wonder over their (own) status." One respondent stated that they family were "supportive but nervous for my future" and "were pushy towards certain preventative measures while others supported whatever decisions I made."

I knew that my sister would understand the physical aspects of our shared experiences, but we were fighting two different battles mentally. I was fighting for the removal of a "healthy" part of my body just to be cut off and changed forever while she was making decisions to fight what was already damaging her physically. We both ended up having the same surgery, but they were two sides of the same mastectomy coin and could not be compared outside of the physical aspects.

**Depression.** I have received support from those who have gone before me on this journey, and we keep those who have lost the fight close to our hearts. BRCA Facebook groups become an open and honest community that does not sugarcoat things. They have an understanding of what you have gone through when others could not begin to comprehend.

I was also fighting the battles of those around me who could not understand why I would "choose" to cut off a "healthy" part of my body, but to me what choice did I really have. I saw a quote written by an unknown Previvor

around this time on Facebook, “Is it really elective surgery, if the alternative is cancer?” although I do not know who said it or when it stuck with me and became a personal mantra of mine.

If I had a big toe cut off in order to stop the spread of cancer, people would not second guess my decision or judge my femininity by it. I knew that preventative surgeries were the best thing for me, to have the option to beat cancer before cancer beats me and to be around for my daughter longer. Initially, I went into the process thinking that the physical necessities were going to be the hardest part. I researched and came up with a game plan for my life in regards to reducing my risk of cancer, but I was not prepared for the emotional toll that hit me only a little while after my mastectomy. What had I gotten myself into and what was going to happen next with me? I hit emotional rock bottom and cried for three days straight. How was I going to make it past this part on my own? What did I need to do to get out of it? I had always turned to art for healing and comfort, but my body was not able to do the one thing that had sustained me throughout my entire life. How do I cope now? Knowing that I no longer had control over my body or my emotions sent me into a downward spiral toward depression. I could not see it at the time, but I needed to find a way back to myself, a goal that I am still working towards.

That whole summer was a blur of having to figure out who could drive me to doctor appointments each week and having my daughter drive me around on her newly received driver’s permit. I knew what was needed to get out of the

funk I was in but did not have the ability emotionally or physically at the time to do so. I now use meditation to keep my stress levels down and have found benefits from keeping my mind clear. When I get overwhelmed at work or even with the writing of this thesis, I have to remind myself of where I have been before and what I need to do to keep myself from going back into that hole.

March 31, 2016:

1 year ago today started my journey to becoming a BRCA2 Previivor. What a journey it has been and continued to be! I sometimes miss the person I once was but look forward to the stronger person I will become.

It has profoundly changed my life and made me look and appreciate the simple things in life in a light of gratitude. (personal journal)

**Identity.** While in a doctor's waiting area, I overheard two men talking about a news story on the television about a transgender person getting breast implants and one of the men said: "well, he's a woman now." Those words cut sharply through me, not because of the person or the story but because I thought, what does that make me? If getting breasts makes a man turn into a woman, and I am a woman who removed her breasts, does that make me less of a woman? I had never thought of it that way before or felt so without an identity in my life. It was a few moments of time before I went back to feeling like an empowered woman who had to do something drastic to save her life, but the



thoughts of gender identity do still come back from time to time and catch me off guard.

I did not regret my decision to do these risk-reducing surgeries, but I did regret not having emotionally prepared myself as much as I had physically prepared my home. I didn't know how to tell others how I was genuinely feeling and felt like I had to hide away from the world. I couldn't let them see that I was an emotional wreck on this journey. I felt that I could not complain about the physical pain I was in or how I was dealing with all these thoughts and emotions because I "chose" to have these surgeries; it was not like I actually had cancer.

## **Chapter 6**

### **Effects on Career**

#### **Graduate Student**

In the Spring of 2015, I was still taking graduate school courses through Stephen F. Austin State University at the time of my surgeries and felt that I would have ample time to work on my thesis that was already started. That thesis was completely different from this paper, but I felt compelled to find meaning in what was happening to me. I knew that I would be confined to a recliner for quite a while when recovering and planned to use this time wisely and continue my work towards my Master's Degree. Below are transcripts of two emails that I had sent out to my professor after I had my mastectomy on April 20, 2015. I was required by my doctor to stop typing on the computer due to the movement causing my body to produce a more fluid output through drains.

May 7, 2015, at 9:31 AM:

I feel that this recovery process is going to be very long and painful for the duration. I have been able to have 2 out of the 4 drains removed, but I am hoping to get the last 2 out next week. That will help to relieve some pressure off of my chest. The expanders rub against my ribs and make it hard to breathe at times. (personal communication)

May 14, 2015, at 8:35 AM:

I am unable to call you; I was trying to the past two days after I left the doctor but I apparently am a non-stop emotional wreck this week. They had limited my use of the computer as it is putting too much strain on my chest wall. I was trying to still work through it, but on Tuesday they told me that I had to stop completely until I can have these drains removed. I am dictating through my phone, but that does not help me type anything or look up information. I am completely at a loss as to how to finish at this point or even if I can.

I do not know what options, if any, I have to finish these courses. I no longer have help at home during the day, and my daughter has to take care of me after school. (I can't stop the tears from flowing) I feel so much like a failure at this point and do not know how to continue working on assignments. I don't even know if there are any extensions that I could use or if I just have to accept a bad grade with option of redoing. Although I do not know the ramifications of that either, will they kick me out of graduate program, financial aid? Any ideas of what I need to do??  
(personal communication).

I feel that these emails show the rapid decrease of ability to continue functioning as I would usually and the increase in frustration I was having with the recovery process and what that meant for my "new normal," a term that refers to a cancer survivor's requirement to adjust to the many complex changes they experience

throughout their journey (Netz-Fulkerson. 2016). I would have to say that this was probably one of my lowest points in terms of anxiety and stress. I was starting to fall into a depression, and I had no idea how to get out of it. Nothing was working out the way I had planned it, and there was absolutely nothing anyone could do to help get me out of it.

After my reconstruction surgery, I emailed another of my professors from Stephen F. Austin State University:

September 13, 2015, at 3:58 p.m.:

I am recovering nicely on all parts that were “worked on” but I had some adverse reactions to the pain meds this time. We are unsure why since it was the same meds I was on previously but I began losing vision more each day, and after three days I took myself off of the pain meds to see if that was what was causing it. Sure enough, it was my eyesight is still a little off (like I need a different glasses prescription or I am just inches away from the page to see) but it is getting better each day. As an artist, nothing is scarier than having blurred vision and it getting worse by the hour.

But I say all that to say that I AM BACK. I had started the readings before my surgery and tried to continue right after to no avail, but I am currently working on them now. I hope I can still finish today before the due date. (personal communication)

## Teacher

When I looked into finding information on how having the prophylactic surgeries would affect me as an art educator, I could not find information that directly related to it. I found not one instance telling of how it might change the way I teach, how I plan lessons, or how I communicate with my students. Not a single one is describing how I would be an emotional wreck at times and would have to teach through the anxiety and physical pain.

As educators, we *must* share our passions with the world and teach others about what we have learned. If I teach only one thing to each person who reads this research, then I will have done what I set out to do.

**Making plans.** My doctors at MD Anderson worked with me to determine the length of time that I would not be able to function in my normal setting as an art teacher after surgeries and recoveries. We used these timeframes to create a schedule that would better serve everyone involved.

As an educator, I wanted to make this work around the school year as much as possible while still not letting my job dictate my health. I scheduled surgeries to take the least amount of time away from my students as I could while getting them done quickly to preserve my health.

One respondent was concerned about clients, while I was concerned for my students as an educator; I did not want to miss out on very much of the school year with them. I determined that I would be better off missing the end of the school year versus the beginning of the next school year, in order to have

better behavior and organization for my substitute. Consideration of children's needs were also a concern for two respondents as they were planning for surgeries: I wrote, "I was concerned with my daughter and how it would affect her emotional(ly) and physically" and Gwen asked, "How can I help them (my children) when I am limited".

All respondents had planned for their regular routines to continue without them being able to do their part while they had surgeries and recovered; they lined up helpers, got others to take over responsibilities, created lesson plans for multiple weeks, and worked long hours to get things done before surgery. Not only does the situation affect the routines of the person having surgery but also those around them.

Unlike preventative testing that requires a bi-annual or annual time off from work, surgeries require a more extended timeframe all at once instead of spreading the testing out over multiple years. The majority of surgeries offered will require an educator to be away from students for quite a while, have a long-term substitute and plan lessons for the length of time away. These types of time requirements and anxieties will have an effect on job performance and stress levels as an educator. Anxieties of what is happening in the classroom without you during this time can increase stress and complications.

I created 10 weeks of lessons that were to be utilized during this time by my substitute while teaching art at the high school level. In the end, my substitute decided on her own to not use them, and all my work had been for

nothing. Students were left to their own devices in the art room; paint was poured into a drawer, the artwork was taken from other students folders, and art materials were used unnecessarily. This environment created a lack of continuity of the art curriculum that was planned and being implemented prior to my medical leave (Netz-Fulkerson. 2016).

Although I was on medical leave, I was still doing some job requirements while recovering just to help my students out. I was getting emails from my art-focused students asking what they could be doing and where they could put their work each day to keep them safe. After I had to let my principal know what was happening, or rather not happening in my art room, he told me to just rest and that he would take care of everything. He personally graded and submitted the art grades to finish out the year for me. I often feel that my students during that time were cheated on knowledge and education of artists, art history, media techniques, and being allowed just to create art within the guidance of an actual artist. That is something that I cannot make up for them; the time has passed.

**Teaching is physical.** Art educators who are unable to move the way they did before physically will significantly decrease working procedures in the art room, including: lifting boxes, carrying supplies, moving drying racks, getting out and putting up supplies on shelves or painting on an easel.

The ability to perform tasks as an art educator can also increase the dangers after a surgery. Due to desensitization of the nerves in multiple locations: chest, sides, upper back, and upper arms and thinned skin over

implants I have to be extremely careful not to carry something too close to my chest or lean into a cabinet. This might sound like an easy task, and it was easy for me before surgeries too. Now that I have no feeling in the chest area, I do not notice until I see the cabinet handle pushing into my chest. Too close to a hot kiln could spell disaster! These are now elements added to an already stressful job that I *have* to think about every day for my own safety.

I returned the next fall to teaching art with the following week as my reconstruction date. I quickly set up my students for success while I was to be away and hoped that this one would be easier, with no complications, as many had said it would be. I pushed myself and returned back to work after eight days as I did not want my students to miss out on any of their curricula.

I began to have severe nerve damage in my chest and required more doctor visits before being prescribed a nerve blocker medication to allow me to continue with my “normal” teaching schedule without the constant pain. It was working, and I was back to work as I did before this journey. Then, I noticed that I was forgetting things and unable to form the correct words all the time which I chalked up to stress. As it progressively got worse, I caught myself forgetting things in the middle of a lesson to my students. Once I was in the middle of a sentence about shading pencils and...nothing, I had completely lost the train of thought and there was nothing there to recover. I gave them a free draw assignment and tried to get the lesson and what I was saying back, but it did not return. I knew that something was not right and it needed to be fixed. It was only



then determined to be a reaction to the nerve blocker, so I weaned myself from them and had not taken anything else for the pain since. I wanted to make sure that I could still teach my students to the best of my ability even if that means I sometimes teach while in pain.

**Acceptance.** I want my students to accept each other's differences and not focus on them. This has always been easy for me to do for others in the classroom, but now I struggle with accepting the *new* me. As an educator, I want to teach my students all that I have learned, but I must advocate in secret due to not wanting disclosure to students and discussions on topics involving my breast and ovaries, as it would be inappropriate for me to do so. A person with an actual cancer diagnosis can easier explain what is happening to them than a person doing preventative surgeries. Thus, I am searching for opportunities to share my story with adults. I hope this research finds a way to help others as much as it is helping me. I have fought for rights in secret due to not wanting disclosure to students.

I have this huge life-changing experience, and I am unable to share with my students or colleagues. In the public education sector, it would be deemed inappropriate to speak on the topic that is most affecting my life: my breasts and ovaries. Can I speak about why I cannot create the Art I want to while still teaching in a public school or why I cannot be honest, in regards to BRCA status, in my profile on Facebook since the public can view what I write and show?

I cannot wholly be myself while teaching; I cannot share life experiences that define who I am today. Maybe I put too much emphasis on being BRCA2 positive in my life, but how can I not. Hopefully, I will be able to find a way to move past such a condition, but right now I cannot.

### **Artist**

In the first online survey, respondents were asked to classify themselves as Artists, identify their levels as an Art Educator, and/or other, in relation to their career or hobby with the option of choosing more than one area. The respondents classified themselves as; two art educators; one at the K-4 level and one at the college level, three Artists, including one Quilt Artist and one owner of a local art gallery in their area.

Only three respondents classified themselves as an “artist”; however, after reading their answers throughout the survey, it became clear that all six are artists of their own kind of media and two are actually involved pretty hands-on with art galleries, one as an owner and another as a commissioned artist.

As artists, we already have a unique way of looking at things, and that is part of the wonderful aspect of doing this research to show that maybe we can see things in a new light and shine that light onto others.

When all six respondents were asked if their genetic mutation affected their beliefs as an artist, half answered no (n=3). Those who answered yes (n=3) stated that they are “more freely open to new ideas and concepts in art” and “truly understanding the meaning of healing through art. Not just appreciating art

for the sake of the art itself.” Another respondent wrote; “I have a stronger satisfaction in my body and the world due to this mutation/risk knowing that my body may change in the future to save my life.”

**Art is physical.** Even with the lengthy process that surgeries and recoveries bring each respondent felt relieved to have regained control over their lives and were ready and able to move on. I am struggling to remember my old self and I need to find comfort in my new body. I believe that Jo Beth Ravitz said it best; the “memory of my original body has diminished” (2015).

So I looked for research into my life as an artist and did not find anything that remotely said I would not be able to carry my case of paints across the room, reach to get a canvas from the top of the shelf or push a carving tool across a woodblock for printmaking. All the things that gave me joy on a bad day were also taken from me. My coping mechanisms, my sanity, and my peace were cut from me the day I had my mastectomy, and I had no idea they would disappear. I thought I had prepared every detail of what the surgery would do physically to me and had everything and everyone ready to help nearby, but there was nothing to prepare me for the emotional toll of it all on my life as an artist and educator.

As an artist, limitations in job performance can be more significant due to the physical nature of creating something. No matter the media, surgeries will affect you in some way, either for a short period of time or an extended period of time. Ravitz wrote that she was “unable to use her arms” (2015) to continue

working on her art, so she had her husband assist her in creating art through photographs along with her journey through breast reconstruction.

Many respondents had an inability to perform tasks needed with regards to their art; Gwen wrote that she “can’t sit as long as I could before, my strength isn’t as much” and I stated, “lifting items has been a struggle.” Mary Catherine also responded that she, “could not do everything I wanted to do... cannot lift the canvas” and was

not able to paint to doing any printing because of my surgery... typically (before surgery) I would produce 3 to 4 paintings weekly and print about 50 to 60 orders. I also stretched my own canvas prints... it’s going to be awhile before that happens again.

The struggles continue for some while others like Rita stated that after a lengthy recovery, she now creates, sews, and embroiders on bags, “I guess it can show others that you can do whatever you set your mind too. I had a double mastectomy, and I use my arms and hands to sew.” She found empowerment through focusing on what she can do now, instead of what she used to be able to do.

**Making plans.** Consideration of job ability when planning on having surgeries was taken into account by half of the respondents (n=3). Jessica thought about “covering gallery hours and ability to attend local holiday sales events” while another thought about changes in ability to complete jobs in a timely manner, “I canceled the orders that I could not finish in time.” Mary

Catherine wrote that she “took time off of work from art” because she knew that she could not continue with her work; “My painting was physical(ly) involved... I painted on canvas that were 30” by 40” or larger. I would stand while painting and would have to lift heavy boxes to get the paints.” She also changed careers during the time of surgeries and recoveries due to limitations. She has been doing more work in Interior Design and Architecture “because it’s all digital” and has been working on getting her real estate license, a profession requiring no physical exertion.

### **Implications for Art Education**

The stronger theme of the artist is acceptance: acceptance of themselves and acceptance by others. One respondent, Amy, wrote;

Art is a mode of communication about aesthetics. Aesthetics can be beautiful. Women often feel a sense of loss with loss of body parts that defined what it meant to be female. It is important to learn how to feel comfortable in your new or changed body.

This could suggest an acceptance of more art forms, techniques, or therapeutic media. I want to explore artists that seek to heal through art more than I ever have before. By understanding the creation process through tragedies, I believe I will better understand creating joy and happiness and the uplifting feelings making art provides.

**Loss of voice.** It is such an isolating feeling, holding in your emotions around the family and friends as you know your struggle is not the same as

actual cancer diagnosis and you do not want to compare the two. The similarities do exist, and yet I remain silent.

January, 24, 2018

My voice has been cut off as well as my breasts. In my own family, I cannot discuss all that I want to while watching my sister battle Stage IV breast cancer. I cannot have a bad day, as her day is always worse. Am I a horrible person for saying that? Am I a bad sister for thinking that just once it would be nice if someone in my family asked how I am doing? I feel bad for even thinking that, but I do feel that this is the only time I can be completely honest with everyone and myself. I have been sitting in silence for three years so I would not offend anyone.

Autoethnography research is designed to let many into a world or experience that only one person has at a time. In my own experience, no one was there inside my head with me as I weighed the pros and cons of having a prophylactic mastectomy or when I cried myself to sleep knowing that I could no longer physically do all the things I once did. These are not things that I shared with others out loud, at the time or even now, but that is changing. It is time to have a voice for myself and for others in the same situation to know that they are not alone; the silence has to be broken.

Acceptance comes also in the beginning of advocacy for myself and understanding more about my “new normal” and sharing my voice in and through art.

**Finding a voice.** With the writing of this autoethnography, I have uncovered many thoughts and emotions that I had forgotten or did not even know were there. I feel a more profound sense of relief in being able to share them now.

I think over time it becomes easier for people to open up about their own experiences and journeys as they move throughout the healing process because the respondents who shared more in-depth pieces of themselves were women who had started the journey several years before. The isolation that is felt could be prevented by others with a BRCA mutation sharing their stories. All respondents to the surveys showed an increased desire to become more vocal about their journeys and help others to become more aware of BRCA and HBOC (Hereditary Breast and Ovarian Cancer).

Seventy-seven percent of the respondents (n=27) from the second survey stated that they felt that they could effect change in their community or even the world. Twenty-six respondents wrote that they could do this by sharing their BRCA story; Alli said, "I will share my story and encourage others who are at risk to be tested so that they can save their own life," and Debbie stated, "I continue to educate myself about research and speak to groups about my experience." Although not all respondents said specifically that they would share their story to empower others, all were already doing so by answering honestly while taking this survey about their own BRCA journey.

Of the educators who were part of the survey; one said that having a genetic mutation did not affect her beliefs as an educator, while the one who had preventative surgeries said, “I am eager to point out the beauty of imperfections to my students rather than focusing on getting something *right*.” Jessica, who is not an educator, answered this question by stating that she now has a “desire to increase HBOC (hereditary breast and ovarian cancer) awareness in the community by sharing my journey.” Mary Catherine spoke about the silencing aspect of having a mastectomy, “my concerns have been about be(ing) vocal about hav(ing) a mastectomy. I feel really awkward talking about it with strangers.”

**Empowerment.** Empowerment for patients with a genetic mutation was defined by McAllister, Wood, Dunn, Shiloh, and Todd as “a set of beliefs that enables a person from a family affect by a genetic condition to feel they have some control over and hope for the future” (as cited in Cragun & Zierhut, 2018). Oxford Dictionary’s definition of empowerment is; “the authority or power given to someone to do something OR the process of becoming stronger and more confident, especially in controlling one’s life and claiming one’s rights.” I feel that the Oxford definition fits better with the attitudes and beliefs of the women I surveyed. McAllister et al. definition is positive but remains weaker than that of the Oxford definition which includes, “becoming stronger and more confident” in relation to what is happening for these women.



Many women who responded to the second survey wrote about how they will continue to and help others to feel empowered and discussed the need to share their stories with others. Art projects can be a way to convey empowerment and facilitate the empowerment of others. Art can speak across languages, cultures, and backgrounds to voice those stories to many viewers, and as artists and art educators we can lead the way by creating projects that help to empower others.

Some respondents noted that they had already participated in community-based art projects to bring awareness of BRCA genetic mutations by “submitting a photo for a college art project...to be part of a display of awareness” and being “paired with an artist who made a bodice sculpture about my body and my story.” This last sculpture project was part of a bigger collaboration project called The Bodice Project.

**The Bodice Project.** The Bodice Project is a “not-for-profit sculptural exhibition that promotes emotional healing, through the arts, for women and men facing the challenge of breast cancer, and life after treatment” (The Bodice Project). This project started when Cynthia Fraula-Hahn made the first bodice sculpture of her friend to showcase her strengths and show “beauty regardless of surgery or other forms of treatment.” Participation in the project continued to grow and became an exhibition at a community college, it was only then that they realized the “full impact of the work” as “the human experience of breast cancer and its aftermath.” Participants who have been a part of this project have been

interviewed and parts of their stories and “deeply introspective” words are placed next to their bodice sculptures.

The project recently had a bigger audience of more than 20,000 at the American Association For Cancer Research in Chicago. Many artists have since joined the project and calls are continuing to go out for both artists and participants in a project that aids in the “emotional healing” of those affected by breast cancer and preventative surgeries for breast cancer.

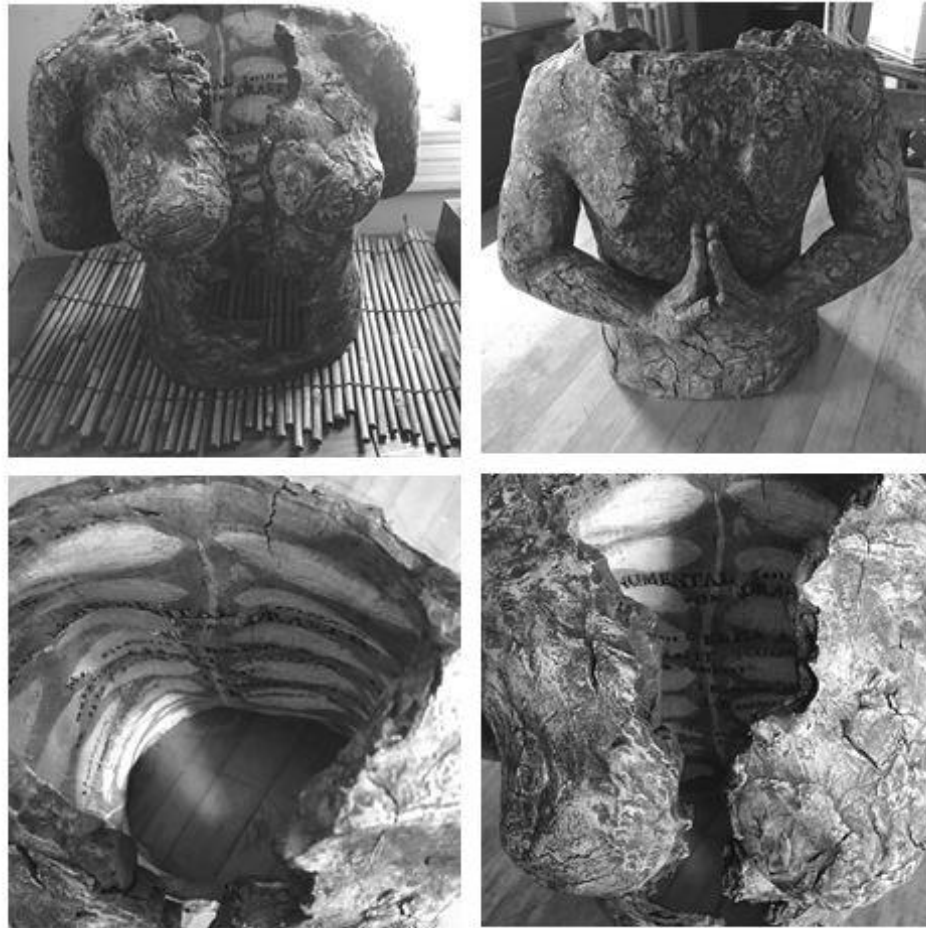
**An individual voice.** I had personal communication within emails from a participant in The Bodice Project, Amy, which allowed me to gain more information on how these types of projects help the women involved. Amy spoke to me about finally having the courage to have a prophylactic mastectomy six years after the discovery of being BRCA2 positive. Then with trying to get used to her new body and life, she had this to say: “I just simply don’t remember how it felt to be in my body before the mastectomy and reconstruction.”

Amy knew of The Bodice Project prior to having her surgery and stated that she was thankful to have the opportunity to present her bodice as part of the Previvor collection;

It is the emotion and the need to communicate that drives the final product, and especially with sculpture, the final product is now a real “thing” that occupies space. So as I was making the enormous decision to lose some body parts, I was already collaborating on a piece to honor this decision and this ridiculous but fortunate opportunity/experience. It gave

me a way to communicate, via an artist, through collaboration, what was happening to me. It gave me an outlet. (personal communication)

Amy wrote in a journal throughout her experience and then shared those with the artist to create this sculpture (see Figure 3). The artist took some of her words and stamped them on the inside of the bodice, which was then lit by a light on the front of the display. “Everything about this piece is symbolic of something I said, or that I do, right down to the yoga pose, the plant, the cracked exterior, the lit interior, etc.,” said Amy.



**Figure 3. Rule-Thompson, Anne. (2017) *Hidden Prayer*. Bodice sculpture created for BRCA positive advocate.**

**Healing process.** The Bodice Project is more than a collection of artworks that evoke emotions by viewing them. These types of projects can offer a healing opportunity for those involved by exploring another part of the experience, focusing on something outside of their own body. Amy wrote this about her experience with The Bodice Project:

Mastectomy was the scariest thing in the world to me. I was utterly terrified. This project gave me some attention...a diversion; a way to

communicate my fear, and ultimately my empowerment; a way to keep a piece of the old me, like a skin that had been shed. It also gives me a platform on which to converse with other people who have been touched by breast cancer, or who are dealing with mutations. (personal communication)

Artists in projects like these can help give voices to those who do not know how to express themselves yet or do not want to stand before others and speak up personally. Art can be the bridge between silence and advocacy.

**Advocacy.** In the public school setting, I cannot bring in all types of art that might be related to BRCA mutations or mastectomies into my classroom as it would be inappropriate for me to discuss the physical aspect of breasts with my students, but I can use my own background to encourage them to create art for social awareness and changes regarding various issues. I can explore ways to share my own role as an advocate in a broader sense of advocacy for women's empowerment to help them develop their own perspectives on how art can be used to effect change.

Often contemporary artists use social issues to guide their body of work within a variety of media. "Through their expressive talents, artists can challenge cultural narratives, shift imagery and inspire emotions in a way that traditional political methods alone rarely do" (Wunderlich, 2016). I feel that students should be able to discuss the art and their views on the issue in a broader context. Discussions of various viewpoints on the same issue should also be done in a

way that is constructive and not intimidating. These artworks should be studied and examined carefully by students to find the messages given, some subtle and some very obvious.

**Art for social change.** Advocacy is becoming more apparent at an earlier age for the next generation, and as teachers, we need to adapt to this. “Art can be a platform for social change because it reaches deep into our souls and speaks a visceral language we all understand” (Hoeve, 2016). I often ask myself what I can do to help foster my students’ creativity in this realm and help them to understand others who produce artwork for advocacy. Exposure to an array of artists can help to foster this kind of art. Awareness projects offer connections to relevant material in our students’ lives and the world.

I should also note that I do not feel that art education should strictly focus on social issues, but encourage our students to discern their own experiences to heighten the level at which we make art. Social issues and advocacy should be used as one of many tools that art educators employ to facilitate the expressions that our students wish to achieve. The more art one has learned about, the more innovative their art can become.

## **Chapter 7**

### **Conclusion**

The writing of this autoethnography research was challenging for me on an emotional level. I wrote about some difficult times in my life that I had not shared with anyone before. I knew from reading about autoethnography that the writing often times would become therapeutic for the writer, but I did not know the extent of how it could help me work through my struggles along my BRCA journey (Holman Jones, Adams, & Ellis, 2016; Bochner & Ellis, 2016). I have learned more about myself through the journey of writing this research.

I needed to know that I was not alone in my thoughts or feelings with regard to the significant physical and emotional changes in my life and that it was okay for me to feel the way I was feeling. I felt understood for the first time in a long time when one of the respondents, Mary Catherine, wrote; “This is the story of my life. Can't believe that you're studying this. Really cool!” (personal communication, October 9, 2017).

Research had been done on the various parts of what I spoke about in this paper separately but none had combined aspects of an artist or art educator living with a BRCA genetic mutation in one place. The emotional and the physical effects are combined and woven together in such a way that I feel addressing one without the other is a disservice. Artwork is a great way to bridge the two together and share the voices of those affected.

The reality of living with a BRCA genetic mutation is a constant focus of my thoughts. Everything I do in life after discovering that I have a genetic mutation has an emotional sidekick, my very own mutant that must go everywhere I go and always remind me of its existence. This tiny part of my DNA is taking up most of my life, a tagalong that is not wanted, an intruder.

Unknown date in 2016:

Every strand of my DNA has a small piece trying to welcome cancer into my life, and it's trying to kill me on an everyday basis. This genetic mutation will always be with you; it is not something you can cure with medication or remove. I do what I can to prevent it from winning but tomorrow is not a guarantee of freedom from it. I cannot escape from it.

(personal journal)

Through this research, I have been able to better reflect on my experiences with genetic mutation testing, procedures, surgeries, and recoveries. I have gone through several emotions, I have cried at the thoughts of my own pain and the pain of my sister still fighting breast cancer, and I have squealed with delight at the fact that I am able to take control of possible cancer before it has control over me. Emotional stress showed throughout the study by the respondents and me also included a determination to make the best of a situation and take control of one's life. I was surprised that many others struggled with the anxiety and emotional stress that I was feeling. I feel that the depression and anxiety that



many feel stems from not having personal contact with others who are going through or have experienced the same things.

For those with a BRCA genetic mutation, a concern for other people in work, business, and personal life is a cause of emotional stress more than usual because those with the mutation cannot do what they once could for stress relief. The physical and emotional issues play a significant role within each context of an artist or an educator's life. For example, healing through creating art was often a tool that they would use before BRCA positive status, but during surgeries and recovery, it became an item of despair as they could not produce art the way they once could. Recovery periods gave them more time to complete art but not the ability to do so. Creating art became a different kind of healing process that had to come much later when they could become more independent with moving, lifting, and caring for themselves again.

The physical side of the BRCA journey can be broken down as before and after surgeries, and once surgery has occurred the physical effects significantly increase, from getting blood drawn for testing to scars and complications from surgeries. During recovery, I thought that there must be something wrong with me to feel this way about something I choose to do, but now it is really comforting to me to know that I was not alone and that others felt the same way.

The culture of the women with a BRCA genetic mutation is unlike any I have ever known or been a part of. The culture of "best friends" in a moment, sharing every intimate detail and often photos helps you cope with what is

happening to you and what will be happening to you. As a member of a BRCA Facebook community, I believe that we are all unique, and yet we immediately have this intense bond that brings us closer together than many of our friends in our physical world. It is a connection like no other that is mystifying to those who have not experienced it. We are intimately connected by this physical part of ourselves and become part of a “club” that we didn’t ask to be a part of, and now we wouldn’t want to be without the other members. We have an instant bond that is difficult to understand. We joined together to become one voice within our own community and rally around those who need our support. Advice and prayers fill the BRCA related Facebook groups to help each other even though many have never met in person.

I feel that further research should be done on the silent nature of having a BRCA genetic mutation and mastectomy. The respondents and I all had a story to tell, unique and intertwined as they are and each one needs to be told.

Having faced many decisions around BRCA genetic mutations have shown me the true meaning of the word empowerment. I was empowered when I decided to have the genetic testing done. I was empowered when I decided to find a different doctor that knew more about it. I was empowered when I made the decision to have a risk-reducing salpingectomy, and I was empowered when I had a mastectomy. But I currently feel the most empowered with the thought of how I can help others on their BRCA journeys, whether through encouraging

messages in Facebook and emails, shared art experiences, or by sharing my story in this research.

After writing most of this paper, I was able to have conversations with family members and friends about what it meant to be a “Previvor” of BRCA2. I feel that I only now have been able to overcome some emotional scars that formed during the physical process and accept that it all happened for a reason.

Having a BRCA genetic mutation has changed my perspective on many aspects in my life, but being open and honest with others on a personal level has been a real struggle for me. I have tried to understand the what and the why of having a genetic mutation and also understand how I can make a difference within our BRCA community now. I have a deeper sense of advocacy for sharing my story and being open about my experiences. I was able to go from what I couldn't do, with regards to physically creating art, into what I could do, tell my story and help others.

The research indicates that creating art projects within the BRCA community, such as The Bodice Project, can give individuals a voice to share their own unique stories. I plan on facilitating art projects within my own community to start conversations about BRCA genetic mutations. I would also challenge other art educators to find a social issue that they can advocate for as well, which I hope will incorporate the arts for social change.

My goal in this research was to help show others that they are not alone in this journey and it ended up with me realizing that I am not alone either. I was

able to find my voice and will continue to share it. Advocacy and empowerment in the arts were gained in the writing of this autoethnography by giving me back my voice!

## References

- Adams, T. E., Holman Jones, S., & Ellis, C. (2015). *Autoethnography: Understanding qualitative research*. [Kindle version]. Retrieved from [https://www.amazon.com/Autoethnography-Understanding-Qualitative-Research-Adams-ebook/dp/B00ON9S7UE/ref=sr\\_1\\_1?s=digital-text&ie=UTF8&qid=1531949316&sr=1-1&keywords=Autoethnography%3A+Understanding+qualitative+research](https://www.amazon.com/Autoethnography-Understanding-Qualitative-Research-Adams-ebook/dp/B00ON9S7UE/ref=sr_1_1?s=digital-text&ie=UTF8&qid=1531949316&sr=1-1&keywords=Autoethnography%3A+Understanding+qualitative+research)
- Anderson, J. (2017, March 28). Illustrating girl empowerment through art. Retrieved June 18, 2018, from <https://www.nwea.org/blog/2017/womens-history-month-illustrating-girl-empowerment-art/>
- Bellcross, C. A., Kolor, K., Goddard, K. A., Coates, R. J., Reyes, M., & Khoury, M. J. (2011). Awareness and utilization of BRCA1/2 testing among U.S. primary care physicians. *American Journal of Preventive Medicine, 40*(1), 61-66. doi:10.1016/j.amepre.2010.09.027
- Beran, T. M., Stanton, A. L., Kwan, L., Seldon, J., Bower, J. E., Vodermaier, A., & Ganz, P. A. (2008). The trajectory of psychological impact in BRCA1/2 genetic testing: Does time heal? *Annals of Behavioral Medicine, 36*(2), 107-116. doi:10.1007/s12160-008-9060-9
- Bjornslett, M., Dahl, A. A., Sorebo, O., & Dorum, A. (2015). Psychological distress related to BRCA testing in ovarian cancer patients. *Familial Cancer, 14*(4), 495-504. doi:10.1007/s10689-015-9811-2
- Bochner, A. P., Ellis, C., (2016). *Evocative autoethnography: Writing lives and telling stories*. New York, NY: Routledge.
- Bodice Project: An exhibit for breast cancer healing, The. (n.d.). Retrieved from <http://www.thebodiceproject.org/>
- BRCA1 and BRCA2 gene mutations - know: BRCA. (n.d.). Retrieved from <https://knowbrca.org/Learn/brca1-and-brca2-gene-mutations>
- BRCA: The breast cancer gene: The national breast cancer foundation. (n.d.). Retrieved from <http://www.nationalbreastcancer.org/what-is-brca>

- BRCA mutations: Cancer risk & genetic testing. (n.d.). Retrieved from <https://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet>
- Burgess, C., Cornelius, V., Love, S., Graham, J., Richards, M., & Ramirez, A. (2005). Depression and anxiety in women with early breast cancer: Five year observational cohort study [Abstract]. *Bmj*, *330*(7493), 702. doi:10.1136/bmj.38343.670868.d3
- Cella, D., Hughes, C., Peterman, A., Chang, C., Peshkin, B. N., Schwartz, M. D., . . . Lerman, C. (2002). A brief assessment of concerns associated with genetic testing for cancer: The multidimensional impact of cancer risk assessment (MICRA) questionnaire. *Health Psychology*, *21*(6), 564-572. doi:10.1037//0278-6133.21.6.564
- Chan, Z. C., Fung, Y. L., & Chien, W. T. (2013). Bracketing in phenomenology: Only undertaken in the data collection and analysis process?. *The Qualitative Report*, *18*(30), 1.
- Chang, H., (2016). *Autoethnography as method, developing qualitative inquiry*. [Kindle version]. Retrieved from [https://www.amazon.com/Autoethnography-Method-Developing-Qualitative-Inquiry-ebook/dp/B01HTW1J9M/ref=mt\\_kindle?\\_encoding=UTF8&me=&qid=1531949034](https://www.amazon.com/Autoethnography-Method-Developing-Qualitative-Inquiry-ebook/dp/B01HTW1J9M/ref=mt_kindle?_encoding=UTF8&me=&qid=1531949034)
- Connor, E. (2013, October 18). Facing life with BRCA gene. Retrieved from <https://www.everydayhealth.com/sanjay-gupta/facing-life-with-brca-gene.aspx>
- Cook, P. S. (2014). 'To actually be sociological': Autoethnography as an assessment and learning tool. *Journal of Sociology*, *50*(3), 269-282.
- Cragun, D., & Zierhut, H. (2018). Development of FOCUS-GC: Framework for outcomes of clinical communication services in genetic counseling. *Journal of Genetic Counseling*, *27*(1), 33-58. doi:10.1007/s10897-017-0145-0
- Division of Counselling Psychology. (n.d.). Retrieved from <https://www1.bps.org.uk/networks-and-communities/member-microsite/division-counselling-psychology/interpretative-phenomenological-analysis>

- Dorval, M., Bouchard, K., Maunsell, E., Plante, M., Chiquette, J., Camden, S., . . . Simard, J. (2008). Health behaviors and psychological distress in women initiating BRCA1/2 genetic testing: Comparison with control population. *Journal of Genetic Counseling*, 17(4), 314-326. doi:10.1007/s10897-008-9150-7
- Ellis, C., Adams, T. E., & Bochner, A. P. (n.d.). Autoethnography: An overview. Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/1589/3095#g2>
- Empowerment. (n.d.). *In Oxford Dictionaries online*. Retrieved from <https://en.oxforddictionaries.com/definition/empowerment>
- Ethnography: when and how to use it. (2017, October 16). Retrieved from <https://www.spotless.co.uk/insights/ethnography-when-and-how/>
- Final recommendation statement: Brca-related cancer: Risk assessment, genetic counseling, and genetic testing. (n.d.). Retrieved from <https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/brca-related-cancer-risk-assessment-genetic-counseling-and-genetic-test>
- Frost, M. H., Schaid, D. J., Sellers, T. A., Slezak, J. M., Arnold, P. G., Woods, J. E., . . . Hartmann, L. C. (2000). Long-term satisfaction and psychological and social function following bilateral prophylactic mastectomy [Abstract]. *Jama*, 284(3), 319. doi:10.1001/jama.284.3.319
- Global Issues: Gender Equality and Women's Empowerment. (n.d.). Retrieved from <https://www.peacecorps.gov/educators/resources/global-issues-gender-equality-and-womens-empowerment/>
- Guillem, J. G., Wood, W. C., Moley, J. F., Berchuck, A., Karlan, B. Y., Mutch, D. G., . . . & Giardiello, F. (2006). ASCO/SSO review of current role of risk-reducing surgery in common hereditary cancer syndromes. *Annals of surgical oncology*, 13(10), 1296-1321.
- Hartmann, L. C., Sellers, T. A., Schaid, D. J., Frank, T. S., Soderberg, C. L., Sitta, D. L., . . . Jenkins, R. B. (2001, November 07). Efficacy of bilateral prophylactic mastectomy in BRCA1 and BRCA2 gene mutation carriers. *JNCI: Journal of the National Cancer Institute*. Retrieved from <https://doi.org/10.1093/jnci/93.21.1633>

- Henderson, E. (2017). *Autoethnography in early childhood education and care: Narrating the heart of practice*. [Kindle version]. Retrieved from [https://www.amazon.com/Autoethnography-Early-Childhood-Education-Care/dp/113873523X/ref=sr\\_1\\_1?s=books&ie=UTF8&qid=1531946938&sr=1-1&keywords=Autoethnography+in+Early+Childhood+Education+and+Care%3A+Narrating+the+Heart+of+Practice](https://www.amazon.com/Autoethnography-Early-Childhood-Education-Care/dp/113873523X/ref=sr_1_1?s=books&ie=UTF8&qid=1531946938&sr=1-1&keywords=Autoethnography+in+Early+Childhood+Education+and+Care%3A+Narrating+the+Heart+of+Practice)
- Hoeve, L. T. (2016, June 14). Teach your students to use art as a tool for social advocacy. Retrieved from <https://www.theartofed.com/2016/06/20/june-art-tool-social-advocacy/>
- Holman Jones, S., Adams, T. E., & Ellis, C. (2016). *Handbook of autoethnography*. [Kindle version]. Retrieved from [https://www.amazon.com/Handbook-Autoethnography-Stacy-Holman-Jones/dp/1598746014/ref=sr\\_1\\_1?s=books&ie=UTF8&qid=1531946840&sr=1-1&keywords=Handbook+of+autoethnography](https://www.amazon.com/Handbook-Autoethnography-Stacy-Holman-Jones/dp/1598746014/ref=sr_1_1?s=books&ie=UTF8&qid=1531946840&sr=1-1&keywords=Handbook+of+autoethnography).
- Holt, A. (2012). Lowenfeld at Hampton (1939-1946): Empowerment, resistance, activism, and pedagogy. *Studies in Art Education*, 54(1), 6-20. Retrieved from <http://www.jstor.org.steenproxy.sfasu.edu:2048/stable/24468127>
- Lather, P. (1997). *Troubling The Angels*. [Kindle version]. Retrieved from <https://www.amazon.com/Troubling-Angels-Women-Living-AIDS/dp/0813390168>
- Lawton, P. (2010). Hand-in hand, building community on common ground. *Art Education*, 63(6), 6-12. Retrieved from <http://www.jstor.org.steenproxy.sfasu.edu:2048/stable/20799848>
- Livingston, D. M., & Scully, R. (2000). In search of the tumor-suppressor functions of BRCA1 and BRCA2. *Nature*, 408(6811), 429-432. doi:10.1038/35044000
- McAllister, M., Wood, A., Dunn, G., Shiloh, S., & Todd, C. (2011). The genetic counseling outcome scale: A new patient-reported outcome measure for clinical genetics services. *Clinical Genetics*, 79, 413-424. <https://doi-org.steenproxy.sfasu.edu/10.1111/j.1399-0004.2011.01636.x>.
- Mersch, J., Jackson, M., Park, M., Nebgen, D., Peterson, S. K., Singletary, C., . . . & Litton, J. K. (2015). Cancers associated with BRCA1 and BRCA2 mutations other than breast and ovarian. *Cancer*. 121(2):269-275. doi:10.1002/cncr.29041.



- Neale, L. (2013, June). The AQAL cube for dummies. Retrieved from <http://integralleadershipreview.com/9013-the-aqal-cube-for-dummies/>
- Netz-Fulkerson, J. (2016). *Investigating residual impacts of teachers with cancer*. Retrieved from ProQuest Dissertations & Theses Global. (Order No. 10112490).
- Nolan, E. (2014). What we see and what we say: Using images in research, therapy, empowerment, and social change. *Art Therapy, 31*(4), 193-194. doi:10.1080/07421656.2015.964057
- O'Connor, J. B. (2014). *A look at community-based art education through multiple lenses: The potentials of empowerment and advocacy through the arts*. Retrieved from ProQuest Dissertations Publishing.
- O'Neill, S. C., Valdimarsdottir, H. B., DeMarco, T. A., Peshkin, B. N., Graves, K. D., Brown, K., . . . Schwartz, M. D. (2010). BRCA1/2 test results impact risk management attitudes, intentions, and uptake. *Breast Cancer Research and Treatment, 124*(3), 755-764. doi:10.1007/s10549-010-0881-4
- PhotoVoice: Vision and Mission. (n.d.). Retrieved from <https://photovoice.org/vision-and-mission/>
- Previvor, P. (2018, February 04). Exactly what i did to heal my body & mind after a double mastectomy. Retrieved from <https://www.mindbodygreen.com/articles/how-i-healed-after-a-double-mastectomy>
- Price Herndl, D. (2014). Virtual cancer: BRCA and posthuman narratives of deleterious mutation. *Tulsa Studies in Women's Literature, 33*(1), 25.
- Ravitz, J. B. (2015, October 12). *New breasts to go with my cancer-free life*. Retrieved from <http://www.health.com/health/gallery/0,,20307061,00.html#implants--0>
- Rini, C., O'Neill, S. C., Valdimarsdottir, H., Goldsmith, R. E., DeMarco, T. A., Peshkin, B. N., & Schwartz, M. D. (2009). Cognitive and Emotional factors predicting decisional conflict among high-risk breast cancer survivors who receive uninformative BRCA1/2 results. *Health Psychology, 28*(5), 569-578. doi:10.1037/a0015205
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. [Kindle version]. Retrieved from

[https://www.amazon.com/Interpretative-Phenomenological-Analysis-Theory-Research/dp/1412908345/ref=sr\\_1\\_1?s=books&ie=UTF8&qid=1531944090&sr=1-1&keywords=interpretive+phenomenological+analysis](https://www.amazon.com/Interpretative-Phenomenological-Analysis-Theory-Research/dp/1412908345/ref=sr_1_1?s=books&ie=UTF8&qid=1531944090&sr=1-1&keywords=interpretive+phenomenological+analysis)

- Tiller, K., Meiser, B., Butow, P., Clifton, M., Thewes, B., Friedlander, M., & Tucker, K. (2002). Psychological impact of prophylactic oophorectomy in women at increased risk of developing ovarian cancer: A prospective study. *Gynecologic Oncology*, *86*(2), 212-219. doi:10.1006/gyno.2002.6737
- Ulbricht, J. (2005). What is community-based art education? *Art Education*, *58*(2), 6-12. doi:10.1080/00043125.2005.11651529
- Vahdaninia, M., Omidvari, S., & Montazeri, A. (2009). What do predict anxiety and depression in breast cancer patients? A follow-up study. *Social Psychiatry and Psychiatric Epidemiology*, *45*(3), 355-361. doi:10.1007/s00127-009-0068-7
- van Oostrom, I., Meijers-Heijboer, H., Lodder, L. N., Duivendoorn, H. J., van Gool, A. R., Seynaeve, C., . . . Tibben, A. (2003). Long-term psychological impact of carrying a BRCA1/2 mutation and prophylactic surgery: A 5-year follow-up study. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, *21*(20), 3867.
- Wunderlich, A. (2017, March 09). What role can art play in creating social change? Retrieved from <https://ww2.kqed.org/education/2016/06/17/what-role-can-art-play-in-creating-social-change-2/>
- White, V., Farrelly, A., Meiser, B., Jefford, M., Young, M., Winship, I., . . . Koehler, J. (2012). What are the unmet support needs of women with a known BRCA1/2 mutation? *Hereditary Cancer in Clinical Practice*, *10*(Suppl 2), A54. doi:10.1186/1897-4287-10-S2-A54

## **Appendix A**

### **Informed Consent for Online Surveys**

You are invited to participate in a research study of the Effects of BRCA mutations on Art Educators. The purpose of this study is to determine how testing positive for a BRCA genetic mutation can change your view on health and your body; more specifically, how does it have an impact on the life of an artist and art educator? You were selected as a possible participant in this study because of your interest in helping obtain research on this subject.

If you decide to participate, please complete the following survey. Your completion of this survey indicates your consent to participate in this research study. The survey is designed to show how testing positive for a BRCA mutation affects your career as an Art Educator. It will take about 30 minutes. You will be asked to answer questions about your BRCA status, job status, physical procedures relating to BRCA status, emotional wellbeing, views on body and beauty, and changes you made in how or what you teach. No benefits accrue to you for answering the survey, but your responses will be used to help develop solutions that are unique to our profession. Any discomfort or inconvenience to you are discussions of past emotions and physical trauma due to health and surgeries you may have undergone, but they are not expected to be any greater than anything you encounter in everyday life. Data will be collected using the Internet; no guarantees can be made regarding the interception of data sent via the Internet by any third party. Confidentiality will be maintained to the degree permitted by the technology used. All information obtained will be stored on a password-protected computer.

We strongly advise that you do not use an employer-issued device (laptop, smartphone, etc.), to respond to this survey.

Your decision whether or not to participate will not affect your future relationships with the Stephen F. Austin State University or Nicki Hornbaker. If you decide to participate, you are free to stop at any time; you may also skip questions if you don't want to answer them or you may choose not to return the survey.

Please feel free to ask questions regarding this study. You may contact me if you have additional questions; Nicki Hornbaker

By clicking the link below, I confirm that I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement, and possible risks and inconveniences have been explained to my satisfaction. I understand that I can discontinue participation at any time. My consent also indicates that I am at least 18 years of age. [Please feel free to print a copy of this consent form.]

I agree to participate (link to survey)     I decline (link to close webpage)

## **Appendix B**

### **First Online Survey**

I am an Art Educator and Artist who is BRCA2 positive. I wish to gather information to better help other artists and educators who may be affected by this in similar ways like ourselves. I will also be answering these questions and sharing information about myself in the research. Please answer as honestly and completely as you can to better help inform others.

The first page of the survey:

You are invited to participate in a research study of the Effects of BRCA mutations on Art Educators. The purpose of this study is to determine how testing positive for a BRCA genetic mutation can change your view on health and your body; more specifically, how does it have an impact on the life of an artist and art educator? You were selected as a possible participant in this study because of your interest in helping obtain research on this subject.

If you decide to participate, please complete the following survey. Your completion of this survey indicates your consent to participate in this research study. The survey is designed to show how testing positive for a BRCA mutation affects your career as an Art Educator. It will take about 30 minutes. You will be asked to answer questions about your BRCA status, job status, physical procedures relating to BRCA status, emotional wellbeing, views on body and beauty, and changes you made in how or what you teach. No benefits accrue to you for answering the survey, but your responses will be used to help develop solutions that are unique to our profession. Any discomfort or inconvenience to you are discussions of past emotions and physical trauma due to health and surgeries you may have undergone, but they are not expected to be any greater than anything you encounter in everyday life. Data will be collected using the Internet; no guarantees can be made regarding the interception of data sent via the Internet by any third party. Confidentiality will be maintained to the degree permitted by the technology used. All information obtained will be stored on a password-protected computer.

We strongly advise that you do not use an employer-issued device (laptop, smartphone, etc.), to respond to this survey.

Your decision whether or not to participate will not affect your future relationships with the Stephen F. Austin State University or Nicki Hornbaker If you decide to

participate, you are free to stop at any time; you may also skip questions if you don't want to answer them or you may choose not to return the survey.

Please feel free to ask questions regarding this study. You may contact me if you have additional questions; Nicki Hornbaker at [nickilynn109@gmail.com](mailto:nickilynn109@gmail.com) or Dr. William Nieberding, Stephen F. Austin State University at [nieberdiwj@sfasu.edu](mailto:nieberdiwj@sfasu.edu). Any concerns with this research may be directed to the Office of Research and Sponsored Programs at Stephen F. Austin State University at (936) 468-6606.

Thank you for your time.

By clicking the link below, I confirm that I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement, and possible risks and inconveniences have been explained to my satisfaction. I understand that I can discontinue participation at any time. My consent also indicates that I am at least 18 years of age. [Please feel free to print a copy of this consent form.]

Click on "I agree to participate" to continue to survey

Click on "I decline" to close the window.

Continue to Survey:

1. Please provide a first name for use in research results; you may provide ANY first name as it does not have to be your own.
2. Which do you classify as? Artist, Art Educator (please click on grade levels; K-4, 5-8, 9-12, college, adult education, other (please specify)) or both
3. Age
4. Gender
5. Please click on all that apply: You are; BRCA1, BRCA2, Other genetic mutation (please list), or considered High Risk only without a genetic mutation - end of the survey for this group.
6. At what age did you have genetic testing?
7. Was genetic testing done as a screening measure or after a cancer diagnosis?
8. What were your specific reasons for having testing done? Please respond with as much information as you can. (family history, precancerous cells discovered, etc.) Ex: "sister had breast cancer and tested positive for BRCA2
9. Please describe how you felt while waiting for results of genetic testing?
10. Agree or disagree? While waiting for results of genetic testing;
  - I felt anxious
  - I felt peaceful
  - I felt afraid
  - I felt nervous

- I felt happy
  - I felt content
11. What were your first thoughts or reactions after finding out you were positive for a genetic mutation?
  12. Agree or disagree? After receiving results of genetic testing;
    - I was angry
    - I was satisfied
    - I was empowered
    - I was determined
    - I was sad
    - I was upbeat
  13. What were your family's thoughts or reactions to finding out your positive status?
  14. Did you decide to have additional testing done? CA 125 blood test, transvaginal ultrasound, breast ultrasound, mammography, breast MRI, breast biopsy, other - please be specific.
  15. Did you have any surgeries related to genetic mutation? (click all that apply) Preventative or After Cancer diagnosis; Salpingectomy, Oophorectomy, Hysterectomy, Lumpectomy, Bilateral Mastectomy, Breast Reconstruction; Direct to Implant, Expanders to Implant, Other - please be specific.

Did have surgery:

16. Any complications with surgeries or recoveries, if applicable? Please describe.
17. Did you consider your job ability when planning on having surgeries? Please describe.
18. Did you consider your students when planning on having surgery? Please describe.
19. Were you concerned about thoughts of others when planning your surgery? Who and why, if you were concerned? Please describe.
20. Did you try to schedule surgery/surgeries around your teaching career? Please describe.
21. How did you plan for time away from work? Please describe.
22. How long did you take off of work for each surgery? (please list surgery and length of time)
23. How did you feel about the surgery before? And after? Please describe.
24. How did surgeries affect your physical abilities?
25. Did the surgery affect your emotional wellbeing? How? Please describe.
26. Does your perception of the human body change after surgeries? Please describe.
27. As an artist, did your concept of beauty change? How? Please explain.
28. As an artist or art educator, how have surgeries changed your ability to perform tasks needed? Explain.

Did not have surgery:

29. Why did you choose to not have surgeries?
30. Do you plan on having them in the future?
31. Are you involved with further preventative screening/testing?

Everyone again:

32. Did your genetic mutation affect your beliefs as an educator? How? Please describe.
33. Did your genetic mutation affect your beliefs as an artist? How? Please describe.
34. optional - Please leave an email address so I can ask any follow-up questions if needed.



## Appendix C

### Second Online Survey

By clicking the link below, I confirm that I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement, and possible risks and inconveniences have been explained to my satisfaction. I understand that I can discontinue participation at any time. My consent also indicates that I am at least 18 years of age. [Please feel free to print a copy of this consent form.] Background:

1. Please provide a first name for use in research results; you may provide ANY first name as it does not have to be your own.
2. Age
3. Gender
4. I am... (please select one that best applies): BRCA1 positive, BRCA2 positive, or considered High Risk only without a genetic mutation - end of the survey for this group.

Empowerment:

“Women’s Empowerment: The fostering of a woman's sense of self-worth, her decision-making power, her access to opportunities and resources, her power and control over her own life inside and outside the home, and her ability to affect change” (“Global Issues,” n.d.).

1. Did you/ do you feel empowered... [when you received genetic testing?]
2. Did you/ do you feel empowered... [after genetic results were given?]
3. Did you/ do you feel empowered... [with your non-surgical options?]
4. Did you/ do you feel empowered... [with your surgical options?]
5. Did you/ do you feel empowered... [when you were in recovery?]
6. Did you/ do you feel empowered... [after returning to your job?]
7. Did you/ do you feel empowered... [with your ability to do the things you previously did?]
8. You may leave additional information or explain further. Please do so here.
9. What does self-worth mean to you in relation to your BRCA journey?
10. Did you have access to opportunities and resources during your BRCA journey? Please list and be specific with telling me if these opportunities and resources were helpful or hurtful to you.

11. Do you feel you have more control over your life knowing your BRCA result?
12. Do you feel that you have control over your physical body?
13. Do you feel that you have control over your emotional life?
14. What are you doing to help and/or continue to feel empowered as a woman?
15. Do you feel that you can use your BRCA journey to affect change in the world?
16. How will you use your BRCA knowledge to affect change?
17. Has any art or art therapy helped you on your BRCA journey?
18. How has Art and/or Art Therapy helped you in your BRCA journey? Leave blank if you answered "NO" to the previous question.
19. Any Artists: How can you use your Art for the empowerment of women?
20. Any Educators: How can you use your abilities as an educator for the empowerment of women?
21. Please leave an email address so I can ask any follow up questions if needed.

## Appendix D

### Testing

BRCA genetic testing was first used in 1996 by the University of Pennsylvania Breast and Ovarian Cancer Risk Evaluation Program (Armstrong, Weiner, Weber, & Asch, 2003) and was available only for clinical testing. Getting testing done for the BRCA genetic mutations requires intensive knowledge of your family's medical history and associated cancers. The use of BRCA testing has risen, but a study on the awareness and utilization of these tests by primary care physicians has found that "many physicians may not recognize the increased-risk family history patterns" (Bellcross et al., 2011) and this leads to misinformation being given to patients.

The United States Preventive Services Task Force (USPSTF) gives recommendations for primary care providers to screen women who have family members with breast, ovarian, tubal, or peritoneal cancer "with 1 of several screening tools designed to identify a family history that may be associated with an increased risk for potentially harmful mutations in breast cancer susceptibility genes" (*BRCA1* or *BRCA2*; "Final Recommendation Statement," 2013) and women who are identified as high risk are to be referred to a genetic counselor before the actual testing occurs.

The screening tools used to identify if a woman, "recommendations do not apply to men", will qualify for having a BRCA genetic mutation test performed is

based on her family's breast and/or ovarian history and the age at onset of cancer ("Final Recommendation Statement," 2013). Their family history is information that many families do not have in our current timeframe, as many site-specific cancers were not identified but just told to the families as "cancer." Not having access to this information may exclude some families from the screening and BRCA genetic testing altogether.

Once a genetic counselor identifies the need for genetic testing to occur, it can be done in two different ways; a blood sample test or through DNA in your saliva, which is obtained by spitting several times into a tube. The sample is then sent to a laboratory to check for mutations of any known harmful genes or on a specific gene, if already identified in other family members ("BRCA Mutations: Cancer Risk & Genetic Testing", n.d.).

## **Decisions**

Guidelines for breast cancer risk management, in those with a BRCA mutation, recommend "enhanced breast cancer surveillance with annual mammography and breast magnetic resonance imaging beginning at age 25-30 and *consideration* of risk-reducing mastectomy (O'Neill et al., 2010). Guidelines for ovarian cancer risk management associated with a BRCA mutation recommend "risk-reducing oophorectomy" after having the children they want or by age 35-40 (O'Neill et al., 2010).

**Non-surgical preventative options.** The non-surgical preventative approaches to being BRCA1 or BRCA2 positive includes the use of various tests

and surveillance that will be performed bi-annually or annually. These tests can be as simple as an exam or as complicated as a biopsy and often include; physical breast exam, mammography, breast MRI, breast ultrasound, breast biopsy, CA125 blood test (a cancer antigen associated with ovarian cancer), physical vaginal exam, transvaginal ultrasound, or an ovarian biopsy.

Breast and ovarian cancer surveillance is “non-invasive with few adverse effects, but does not reduce cancer risk” unlike surgical prevention options (O’Neill et al., 2010).

### **Surgical options.**

National guidelines recommend that women with BRCA mutations have their ovaries and fallopian tubes removed to reduce their risk of ovarian cancer and it can reduce their breast cancer risk by about 50% (Rezende, 2016).

***Salpingectomy and oophorectomy.*** A newly researched method of surgical prevention that is done in clinical trials includes the removal of only the fallopian tubes; this is called a salpingectomy and then later removing the ovaries when the patient is closer to natural menopausal age. This type of surgery can be done in BRCA positive patients who are pre-menopausal and wish to not have an oophorectomy, the removal of the ovaries, at this time.

Dr. Denise Nebgen, associate professor of Gynecologic Oncology and Reproductive Medicine, states, “Within the last five years, we’ve come to understand that many genetic ‘ovarian cancers’ appear to start in the fallopian tubes. So removing these tubes may greatly reduce risk.” Before that time,

“almost everyone thought ovarian cancer arose on the surface of the ovaries” says Dr. Nebgen (Wendler, 2015). Removing the estrogen-producing ovaries too soon in a woman’s life causes immediate surgically-induced menopause.

An oophorectomy is the removal of one or both of the ovaries. This surgery will cause the patient of any pre-menopausal woman to go into full-blown menopausal immediately and can cause a negative impact on the health of the woman.

In the case of those with a BRCA genetic mutation, many chose to have both a salpingectomy and oophorectomy done at the same time; this is called a salpingo-oophorectomy. A bilateral prophylactic salpingo-oophorectomy can reduce the risk of ovarian cancer by 90 percent and the risk of breast cancer by 50 percent (Guillem, Wood, Moley, et al., 2006).

**Hysterectomy.** BRCA positive patients having a Hysterectomy, the removal of the uterus, is still a controversial decision that is widely debated among the medical and BRCA communities. Overall research has not proven or disproven that there may also be an increased risk for uterine cancer in those who have a BRCA genetic mutation. A survey by Facing Our Risk of Cancer Empowered (FORCE) of BRCA1 and BRCA2 women showed that 49.5% had chosen to have their uterus surgically removed and 50.5% had kept theirs. “This lack of consensus is not surprising because currently, no national guidelines exist on whether or not a BRCA mutation carrier should remove her uterus. In the

absence of guidelines, women and their doctors make the choice together”  
(Rezende, 2014).

***Mastectomy.*** A mastectomy is the removal of breast tissue and sometimes lymph nodes to remove cancer or aide in preventing cancer. Having a prophylactic mastectomy significantly reduces the risk of breast cancer, up to 95% (Hartmann, Sellers, Schaid, et al., 2001).

A bilateral mastectomy is often referred to as a drastic surgery (Litton et al., 2009) for those who test positive for a BRCA genetic mutation due to the physical change of a body part most associated with femininity and sexuality on a woman. However, a mastectomy is also the most effective way to prevent breast cancer from appearing or reappearing since they are removing all of the breast tissue and sometimes lymph nodes as well (Karakose, 2013).

## VITA

After completing her work at Harmony High School, Farmington, Iowa, in 1999, Nicki Lynn Hornbaker entered Indian Hills Community College in Ottumwa, Iowa. She received the degree of Associate of Arts from Indian Hills Community College in May 2001. She then received the degree of Bachelor of Arts in Art Education from Iowa Wesleyan College in May 2005. During the following thirteen years, she was employed as an art teacher at Presidio Independent School District in Presidio, Texas, Brady Independent School District in Brady, Texas, Cleveland Independent School District in Cleveland, Texas, and Newton Community School District in Newton, Iowa. In August 2013, she entered the Graduate School of Stephen F. Austin State University and received the degree of Master of Arts in Art Education in August of 2018.

Permanent Address:       712 W 5th St S  
                                      Newton, IA 50208

APA, 6th edition

This thesis was typed by Nicki L. Hornbaker