TRANSFORMATIONAL LEARNING AND SELF-EFFICACY:

AN INVESTIGATION INTO THEIR ROLE IN PROPHYLACTIC MASTECTOMY

by

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ABSTRACT

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Title: Transformational Learning and Self-Efficacy: An Investigation of their Role in Prophylactic Mastectomy

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Breast cancer affects one in eight women in the United States. Estimated new breast cancer cases for 2012 in the U.S. are 229,060 women (American Cancer Society, 2012). For all women it is important to be informed regarding all current treatment options. For women in high-risk categories of breast cancer it is even more important. Risk-reducing strategies for women at high-risk of breast cancer include surveillance, chemoprevention, and bilateral prophylactic mastectomy. Prophylactic mastectomy reduces the risk of breast cancer by excision of most breast tissue. Breast cancer among those initially diagnosed as high-risk is 90-94.3% (Hartmann et al., 1999). This procedure entails serious surgeries with numerous physical, social, and emotional ramifications and is not without side effects. The patient has the right to be informed and base her decision-making on the suitability of the procedure for herself. This research describes six (6) woman's experiences, focusing on the role of transformational learning

and self-efficacy, as these women progressed through the stages. Prophylactic mastectomy is radical, irreversible, and costly at the onset. The procedure may preclude a whole lifetime of surgeries, radiation, and chemical treatments. If this treatment is the right fit, and has been fully researched, balanced with options, family history, genetic predisposition, personal concerns, and anxiety levels, along with physician recommendations, a woman should consider pursuing it.

Findings from this research indicate that all participants had observed first-degree relatives go through the process of battling breast cancer, and most had been primary caretakers. Participants sought to avoid this experience for themselves. Participants with children wanted to protect their children from similar experiences. All stated that they wished to survive, thrive, and become examples for those around them, and most indicated that they came through the experiences feeling stronger. Benefits include subjective insight of participant experiences and the part that self-efficacy and adult learning played in their decision-making. The results of this study may assist those recently diagnosed too have a realistic view of the process. Gathered knowledge may help educators, practitioners and curriculum developers create best practices programs with insight possible only from one who has “lived” an experience.

DEDICATION

I dedicate this work to my loving family: my husband Steve, our daughter Jessica, and her husband Patryck, without whose complete encouragement and support I would have been unable and uninspired to undertake this scholarly and valuable pursuit. Hopefully it will benefit families everywhere.

"To good women…may we know them, may we be them, and may we raise them."

Author unknown

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I. INTRODUCTION

Breast cancer affects one in eight women in the United States (U.S.). The estimated new breast cancer cases for 2012 in the U.S. are 229,060 women (American Cancer Society, 2012). For all women it is important to be informed regarding all current treatment options that are available. For women in high-risk categories of breast cancer it is even more important that they are informed.

Women learn about diagnosis and treatments for those at high risk of breast cancer in a variety of ways. These may include research on the Internet, the library, their family physician, their gynecologist, a health publication, a public health service in the form of posters and brochures, or from friends and family. Some women discover symptoms of breast abnormalities and are directed to a specialist.

Statistical risk of breast cancer is sometimes determined with the help of a genetic educator who is associated with a cancer center or hospital. Educators explain the risk rates, percentages of projected diagnosis at a variety of ages, potential outcomes, and give each patient a percentile number of risk of breast cancer. With that percentile number and supporting information the patient makes difficult choices about action plans for their own survival and longevity.

Risk-reducing strategies for women at high risk of breast cancer include surveillance, chemoprevention, and surgical prophylaxis with bilateral prophylactic mastectomy. The most conservative of these strategies is a surveillance approach. This surveillance approach consists of high-risk surveillance regimen including annual

mammography, annual magnetic resonance imaging in selected individuals, and semiannual clinical breast exams (Willey & Cocilovo, 2007). Some benefits to this approach include minimal action and minimal risk. Disadvantages to this approach include possible long-term fears and anxieties; fear of the unknown, fear of disease, and fear of death.

Chemoprevention is another risk-reducing strategy in an attempt to reduce the risk of breast cancer. Medications are used in an attempt to reduce the risk of breast cancer. Chemoprevention has benefits and detriments that are dependent upon the individual patient. Effectiveness may be unpredictable. This strategy, although available for treatment, is beyond the scope of this research.

Bilateral prophylactic mastectomy is another risk-reducing strategy. It is defined as the surgical removal of one or both breasts to reduce the risk of breast cancer in those at high-risk of developing the disease. The National Cancer Institute defines prophylactic mastectomy (which is also called preventative or risk-reducing mastectomy), as the surgical removal of one or both breasts in an effort to prevent or reduce the risk of breast cancer. The procedure is selected to prevent or reduce the risk of breast cancer in women who are at a high risk of developing the disease.

Benefits of bilateral prophylactic mastectomy include a success rate of between 90% and 94% for reducing the occurrence of breast cancer for those at high risk (Hartmann et al., 1999). Detriments to this approach include risk of multiple surgeries, disfigurement, and the permanence of this approach. All options should be understood to individuals in high-risk categories.

Background

Prophylactic mastectomy reduces the risk of breast cancer by removal of all or most of the breast tissue. The absence of breast tissue prevents breast cancer from developing; however, this procedure entails serious surgery, or surgeries, with numerous physical, social, and emotional ramifications and is not without numerous side effects. The patient has the right to be informed and base her decision-making on the suitability of the procedure for herself.

This study explored first-person experiences and perceptions of those who have selected the procedure to prophylactically remove all, or the largest part, of their breast tissue. Research-based experiential interviews for individuals who are considering this procedure are limited (Metcalfe, 2004). This study may provide insight for those considering undertaking the procedure and may help to alleviate fears and misconceptions perpetuated by misinformation or lack of knowledge.

All at-risk women have the right to be informed regarding all health options available including the option of choosing prophylactic mastectomy to reduce the risk of breast cancer. This research compiled first-person experiences, in their own words, focusing on the role of transformational learning and self-efficacy, as these women progressed through the stages of: (a) diagnosis, (b) information gathering and discovering options, (c) decision-making, (d) surgeries, (e) healing, and (f) recovery.

Role of the Researcher

The researcher is a 58-year old mother of one child whose nuclear family consisted of a sister, five years older, and a brother, 10 years younger. Every female member of the researcher's family has died either with, or of, breast cancer, including the

researcher's mother, maternal grandmother, maternal aunt, maternal great aunt, and paternal grandmother. The researcher's paternal grandmother, Granny Eddison, passed away with a bright red scar from her sternum to her armpit. "Look what they've done to me dear," she wept from her hospital bed.

This researcher is compelled to gather and share these stories, focused on first-person experiences, which may help guide others if they must walk down this frightening path—facing breast cancer, head on. The researcher hopes that others will find the research beneficial and that the information may save or improve their lives through insight, from women who choose proactive measures to insure future breast health and continued survival. This gathered research may provide recently diagnosed at high-risk women, health care providers, and educational leaders and designers to improve patient care armed with insight from the perspective of the patient themselves. Participant responses may assist in the development of training programs for medical caregivers and participant caregivers.

The researcher in this study is a Mental Health Counselor (Registered Intern) in the State of Florida and a member of the American Counseling Association and followed all Association Ethics in conducting this study (American Counseling Association, 2005).

Statement of the Problem

Evidence suggests that early detection and action may save lives for those at high risk of cancer (American Cancer Society, 2012). Information gathered from women who have been diagnosed at high-risk for breast cancer, have progressed through the decision-making process, and have undergone bilateral prophylactic mastectomy can share deep knowledge and detailed experience for those facing the same diagnosis. The focus of this

research will be on the experiences of six women as they progress through the process of undertaking prophylactic mastectomy and the roles (if any) that transformational learning and self-efficacy play.

Many factors influence a woman who is at high-risk of breast cancer in her action plan. These include her objective risk; clinical features; and personal characteristics such as her experience with cancer in her family, her role in the family, her values, her experience and understanding of the medical community, and options available to her. Each woman should be encouraged to take as much time as she needs to consider a decision of this importance to her life (Hartmann et al., 1999).

Purpose of the Study

For all women it is important to be informed regarding all current treatment options that are available to prevent breast cancer. For women in high-risk categories of breast cancer it is even more important that they are informed. The purpose of this study was to examine the experiences of six women who have undergone prophylactic mastectomy (see Table 1) to gather firsthand experiences to assist newly diagnosed women with information to guide their decision-making. Information gathered from this study adds to the body of knowledge to assist newly diagnosed women to make informed decisions regarding their health care.

Further, this information informs health care providers of the patient's perspective, enabling them to provide improved patient centered health care. Finally, this information assists educators and curriculum developers to create and improve programs and protocols to assist women through this process. The research includes investigation through the stages of: (a) diagnosis, (b) information gathering and option discovery, (c)

decision-making (d) surgeries, and (e) healing and recovery. The focus of this study was on transformational learning and self-efficacy.

Table 1

Six Stages in the Process of Undertaking Bilateral Prophylactic Mastectomy

Stage	Possible Responses/Questions
1. Diagnosis	The woman may be shocked to learn of her at-risk status.
2. Gathering Information and Option Discovery	Many questions will arise. The woman may feel strongly motivated to learn about the risks and rewards of risk-reducing strategies. Conversely, the woman may also be disposed to avoid learning anything about risk reduction.
3. Decision Making	The woman will weigh the pros and cons of each strategy and decide on her own action plan.
4. Surgery/Surgeries	Some women may elect to undergo prophylactic mastectomy to reduce their lifetime risk of breast cancer.
5. Healing	Time and rest along with support from medical caregivers, family or friends may benefit the healing process. Lack of support may be detrimental to healing.
6. Recovery	The woman may enjoy full recovery or suffer from effects of the surgery. Some women may reflect on this.

Self-efficacy is a measurement that an individual believes that he or she will be able to achieve their objectives (Bandura, 1977). Self-efficacy plays a part in decision-making. Research suggests that self-efficacy is directly related to the selection of actions, persistence and amount of effort exhibited in challenging situations (Bandura, 1977).

Transformational learning theory is another way to view adult learning and may be especially meaningful to this research by providing a possible analytic framework for decision-making.

Research Questions

1. What was the role, if any, of transformational learning as these women progressed through the (a) diagnosis, (b) information gathering and option discovery, (c) decision making, (d) surgeries, (e) healing, and (f) recovery stages of the process?
2. What was the role, if any, of self-efficacy on this process, and did it change as the women progressed through the stages?

Figure 1 below outlines the interconnectedness of self-efficacy, transformational learning, and it's circular relationship with the decision making process of selecting prophylactic mastectomy to reduce high-risk of breast cancer.

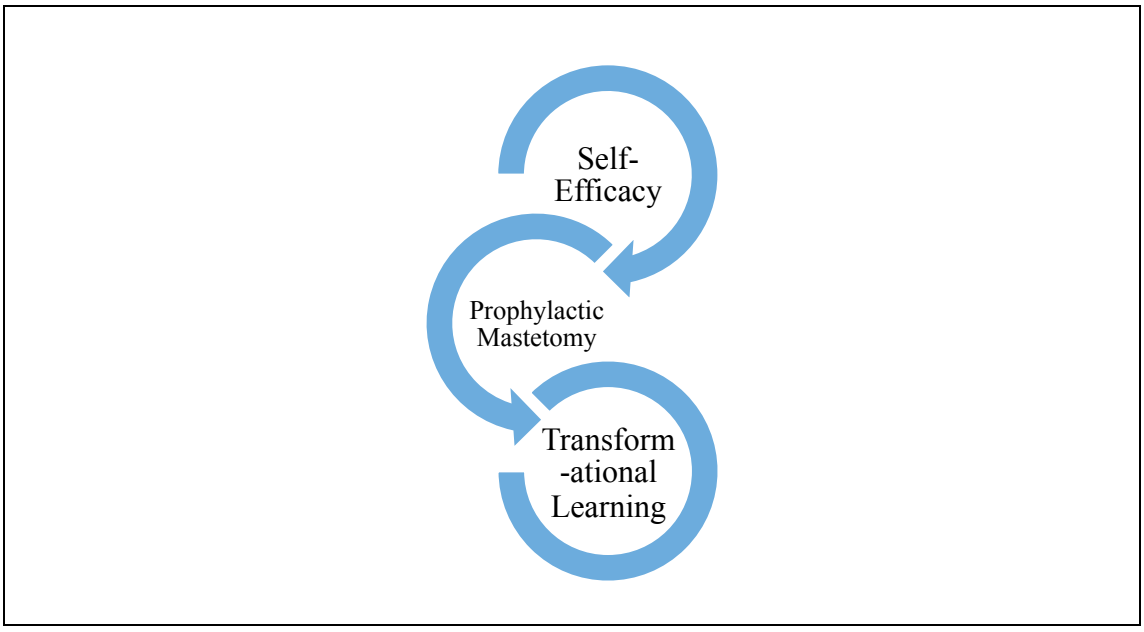

Figure 1. The role of transformational learning and self-efficacy in prophylactic mastectomy.

Significance of Study

This eclectic qualitative research describes six women's experiences as they undertook prophylactic mastectomy to reduce their status of being at high-risk of breast cancer. The focus was on the role of transformational learning and self-efficacy during the process. The researcher hopes that these stories will help inform others at high-risk of breast cancer who face this difficult decision-making process. According to the SEER Cancer Statistics Review, 1975–2011 (Howlader et al., 2014), one in eight women will be diagnosed with breast cancer during her lifetime.

> The loss of body parts can have distinct but overlapping psychological consequences. These can be bodily changes—alterations in the way patients, their families, and other perceive their bodies—or changes of function—alterations in the activities and roles that they are able to carry out. Some types of surgery affect one more than the other. Thus a unilateral mastectomy may have little influence on a woman's functional ability, but the effect on her body image will usually be profound. (Maguire & Parkes, 1998, p. 1,087)

The study reveals that this procedure may be right for those women facing the choice of prophylactic mastectomy. The first-person experiences of those women who have made the proactive health care choice to undergo mastectomy to reduce their risk of breast cancer may help others to decide to embrace or avoid the process.

Definitions

The following definitions apply to this research: *coping, high risk of breast cancer, prophylactic mastectomy, self-efficacy, transformational learning.* Operational definitions are detailed below.

Coping: is defined as "expending conscious effort to solve personal and interpersonal problems, and seeking to master, minimize or tolerate stress of conflict" (Lazarus & Folkman, 1984, p. 141).

High Risk of Breast Cancer: Numerous factors have been implicated in the cause of breast cancer and quantifying them is difficult. Risk stratification is performed using population models, as well as the patient's personal and family history and genetic testing (Willey & Cocilovo, 2007). Patients identified at very high risk of developing breast cancer include those who carry a gene mutation, those with a personal history of atypical ductal hyperplasia or lobular carcinoma in situ with associated family history, those who have undergone therapeutic or similarly significant radiation exposure, and those with a history of a gene mutation in the family of an untested individual (Willey & Cocilovo, 2007).

Prophylactic Mastectomy: The surgical removal of one or both breasts to reduce the risk of breast cancer in those at high-risk of developing the disease. The National Cancer Institute defines prophylactic mastectomy (which is also called preventative or risk-reducing mastectomy), as the surgical removal of one or both breasts in an effort to prevent or reduce the risk of breast cancer. The procedure is selected to prevent or reduce the risk of breast cancer in women who are at a high risk of developing the disease. Existing data suggest that prophylactic mastectomy may significantly reduce the chance of developing breast cancer in moderate and high-risk women. It further suggests that women considering this procedure should consult with a physician regarding their risk of developing breast cancer, the surgical procedure, its potential complications and alternatives

to surgery. Many women who chose to have prophylactic mastectomy also decide to have breast reconstruction to restore the shape of the breast according to the National Cancer Institute (2012).

Self-Efficacy: Self-efficacy is a belief that an individual believes that he or she has the ability to achieve their objectives (Bandura, 1977). Self-efficacy plays a part in decision-making. Research suggests that self-efficacy is directly related to the selection of actions, persistence and amount of effort exhibited in challenging situations (Bandura, 1977). This research describes self-efficacy as it applies to this research to each participant, and then used a guided interview including open-ended questions, along with a brief self-efficacy survey, to investigate each individual's self-efficacy as they progressed through the process.

Transformational Learning: Transformational learning theory is one way to view adult learning and may be especially meaningful to this research by providing a possible analytic framework. Transformational learning is defined as a meaning making activity: "Learning is understood as the process of using a prior interpretation to construe a new or a revised interpretation of the meaning of one's experience in order to guide future action" (Mezirow, 1996, p. 162). Adults are life-long learners; learning by experience, observation, or study. In Knowles, Holton, and Swanson's, (2011) book, *The Adult Learner, The Definitive Classic in Adult Education and Human Resource Development*, adult learning was defined as consisting of the following principles:

1. The need to know
2. Learner self-concept

3. Prior experience
4. Readiness to learn
5. Orientation to learning
6. Motivation to learn
7. Adults are internally motivated and self-directed
8. Adults bring life experiences and knowledge to learning experiences
9. Adults are goal oriented
10. Adults are relevancy oriented
11. Adults are practical
12. Adult learners like to be respected

Delimitations

The participants of this research study were self-volunteered women who have undergone bilateral prophylactic mastectomy and who responded to a breast cancer outreach program located in Southeast Florida. Their experiences and reflections upon them are subjective experiences as they pertain to the role of transformational learning and self-efficacy. The risk reducing strategies of surveillance and chemoprevention are beyond the scope of this study.

Limitations

This researcher has a great deal of first-person experience and knowledge on this topic. This may introduce bias to this study. As an individual who has progressed through these stages, and the phases of transformational learning and changes in self-efficacy, interpretations may be tinted by subjective experiences. Stage of recovery may impact participant response; this will not be investigated in this research. A broader

sample size may encourage a greater number and diversity of responses to the research questions, and could be considered for future study.

Validity and Reliability

This research study was written to explore several women's experiences and perceptions and accordingly and may not be generalizable beyond these women. Validity can be defined as the degree to which a test measures what it is supposed to measure (Key, 1997). This research study was designed to investigate the experiences of women who have undergone bilateral prophylactic mastectomy. It was assumed that participant responses accurately reflect their experiences.

The reliability of a research instrument concerns the extent to which the instrument yields the same results on repeated trials. Although unreliability is always present to a certain extent, there should be expected, generally, a good deal of consistency in the results of a quality instrument gathered at different times. The tendency toward consistency found in repeated measurements is referred to as reliability (Carmines & Zeller, 1979; Key, 1997). After the initial interview, study participants were given a written transcript of their responses and were asked to review them and add any comments or changes. This process of member checking increased the reliability of the data collected. Double-checking responses over time increased the reliability of this research study as well.

Overview of the Chapters

Chapter One introduces the nature of the study, the purpose of the research and the research questions. Breast cancer is a frightening diagnosis to most women. Women who learn that they are at high-risk of developing breast cancer face difficult decisions.

The primary treatments for those at high risk are surveillance, chemotherapy/radiation, and bilateral prophylactic mastectomy. Each of these risk-reducing strategies has advantages and disadvantages. For many women, the choice between them may be difficult. Sharing the insights of those who have selected the proactive health care choice of prophylactic mastectomy may provide guidance to those in the decision making process.

Surveillance is useful for those who can tolerate the uncertainty of living with the high risk of breast cancer. Chemoprevention shows some benefits; however has debilitating side effects for some women. Prophylactic mastectomy is a good choice for those who are able to undergo the rigor of the surgeries and the healing and recovery time, however this strategy entails irreversible surgery, with the attendant risk of complications, and is too costly for some.

This research design used six stages in the process of undertaking prophylactic mastectomy to reduce the lifetime risk of breast cancer: (a) diagnosis; (b) information gathering and option discovery: (c) decision making; (d) surgery/surgeries; (e) healing; and (f) recovery (see Table 1). This research study examined the first-person experiences of women who have forged a path to health by making the proactive health choice of prophylactic mastectomy.

Chapter 2 will provide an in-depth review of the related literature that guided the study design. Chapter 3 provides the research methodology. Chapter 4 presents the findings of the study, and Chapter 5 analyzes and summaries the findings and relates them to the related literature. Discussion of the findings, their implications and recommendations for future study conclude this research.

II. REVIEW OF THE LITERATURE

Breast cancer affects one in eight women in the U.S. The estimated new breast cancer cases for 2012 in the U.S. are 229,060 women (American Cancer Society, 2012). For all women it is important to be informed regarding all current treatment options that are available. For women in high-risk categories of breast cancer it is even more important that they are informed. At present risk-reducing strategies for women at high risk of breast cancer include surveillance, chemoprevention, and surgical prophylaxis with bilateral mastectomy. Prophylactic mastectomy reduces the risk of breast cancer by removal of all or most of the breast tissue. The absence of breast tissue prevents breast cancer from developing. Research has revealed a reduction in the risk of breast cancer among those initially diagnosed with a high-risk is 90-94.3% (Hartmann et al., 1999). However, this procedure entails serious surgery, or surgeries, with numerous physical, social and emotional ramifications and is not without side effects. The patient has the right to be informed and base her decision-making on the suitability of the procedure for herself. This study included recorded interviews describing each woman's experiences, in their own words, focusing on the role of transformational learning and self-efficacy, as these women progressed through the stages of diagnosis, information gathering and discovering options, decision-making, surgeries, healing, and recovery. Although prophylactic mastectomy is radical, irreversible, and costly at the onset, it may preclude a whole lifetime of surgeries, radiation, and chemical treatments. If this treatment is the right one, and has been fully researched, balanced with options, family history, genetic

predisposition, personal concerns, and anxiety levels, a woman should pursue it. Information gathered in this study may add to the body of knowledge regarding the relationship between self-efficacy and transformational learning as they apply to health care choices specific to mastectomy and possibly generally to other health care choices. Each woman must ask, and find the best answer for themselves regarding whether prophylactic mastectomy, with or without reconstruction, is an appropriate step, for them to undertake to help assure a healthier future (Hartman et al., 1999).

Benefits to participants and to society include the gathered knowledge of their experiences undertaking prophylactic mastectomy and what part, if any, adult learning, transformational learning and self-efficacy played. Sharing these experiences may assist those recently diagnosed to gain an added perspective regarding the process, minimizing fear or uncertainty. The collected knowledge may also help health care providers and educational leaders and curriculum developers create best practices from the gathered insight of the participants themselves. This can lead to improvement at every level to create effective programs, with the insight possible only from one who has "lived" an experience.

Literature suggests that prophylactic mastectomy for high-risk women can be a useful proactive health care strategy (Frost, 2000; JAMA, 2005). Some women exhibit concerns regarding self-efficacy, general health, and satisfaction with the procedure (Fallowfield, Baum, & Maguire, 1986; Maguire, 1989; Maguire et al., 1978). Conversely, for others, the important psychological benefits gained may include a lessening of worry or chronic anxiety and distress associated with positive

mammography results, dependence on screening and self-examination (Hatcher, Fallowfield, & Ahern, 2001).

Survival is a pre-potent need for everyone. In Hartmann et al.'s (1999) article, *Efficacy of Bilateral Prophylactic Mastectomy in Women with a Family History of Breast Cancer,* the authors provide a retrospective analysis of all women with a family history of breast cancer that underwent prophylactic mastectomy at the Mayo Clinic between 1960 and 1993. This research revealed that the reduction in the risk of breast cancer among those initially diagnosed with a high risk that underwent mastectomy was 90–94% during the period of investigation (Hartmann et al., 1999). The high efficacy rate of this surgery can help meet this survival need.

Overview of Influence of Adult Learning

Adult learning may play a role in decision-making. Rose (1998) in her article, *Challenges in Training Adult Educators,* proposed that there are certain resources that adult learners use for motivation, including their social relationships, to meet their need for social welfare. Friends, family, coworkers all serve as social supports for women in the decision-making process regarding proactive health care. Adults require some sort of interest in the material given them (Nekhlyudov et al., 2005). In this case, survival is the underlying inherent interest.

Adult learning may influence the self-efficacy of people as they cope with threatening situations and health transitions such as prophylactic mastectomy. Bandura's social learning theory tries to predict and explain behavior using key concepts, including incentives, outcome expectations, and self-efficacy expectations. All are important, yet

the self-efficacy expectation is especially relevant to health education (Strecher, McEvoy DeVellis, Becker, & Rosenstock, 1986).

Studies show that the intensity of distress following the onset of risk of cancer is determined by such factors, and by the degree to which people feel that their losses caused by the illness have made them different from others. This in turn, can give rise to depression, problems of sexual adjustment, and other psychological difficulties (Payne, Biggs, Tran, Borgen, & Massie, 2000).

Another role of adult learning is to provide opportunities to examine community and societal issues, foster change for the common good, and promote a civil society (Caffarella, 2002). In this case, sharing knowledge about how to deal with a high-risk of breast cancer is an important community and societal issue that affects individuals, families, schools, the community, and the workplace. Those with personal experience with this issue may be best able to empathize and understand the needs of the newly diagnosed woman by sharing their experiences and guiding her through the complex and difficult decisions regarding what to do with this information. It is possible that research participants may benefit from the knowledge that they are helping another women with their decision making process.

Self-efficacy

The decision to undertake a significant surgery is a complex one. Many issues factor in, including the woman's degree of self-efficacy (Guadagnoli & Ward, 1998). Self-efficacy is the degree that an individual believes that he or she will be able to achieve their objectives. Self-efficacy plays a part in decision-making. Research

suggests that self-efficacy is directly related to the selection of actions, persistence, and amount of effort exhibited in challenging situations (Bandura, 1977).

Albert Bandura, an eminent scholar at Stanford University, focuses his research on how people regulate their own motivation, thought patterns, affective states, and behavior through personal and collective efficacy. Bandura defines perceived self-efficacy as the belief that each individual has regarding their capabilities to produce given attainments (Bandura, 1997). Each person has a personal and unique sense of perceived self-efficacy. According to Bandura, this self-efficacy, or the individual's perception regarding the amount of control that they have over their environment and behavior, determine their beliefs and their actions. The selection of a treatment method is impacted by the women's view of what is best for her. Prophylactic mastectomy may more likely be selected by a person who believes that the procedure may benefit her, minimizing her high risk of breast cancer. An individual with low self-efficacy may not take on the risk of this procedure.

Schwarzer and Luszczynska (2003), in their article, *Perceived Self-Efficacy*, define self-efficacy is a direct predictor of intention and of behavior. According to social cognitive theory (Bandura, 1997), a personal sense of control facilitates a change of behavior, in this case, proactive health care behavior. Self-efficacy relates to a sense of control over one's environment and behavior. Self-efficacy beliefs are mental constructs that determine whether behavior change will be initiated, how much effort will be expended, and how long it will be sustained in the face of failures or obstacles. Self-efficacy influences the effort an individual puts forth to change behavior, and the

persistence to continue striving despite barriers and obstacles that may undermine motivation (Bandura, 1997).

Self-efficacy as it relates to health behavior. Self-efficacy is directly related to health behavior and individual health decisions and affects health behaviors indirectly through its impact on goals. Self-efficacy influences the challenges that people take as well as how high they set their goals. Individuals with strong self-efficacy select more challenging goals and make choices more efficiently. Those with strong self-efficacy focus on opportunities, not on obstacles (DeVellis & DeVellis, 2000).

Ajzen, in a 1991 article titled, *Organizational Behavior and Human Decision Processes*, proposed the theory of planned behavior. This theory posits that intention is the most proximal predictor of behavior. Cognitions, including specific attitudes, subjective norms, and degree of behavioral control or the perception about being able to perform a specific behavior, all affect intention.

Behavioral control and self-efficacy are nearly synonymous cognitive constructs. Self-efficacy is distinctly related to an individual's competence and to future behavior (Ajzen, 1991). Thus, according to the theory of planned behavior, an individual who believes that they have the ability to control their health destiny may elect to undergo the rigors of prophylactic mastectomy with the belief that they will gain a healthier future.

Self-efficacy is an important part of decision-making in survivors (Forsythe et al., 2014). Perceived social support and marital status were positively associated with improved outcomes. Support from family may facilitate survivor efficacy for decision-making. Other factors, including marital satisfaction, appear to influence ongoing care.

Risk Reducing Strategies

There are three primary risk-reducing strategies for women at high risk of breast cancer; surveillance, chemoprevention, and prophylactic mastectomy. The surveillance approach consists of a regimen including annual mammography, annual magnetic resonance imaging in selected individuals, and semiannual clinical breast exams (Willey & Cocilovo, 2007). This strategy involves multiple visits to clinics, hospitals, physician's offices and medical centers.

The surveillance strategy requires less effort and action on the part of the woman, but may result in fear, anxiety, and depression regarding the unknown. Chemoprevention can create significant negative side effects. Prophylactic mastectomy requires invasive surgery, is irreversible and although highly effective, it does not insure against breast cancer, as breast tissue is not confined to the breast only, but may lie throughout the chest wall.

Medical testing to determine at-risk status has been developed and includes genetic testing, geno-grams, individual medical history, family history, history of lumps or tumors, mammography, and ultrasound screenings (National Cancer Institute, 2012). With these test results and a history including the patient's previous surgeries, "suspicious" looking shadows, age, general health, and a medical professional can create a prognosis of the degree of risk for the individual patient. When a high risk is indicated, patients are overwhelmed with questions. For example:

> Am I going to die? When? Should I just wait this out and see what happens? Let nature take her course? If I'm proactive, what are the treatments? What will the procedure and treatments be like? What will my chest and breasts look like? Feel

like? Will my mate, or potential mate, my family and friends still find me attractive?

It is possible that freedom from fear, from monthly check ups, the uncertainty, the repeated mammograms and ultrasounds, the biopsies, the lumpectomies may all help a woman to live more fully, adjusting to her new status from "high risk" of breast cancer to that of recovery and health.

Role of Adult Learning

Women who are faced with a high risk of breast cancer are faced with complex choices. As adults, most have had a great deal of life experience that they bring to the decision making process. Adult learning theorist Malcolm Knowles, one of the "fathers of andragogy," the theory and practice of adult learning, indicates that there are four fundamental principles used by adults in learning. These four principles outlined in his book, *The Modern Practice of Adult Education* (Knowles, 1980) include:

1. Adults need to be involved in the planning and evaluation of their experience.
2. Experiences, both good and bad provide the basis for learning.
3. Adults are most interested in learning about subjects that have immediate relevance to their employment or personal lives.
4. Adult learning is problem centered-rather than content oriented.

Decision making by adults is based primarily upon their own life experiences and their own research. Difficult decisions such as whether or not to undergo prophylactic mastectomy reveal the accuracy of Knowles' (1980) principles. Knowles et al. (2011) defined adult learning as consisting of the following principles:

1. The need to know

2. Learner self-concept
3. Prior experience
4. Readiness to learn
5. Orientation to learning
6. Motivation to learn
7. Adults are internally motivated and self-directed
8. Adults bring life experiences and knowledge to learning experiences
9. Adults are goal oriented
10. Adults are relevancy oriented
11. Adults are practical
12. Adult learners like to be respected

Adults utilize these strategies as they understand them to the best of their abilities in order to continue to survive. The variability of each adult's understanding of these concepts is endless, as we are all unique and have multiple and various experiences and educations upon which to draw. Each individual is deeply involved in the outcome of the planning and evaluation of their options, and seeks the best health outcomes that they believe are possible.

Personal life and health experiences, both good and bad, information gathered from numerous sources and resource programs, observations of the experiences of family and friends, and experiences with health care providers all affect an individual's decision-making process. The choice to have prophylactic mastectomy is one that has immediate relevance to the individual's life, and this decision is problem, or in this case, solution oriented.

Transformational Learning

Transformational learning is one way to view adult learning. Dr. J. Mezirow, transformational learning theorist, defines learning as a meaning making activity. "Learning is understood as the process of using a prior interpretation to construe a new or a revised interpretation of the meaning of one's experience in order to guide future action" (Mezirow, 1997, p. 162). Mezirow's theory of transformative learning centers on the cognitive learning process and its role in transforming how a person views the world and views oneself. According to Mezirow, there are three phases to transformative learning:

1. Critical reflection on one's assumptions
2. Discourse to validate the critically reflective insight
3. Action

Transformative learning often results from a disorienting dilemma that an individual would experience as a crisis that cannot be resolved through previous problem solving strategies. The individual engages in self-examination. This is frequently accompanied by shame and a focus on religion as a support (Mezirow, 1997).

Mezirow (1997) indicated that this self-examination includes a critical assessment of assumptions that results in the realization that others have gone through a similar process. This leads to exploring options for forming new roles, relationships, or actions, which lead to the formulation of an action plan. The action plan includes acquiring new skills and knowledge, trying out new roles, renegotiating relationships, and negotiating new relationships and building confidence and competence. Finally the individual reintegrates back into her life with a new transformed perspective (see Table 2).

Table 2

Mezirow's (1978) Ten Phases of Transformative Learning

Phase	Transformative Learning
1	A disorienting dilemma
2	A self-examination with feelings of guilt or shame
3	A critical assessment of epistemic, sociocultural, or psychic assumptions
4	Recognition that one's discontent and the process of transformation are shared and that others have negotiated a similar change
5	Exploration of options for new roles, relationships, and actions
6	Planning of a course of action
7	Acquisition of knowledge and skills for implementing one's plans
8	Provisional trying of new roles
9	Building of competence and self-confidence in new roles and relationships
10	A reintegration into one's life on the basis of conditions dictated by one's perspective

Note. Adapted from Kitchenham (2008).

Two major elements of transformative learning are critical reflection, or critical self-reflection, on assumptions and critical discourse, where the learner validates a best judgment (Mezirow, 1997). Mezirow emphasized the importance of critical reflection in transformative learning theory. Straightforward reflection is the act of "intentional assessment" (Mezirow, 1996, p. 158) of one's actions, whereas critical reflection not only involves the nature and consequence of one's actions but also includes the related circumstances of their origin. He presented three types of reflection and their roles in transforming meaning schemes and perspectives. They are content reflection, process reflection, and premise reflection.

Mezirow (1978) articulated a taxonomy of critical reflection of, and on, assumptions that involved objective reframing and subjective reframing. The distinction between the objective and subjective reframing is that the former is a consideration of the assumption, whereas the latter is a consideration on what caused the assumption to occur. Objective reframing is either: (a) a narrative critical reflection of assumptions and requires critically examining something that was being communicated to a person (e.g., a friend tells you that prophylactic mastectomy will not work), or (b) an action critical reflection of assumptions and requires taking a moment to critically consider one's own assumptions in a task-oriented problem-solving situation to define the problem itself (e.g., considering what you believe about the effectiveness of prophylactic mastectomy being worthwhile).

Subjective reframing is, in fact, critical self-reflection on, rather than of, assumptions. Subjective reframing can include one of four forms of critical self-reflection on assumptions: narrative, systemic, therapeutic, and epistemic.

1. Narrative critical self-reflection on assumptions is the application of narrative critical reflection of assumptions to oneself (Kitchenham, 2008). For example, a friend tells you that it is impossible to predict whether you will get a certain disease. You reflect on your at-risk status and that although it's impossible to know there is a high-risk for you. You decide you will go through with the prophylactic mastectomy. This demonstrates narrative self-critical reflection on assumptions as the individual critically examined something communicated to him or her (i.e., narrative reflection of assumptions), considered the problem as applied to himself or herself, and came to a resolution.

2. Systemic critical self-reflection on assumptions is going beyond the action critical reflection of assumptions to self-reflect on the taken-for-granted cultural influences, which might be organizational (e.g., health care settings) or moral-ethical (e.g., social norms) (Kitchenham, 2008). An individual who thinks that they are too young or too old to undergo prophylactic mastectomy, who self-reflects on the assumption that he or she is not able to do so and then realizes that their age is irrelevant to the process, is demonstrating systemic critical reflection on assumptions.
3. Therapeutic critical self-reflection on assumptions is examining one's problematic feelings and their related consequences (Kitchenham, 2008). When a woman is diagnosed at high-risk she reflects on the belief that she will never get through it without help and that she must build her support system, she is demonstrating therapeutic critical reflection on assumptions.

Epistemic critical self-reflection on assumptions is investigating not only the assumptions but also the causes, the nature, and the consequences of one's frame of reference to surmise why one is predisposed to learn in a certain manner (Kitchenham, 2008). When an individual self-reflects on the fact that she is conflicted about prophylactic mastectomy and that her friend's opinion that it is impossible to predict whether she will get a certain disease has negatively affected her desire to undertake prophylactic mastectomy, she is demonstrating epistemic critical reflection on assumptions.

Coping Skills as a Component of Adult Learning

The ability to develop coping strategies or skills is another component of adult learning. Coping is defined as expending conscious effort to solve personal and

interpersonal problems, and seeking to master, minimize or tolerate stress or conflict (Lazarus & Folkman, 1984; Weiten & Lloyd, 2008). Psychologists Weiten and Lloyd have provided a useful summary of three broad types of coping strategies:

1. Appraisal-focused: Assessment of risk, acceptance of status quo or distancing self from problem
2. Problem-focused: Directed behavior to reduce or eliminate a stressor, or adaptive behavior
3. Emotion-focused: Changing emotional reaction to a stressor (Weiten & Lloyd, 2008)

In the case of coping with a diagnosis of high-risk of breast cancer, appraisal-focused coping strategy may be useful for those able to live with the uncertainty of being at high-risk. Those who use problem-focused strategies attempt to address the cause of their problem. Those using problem-focused coping often do so by researching information on the problem. Problem-focused coping is aimed at changing or eliminating the source of stress. Those who use emotion-focused strategies, focus on releasing emotions, distracting themselves, meditating or using systematic relaxation procedures. Emotion-focused coping is oriented toward managing the emotions that accompany stress. People use a mixture of these three strategies to cope (Brannon & Feist, 2009).

Schwarzer (2001) proposed that a distinction be made between: (a) pre-intentional motivational processes that lead to a behavioral intention, and (b) post-intentional volition processes that lead to actual health behavior. In the motivation phase, one needs to believe in one's capability to perform a desired action (e.g., "I can go through with the process of surviving a mastectomy, in order to minimize my risk of breast cancer.")

otherwise an individual will not initiate the action. In the subsequent volition phase, after a person has developed an intention of adopting a specific health behavior, this intention has to be transformed into a detailed plan of action. Coping strategies and adult learning dictate what this plan of action will be and how it will be determined.

Research indicates that prophylactic mastectomy provides favorable psychological and social outcomes for most, but not for all women (Frost, 2000; Spear, Schwartz, Venturi, Barbosa, & Al-Attar, 2008). Women who have undergone this decision-making process, and have elected to have prophylactic mastectomy can serve as effective leaders and role models for those who are facing this decision. The limited research that has been done on the roles of adult learning and self-efficacy on women who have undergone prophylactic mastectomy suggests prophylactic mastectomy may be effective in reducing distress levels, all of which may relate to adult learning and self-efficacy, in high risk women (Metcalf, 2004).

In summary, this chapter has provided an overview of the process of adult learning, including a review of self-efficacy and how it relates to health decisions. Risk reducing strategies have been introduced. Prophylactic mastectomy has been viewed through the perspective of transformation learning theory. Coping skills as a component of adult learning have also been introduced.

Being diagnosed at high risk of breast cancer can be a disorienting event that is a catalyst for action and personal growth. Fundamental adult learning theory as it applies to coping strategies including, appraisal-focused coping, emotion-focused coping, and problem-focused coping can be useful strategies for women at high-risk of breast cancer were reviewed. Chapter 3 will provide the detailed methodology for this research study.

III. METHODOLOGY

This chapter provides the study's purpose, a detailed methodology, and explains the sample selection. In addition, the interview protocol, data collection, and data preparation are explained and detailed along with an identification of the data analysis procedures used in the study. Validity, reliability, limitations, and delimitations are also addressed. It includes the rationale for a qualitative case study and details the research questions.

Background and Rationale

Diagnosis of being at high-risk for breast cancer is a frightening experience for many women. Due to the variety of risk reducing strategies presently available to those at high-risk, first-person information must be available to inform those at risk. Research-based experiential interviews for individuals who are considering this procedure are limited (Metcalfe, 2004). This study provides insight for those considering undertaking the procedure and may help to alleviate fear and misconceptions perpetuated by misinformation or lack of knowledge. Due to the highly disorienting effect of this experience, transformational learning experiences may occur for these women during the process. This research may help others prepare for this life-changing process.

Rationale for a Qualitative Case Study

An eclectic qualitative approach was used to elicit the descriptions of how participants who have undergone prophylactic mastectomy view the role of transformational learning and self-efficacy as they proceeded through the process from

diagnosis through recovery. Qualitative research provides a lens to focus and describe the meanings that participants place on their experience. Qualitative research has been defined as "an inquiry into the process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting" (Creswell, 1994, p. 2). Researchers Gall, Borg, and Gall (1996) stated that a qualitative study is the appropriate method for analyzing perceptions. This research utilized a case study method, which has been defined as "an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident…[and] relies on multiple sources of evidence" (Yin, 1994, p. 13). Researchers have identified a case study as research that investigates a few cases in considerable depth (Gomm, Hammersley, & Foster, 2000). Many scholars agree that a case study is not a particular method but a strategy (Yin, 1994). Yin further explained that a case study implies collection of unstructured data and qualitative analysis of data.

The objective of this strategy is to "attempt to understand the meaning of events and interactions to ordinary people in particular situations" (Bogdan & Biklen, 2007, p. 25). This study examined the impact of a phenomenon (being diagnosed at high-risk of breast cancer in this case) to learn the roles, if any, that self-efficacy and transformational learning play in the process of undertaking prophylactic mastectomy. This study examines the experiences of six women as they progressed through the process of diagnosis, information gathering and discovering options, decision-making, surgeries, healing, and recovery. This research provides women at high-risk of breast cancer with a detailed description of the process.

Yin (1994) described a case study as a comprehensive research strategy that deals with situations:

> in which there will be more variables of interest than data points…relies on multiple sources of evidence, with data needing to be converged in a triangulating fashion…[and that] benefits from the prior development of theoretical propositions to guide data collection and analysis. (p. 13)

Case studies enable researchers to investigate different outcomes of general processes suggested by theories depending upon different contexts.

Types of Case Studies

A variety of different types of case studies have been identified (Stake, 1995). This research utilized a collective case study that refers to extension of an instrumental study to several cases (Stake, 1995, pp. 3–4). Depending on the type of research question, case studies have been identified as exploratory, descriptive, and explanatory (Yin, 1994). This study, which is primarily focused on questions that answer the question "what," is an exploratory study.

Purpose Statement

It is important for woman to be informed regarding all current available treatment options that are available to prevent breast cancer. For women in high-risk categories of breast cancer it is even more important that they are informed. The purpose of this study was to examine the experiences of six women who have undergone prophylactic mastectomy to gather firsthand experiences to offer newly diagnosed women with information upon which to guide their decisions. Information gathered from this study adds to the body of knowledge to assist newly diagnosed women to make informed

decisions regarding their health care. Further, this information informs health care providers of the patient's perspective enabling them to provide improved patient centered health care. Finally this information assists educators and curriculum developers to create and improve programs and protocols to assist women through this process. The research included investigation through the stages of: (a) diagnosis, (b) information gathering and option discovery, (c) decision-making (d) surgeries, (e) healing and (f) recovery. The focus of this study was on transformational learning and self-efficacy.

The limited research that has been done on the implications of adult learning and self-efficacy suggests that prophylactic mastectomy may be effective in reducing distress in high-risk women (Metcalf, 2004). Counseling provided to high-risk women should include a discussion of prophylactic mastectomy including all known risks and benefits. Detailed reporting on risks and benefits, as described by those who have undertaken this process, addresses and adds to the body of knowledge.

Research Questions

This research study specifically addressed the following questions:

1. What was the role, if any, of transformational learning as these women progressed through the (a) diagnosis, (b) information gathering and option discovery, (c) decision making, (d) surgeries, (e) healing, and (f) recovery stages of the process?

What was the role, if any, of self-efficacy on this process, and did it change as the women progressed through the stages? Three types of qualitative data include interviews, surveys, and documents, usually acquired through fieldwork (Patton, 2002). This study included these three via a guided interview (see Appendix C), self-efficacy survey (see Appendix E), and document review of participants' brief autobiographical paragraph

provided by participants themselves. To examine the roles of transformational learning and self-efficacy as they apply to prophylactic mastectomy, participants were interviewed with guided, open-ended questions. They were formatted in the order through the stages of this process. They were shepherded to focus on the role of transformational learning and self-efficacy.

Phenomenological understanding will be part of the data analysis. Phenomenological researchers "attempt to understand the meaning of events and interactions to ordinary people in particular situations" (Bogdan & Biklen, 2007, p. 25). This study examines the impact of a phenomenon (being diagnosed at high-risk of breast cancer in this case) to learn the roles, if any, that self-efficacy and adult learning take in the process of undertaking prophylactic.

Research Plan

Data were collected from three sources; (a) open ended interview, (b) self-efficacy survey, and (c) autobiographical sketches provided by the participants. Guided interview questions were presented with prompts to help participants focus on the research topic, the role (if any) of adult learning, and the role (if any) of self-efficacy as participants progressed through the process of diagnosis, information gathering and discovering options, decision making, surgeries, healing, and recovery. The researcher transcribed the data, and then sent the transcript via email to the participant for additions and changes. Upon return the researcher then coded the data starting the data analysis. A peer de-briefer was used. Both the peer de-briefer and the researcher coded independently.

The second source of data was the five-question self-efficacy survey. It asked the participants to rate their self-reported levels of self-efficacy as they progressed through the stages of prophylactic mastectomy. Responses were analyzed for trends.

The third source of data included brief autobiographies provided by each participant. These were analyzed using traditional document analysis to find commonalities and differences between and within the experiences of these women, and the role (if any) played by adult learning and self-efficacy as they progressed through the process. Emerging themes from the data may add to the specific topics of adult learning and self-efficacy. These sources provided information needed to create an in-depth triangulation necessary to minimize bias and reveal the self-described experiences of these women.

During the interview, prompts were used to shepherd the participants' focus on their experiences regarding self-efficacy and adult and transformational learning. To ensure protection of participant confidentiality, at the end of the interview, the researcher cleaned the data of all identifiers, and e-mailed it to the qualified, confidential transcriber for transcription. It was returned to the researcher via e-mail. Completed transcripts were then e-mailed to participants who were asked to make additions or changes, and return to the researcher within five days. The self-efficacy survey was reviewed to identify trends, and the autobiographies were analyzed using a standard document review. Data analysis took place after the interviews had been completed, cleaned of any identifiers, and transcribed, and after the surveys and brief autobiographies had been provided.

Document analysis included reviewing papers provided by participants. Not all participants provided documents. However, one provided an entire video cd of her experience. This is a one-person show that she presents across the country. Excerpts from this video are presented throughout this research. Another participant has started a blog and web site, referring women to new resources. Concepts from this web site are included throughout this research, however, the blog changes on a weekly basis as updates and innovations in breast health are discovered. It can be found on the Internet under the topic of BRAC I Responder.

Benefits

Study participants benefit from this study by having the opportunity to have their story be told. Benefits to the newly diagnosed, and to society on the whole, are many. Some of the many ways this insight can be transferred include sharing these experiences to assist those recently diagnosed to have a realistic view regarding the process, thereby minimizing fear or uncertainty. Also, knowledge gathered assists educators at every level to create effective programs with the insight possible only from one who has "lived" an experience.

Minimal Participant Risk

There was minimal risk in this study. All information was anonymous. To further protect participant anonymity, each participant was given a pseudonym. Participants were offered no incentives. Information was collected with a digital recorder, a computer, and written notes. Research information was stored in the office of the student researcher in a locked file drawer. All computer files were password protected. Those on hard drive were kept in aforementioned file cabinet. The research

information is for dissertation use. Findings may be used in future studies or publications with the permission of the participants. All computer documents will be deleted and the portable hard drive will be deleted within two years of study completion. Access to documents was only given to student researcher, faculty advisor, dissertation committee, and those signing IRB package.

Risks

Participants were asked to recall memories that were associated with powerful emotions. This may have been disorienting or uncomfortable for some. If, as part of this study anyone experiences psychological discomfort or distress, psychological counseling was made available. The researcher is a Registered Mental Health Intern in the State of Florida and a member of the American Counseling Association and followed all American Counseling Association protocols and Code of Ethics (American Counseling Association, 2005). Each participant had the right to discontinue study participation at any time for any reason.

Informed Consent Process

Participants were asked to sign a written consent form at the beginning of the interview (see Appendix B). All study participants are over the age of 18. There was no use of deception in this study. If a participant did not wish to go forward, another subject was selected by the researcher.

Data Analysis

Data were analyzed and emerging themes identified. Interpretation of the content analysis was tailored by the substance of the data collected. Data were tracked by individual participant and was anonymously coded by participant with their identifiers

removed so their anonymity would be reserved. The data was coded according to the identified stages of undergoing prophylactic mastectomy. Emerging themes were identified that created new classification categories for coding.

Data were categorized by theme or pattern then organized into coherent categories by assigning abbreviated correlated codes noted next to the data. Subcategories were created as they were identified and labeled as they relate to preset categories prior to data collection.

1. Emerging themes, categories identified after the data has been collected and reviewed, were added (Creswell, 2005).
2. Next, patterns and connections between and within categories were identified. Their importance was determined by summarizing information relating to one theme and capturing the similarities or differences in subject's responses within a category. The relative importance of each category emerged as the number of times certain themes came up versus the number of unique responses to the same questions to provide a rough estimate of relative importance and helped to reveal patterns from the data. Relationships between two or more themes were explored. Patterns in the data were identified by means of thematic codes. "Patterns, themes, and categories of analysis come from the data; they emerge out of the data rather than being imposed on them prior to data collection and analysis" (Patton, 1980, p. 306).
3. Data were interpreted creating meaning and significance to the collected data and has been reported in narrative and table format.

In sum, interviews were audio recorded, transcribed, and coded into emerging themes. Words and phrases coded and counted, and charts developed. Themes were color coded and sub themes were identified (see Table 3).

Table 3

Select Coding Frequency Table

Code	Frequency
Family	19
Children	15
Overwhelmed	14
Child	13
Survival	13
Support	12
Husband	9
Exercise	8
Internet	8
Live	8
Friends	7
Scared	7
Social Media	7
Run	6
Fear	4
Pain	4
Cried	3
Runner	3
Sick	3
Anger	2

The collected data were analyzed by summarizing the data in an accurate and dependable manner, which lead to findings that, using patience and the reflective process,

made sense of multiple data sources. Participant responses were analyzed and interpreted through the lens of transformational learning and self-efficacy. Analysis included three repeating steps: reading/memos, describing, and classifying. This process focused on familiarity with the data and identifying potential themes, examining the data in depth to provide detailed descriptions of the setting, participants, and activity, and finally was classified by categorizing and coding pieces of data and grouping them into themes (Gay, Mills, & Airasian, 2009). Participant responses were explored according to emergent themes. The data were organized using recommendations by Gay et al. (2009) as presented below. Data organizing activities:

1. Record dates (month, day, year) on all notes
2. Sequence all notes with labels (note 2 of 3)
3. Label notes according to type (interview transcript, observer's notes)
4. Make two photocopies of all notes and retain original copies
5. Organize computer folders according to data type and stage of analysis
6. Make back-up copies of all files
7. Read through data and insure all information is complete prior to analysis and interpretation
8. Noted themes and patterns that emerge

This method of research sought to understand a given research problem or topic from the perspectives of the local population it involves. It was selected as a research method because qualitative research is especially effective in obtaining culturally specific information about the values, behaviors, and social contexts of particular populations. First person experiential evidence, rich with insight into other's thoughts, feelings, and

behaviors from: (a) initial diagnosis, through (b) information gathering and option discovery, (c) decision making, (d) surgical procedures, (e) recovery and (f) healing stages can inform, in a personal way, newly diagnosed women about the experience that they may be considering (Merriam, 2009).

Participants

Six volunteers were recruited from among patients identified as having a high-risk of developing cancer who have elected to undertake prophylactic mastectomy in an effort to minimize their lifetime risk of breast cancer. Volunteer participants were recruited through a website of a breast cancer awareness program headquartered in Southeast Florida (see Appendix D).

Sampling Plan

Volunteers initially responded via email to the researcher. They were forwarded a consent form to sign and return as well as a convenient time for the interview and data collection. Participants were selected through convenience sampling and included six women, who have undergone bilateral prophylactic mastectomy due to a high risk of breast cancer. They were all post-initial surgery three months to 10 years. This time span enabled the collected data to be broad reaching and enabled the research to explore a broad perspective of experiences (see Appendix A). Participant criteria was as follows:

1. Adult female.
2. Diagnosed at a high risk of breast cancer due to genetic predisposition or strong family history of breast cancer.
3. Have undergone bilateral prophylactic mastectomy for the purpose of minimizing risk.

4. Able and willing to participate in the research study by giving an one hour interview, completing a self-efficacy survey and providing their brief autobiographical story as presented to the recruiting organization (if available).

Chapter Summary

This chapter began by describing the background and significance of this research. Newly diagnosed women may benefit from the insight gained from these individuals and from their comments and descriptions. Those who have undergone the surgery may benefit from the opportunity to share their story. The research questions included the self-reported roles of transformational learning and self-efficacy as participants progressed through the stages.

Chapter 4 offers an analysis and summary of the data. Abundant quotations gleaned from the interview transcripts have been included. Interpretive narrative analysis of the triangulated data, including themes, patterns, and an analysis of emerging themes from the participant responses will be presented.

IV. FINDINGS

Chapter four presents findings from the research data gathered. The purpose of this study was to examine the experiences of six women who have undergone prophylactic mastectomy. These first-person experiences have added to the body of knowledge regarding health care and may assist newly diagnosed women to make fully informed decisions. Further, this information informs health care providers of the patient's perspective, enabling them to provide improved patient centered health care. Finally, this information can assist educators and curriculum developers to create and, improve programs and protocols to assist women through this process.

The research included investigation through the stages of: (a) diagnosis, (b) information gathering and option discovery, (c) decision-making (d) surgeries, (e) healing, and (f) recovery. The lenses used for this study were transformational learning and self-efficacy. Findings are organized according to the overarching research questions investigating the role of transformational learning and self-efficacy as they pertain to prophylactic mastectomy.

Role of Transformational Learning and Self-efficacy

Data analysis reveals that transformational learning and self-efficacy do play a role in the process of undertaking prophylactic mastectomy. Self-efficacy tended to increase as the participants progressed through the process. Most participants used coping strategies that had already been part of their lives, modified to account for new

physical changes. Discussion of these findings and their relationship to current reviewed literature follow in Chapter 5.

Research Questions

This research study addressed the following questions:

1. What was the role, if any, of transformational learning as these women progressed through the (a) diagnosis, (b) information gathering and option discovery, (c) decision making, (d) surgeries, (e) healing, and (f) recovery stages of the process?
2. What was the role, if any, of self-efficacy on this process, and did it change as the women progressed through the stages?

Interview Questions

Participants were asked to respond to the following questions. Their responses follow this introduction.

Introduction. Before we begin, I'd like you to take a moment to silently reflect on your experiences as you went through the process of being diagnosed at high-risk of breast cancer, and then moving through the process of diagnosis, gathering information and option discovery, decision making, surgeries, healing and recovery. Please consider your emotional, social, physical and intellectual states.

Diagnosis. What were you doing before and at diagnosis? (e.g., working, traveling, attending school, raising a family, training for a marathon). The purpose of this question was to break the ice and start the sharing process.

Participant 1 is a 45 year old, married mother of two. Asked what she was interested in prior to diagnosis, Participant 1 replied:

I am interested in dance and I have many interests. My sister was diagnosed with ovarian cancer. No tests were recommended. A year later at her own request, genetic testing took place. She tested positive for genetic mutations indicating high risk of breast cancer, and it was suggested that I get tested also. I tested positive. My family history suddenly started to make sense. My dad's mom died at age 33 of breast cancer. All of her seven siblings were afflicted with cancer. My mother and great grandmother died of breast and ovarian cancer. That's pretty much it.

Getting the genetic test result, I realized at that point, only at that point, that my life and my journey the path was going to change. I didn't know how at that point. I didn't know all that I know now, and I hadn't done the full research yet. I knew that changes were coming. I'd had enough life experiences to know. I knew that I needed to start researching, and I knew that I needed to take some sort of action. I'm a confident person. I set goals and I achieve them. I didn't know much at that time. I was about 20% confident at that time.

Participant 2, a 52 year old, divorced mother of two, responded:

When I was diagnosed, I was doing, what I do on a daily basis. My highest level of education is an MBA, and I am a specialist in accounting and finance. I am a single mom with two kids and I need to take care of everything at home. I was working, raising my family and finalizing my divorce-sometimes I think it might have been stress, too.

After diagnosis, I found that I had family history, but nobody had told me about the gene before that. In my family I always knew that I would die of breast

cancer. In my family my mother and three of her sisters died of breast cancer between 29 and 44 years of age. I always communicated that to the doctors but nobody told me that there was a genetic test…The doctor told me not to worry that these lumps were just benign. Sad. I was following a six-month surveillance with multiple biopsies, and one they found was not benign. It was aggressive cancer; grew fast in four months. It grew a lot and was a big lump here. I had lots of benign lumps, the doctor had to remove them because they could not tell, and then…

When Participant 3, a 58 year old, married mother of two, was asked about her experience at diagnosis, she responded:

I was really scared. I don't think that I doubted that I would do it I was afraid of what would happen if I didn't do it. When I was diagnosed—great story—I was at home I had been waiting 10 days to get the results of my tests and I was fretting the whole time not knowing. My sister and mom and I all tested at the same time and we were tearing our hair out waiting. We are not good waiters. I knew the genetics counselor had the results and she was going to call me first thing on Friday morning. I was sitting by the phone waiting for it to ring and it rang right on the dot at nine o'clock and I got to the phone and this cheery voice says, "Hi this is the Major Metropolitan Cancer Institute and I have good news." Well I leaped off my chair and my heart is jumping, and then she says. Thanks to your generous donations we were able to add 18 new beds to the center this year. May we count on your support again next year? It's true. The shock when I realized…

Participant 3 continued:

> A call came in fifteen minutes later from a genetics counselor saying that I was positive. It was a real roller coaster of emotions. I had a lot of tears to go through. It was almost a relief after the waiting and not knowing. I was 50% positive I could do it. I cried and my husband was there.

Before Participant 4, a divorced, 46-year old woman was diagnosed, she was working: "Working, going to the gym, out with friends." Her thoughts regarding breast cancer were:

> When I found it, in my mind, I thought it would be small, and I'd have a bilateral mastectomy, just like I did. But then after I spoke with more physicians and did more reading I learned that I wouldn't necessarily be diagnosed when it was small and treatable with just surgery.

At diagnosis, this participant found it difficult to label her self-efficacy:

> Dependent on different moments that you caught me. I thought there was no way I could possibly do this. I curled into a ball crying about it. Not achievable. There was no way I could do this. It was unachievable. My sister was diagnosed with breast cancer. Didn't think results would be positive. Then when they came in four days later, I wasn't overwhelming surprised. This participant learned of her diagnosis while driving alone on Interstate 95.

When asked about diagnosis, Participant 5 responded that, "At diagnosis the best word is "overwhelmed." The feeling of being overwhelmed presented itself as a recurring theme in this data collection. Participant 5 stated that her self-efficacy was at 0. She said that:

> Initially I had avoided the whole subject for many years. When I did pursue it I didn't think I'd get a phone call. I was at work, I was dumbfounded. "Wow I can't believe this." Everything was supposed to continue on as it was then…a big flap across the face. When they said we have to see you tomorrow, I knew that I had to start gathering information. I knew what I'd have to say, what to expect and that I needed to be prepared to meet the physician.

For Participant 5, "Diagnosis was a 'Crap your pants moment.'" She had learned of her diagnosis while at work, in her office, alone. Participant 6, a 28 year old, married, mother of two, was diagnosed at 22. When asked about this, Participant 6 responded:

> My mom was going through breast cancer. They were going through her family tree and stuff like that and they found out that her sister, mother, father had all had breast cancer. That reminded my mom that a long time ago one of her great aunts had also been diagnosed at risk.

At diagnosis, Participant 6 reported self-efficacy at diagnosis of:

> "100% certain…Although I wasn't certain at that point in time exactly what my objectives were…and they have changed since then. At that point in time I was very much against doing the prophylactic mastectomy. I believed that with exercise and a better diet I could change the outcome.

Participant 6 went on to say, "My opinion changed over time." Participant 6 related how her mom's disease affected her decision-making regarding her own future health choices. This is a repeating theme among all participants.

> When I was diagnosed I was enrolled in school, but I decided to not go to school and just help with my mom. I was just taking my mom to chemo, to radiation, to

> the hospital, when she needed to go, when she was really sick. She had surgery after surgery…and then just dealing with that. I was lucky that I was in a position that our rent was extremely cheap and my husband boyfriend at the time said to just take care of your mom and we can handle it…so yeah. So I was helping my mom out. (Participant 6)

To each of these participants diagnosis at high-risk of breast cancer was a disorienting dilemma. Most study participants had been caretakers and observers of close family members who were in the process of coping with breast, ovarian, and other cancers. Proximity, observation, and caretaking to those undergoing similar health challenges may influence personal health choices. Chapter 5 will discuss this emerging theme.

Transformative Learning

A review of participant responses as it applies to transformative learning follows.

All participants agreed that they were transformed by this experience. In what way, if any do you think that this experience has changed or transformed you? If so, how so? Participant 1 believes that she:

> Was transformed, naturally and I've matured, and I think that when you hit forty in general, you just don't care what people think anymore. I've always been an athlete, and strong. This whole experience has empowered me and has made me stronger. I think much of this is I'm paying it forward and sharing the knowledge and that I think just is good for your own soul and makes you feel good about yourself. I've always been a kind person but maybe this has allowed me to become who I was meant to be.

When Participant 4 was asked about transformation, she responded:

> Yes. Wow. Uh, I think that there is so many changes in myself from going through this. On one hand I am so much more tolerant of people. I cut people so much more slack on things. Because I always wonder now what battle people are fighting. You can't look at somebody and know what it is they are going through. You need to give them the benefit off the doubt. On the other hand it's made me less tolerant about things. Picking on people for their appearance or TV shows where they laugh at someone's dress, it kind of helped me sort out in life what is more important. Made me want to focus on bigger picture. It's made me realize you just don't know what other people are going though.
>
> Other people didn't know what I was going through and didn't know how difficult it was. You often don't recognize when you are being insensitive to someone else. Can't count the number of times I got comments like "well look at the bright side you get great new boobs." Yuck. There were so many people at work who said that.

Participant 5 described how she had been transformed:

> In a lot of ways. Health-wise it has increased my living a long and happy and basically cancer free life and it's made me be able to look back and say, "Wow, this has been a horrible year, but I made it, I'm stronger for it." I've shown it to my children who see and have seen this, even my youngest one said, "If you can do this, I can do this." So, I may be less of person percentage body wise but… (With things taken out and all), but in the end I'm a stronger person than I was

before stronger mentally. There couldn't be a whole lot that I couldn't be able to get through. It can be difficult, but I can do it, I can get through it.

Participant 6 has learned that:

> I'll get there. There may be bumps in the road. Not exactly what I planned on it being, but I will get there, especially where it comes to the surgeries. In the long run even if you have complications, you will get there. I feel very positive. No matter what happens we'll get there.

The following question regarding transformative learning was open-ended and worded accordingly: Let's talk about the role of transformational learning. What was the role of transformational learning as you progressed through the stages: diagnosis, gathering information and option discovery, decision-making, surgeries, healing, and recovery? After the process Participant 2 said:

> Two things, one, it changed my perspective from being a high achiever, thinking about work all that was very important, to work is something that is necessary, but it is not my life. My life now is more my friends, my family, and that comes first. So, before I had it, it was a different scale. First was work, responsibility, saving for when I am old. Right now if a friend calls, that is more important, if my kids need me that is more important.

This theme represents changing priorities from worldly things to relationships and experiences with loved ones. Chapter 5 will discuss this emerging theme.

"My priorities changed and that is that..." continued Participant 2, "right now is I believe that God kept me here because he wants me to do something special and that something special, is to help other ladies as they are going through this process." This

theme is one of helping others through what was to each participant a difficult time. "Nearly every other day," said Participant 2:

> I get calls from women for help about how to get through the process. I would have not done this before. I am not an emotional person. Now I try to be very helpful. That is what changed from before and after.

Participant 4 stated that she gained confidence as she learned more. She said:

> As I learned more it definitely helped me with my decision for treatment. I had just lost my brother to cancer. When my brother passed away I realized that it was time to seriously consider the surgeries. I had already had my ovaries removed. I was the only person in my immediate family who had not had cancer. My mother, my brother, my sister and my father all have cancer and I realized that this was really deep. I knew that I could do what I could, so I wouldn't and that was my tipping point. God, I don't think I can do this now. She was so overwhelmed trying to care for her brother.

When Participant 4 was going through the stage of *option discovery*, her sister had just been diagnosed with breast cancer. She said, "I had to watch her go through this with first brother, then sister, then mother, then her had experienced this process. At least we had each other to do this with. Research is important to me."

Participant 4 sought reputable health care web sites, including the National Institute of Health (NIH) and Cancer.org:

> I found a lot of out there, wack-job sites, but didn't pay attention to that. I started to visit doctors to find out what was reasonable. Weighing benefits of what my

options were as I start to do more research, seemed like something achievable became in the 70% range regarding self-efficacy.

Participant 4 recognized a relationship between knowledge, power, and control. She said:

> Knowledge and power. Absolutely knowledge gave control. I knew options and choices. I believed one thing in my mind, with surveillance absolutely it would be OK. When I would be diagnosed, it would be small, I would have a bilateral mastectomy. I could just wait. Then when I did more research, spoke to more doctors, I learned that it would not necessarily be diagnosed when it was small and just treatable with surgery.

As Participant 5 was discovering her options, and considering her decision "I thought of my family what would happen if I did act, if I didn't act, and the consequences of everything all in one." She had just watched as her mother and her grandmother went through the rigors of chemotherapy. "Watched mother and grandmother go through chemotherapy. My mom was the strongest person I knew." Participant 5 went on to reveal that, "I got married without my mother, had my children without her, the last thing I wanted was to see my children go through that. That's why I went through with the surgery."

Participant 6 at first believed strongly that lifestyle changes would favorably impact her risk of breast cancer. As she learned more, her "efficacy was at 70%." At decision-making, Participant 6 was "100% sure of her decision." This would support the theme that thorough research of quality supportive sources women feel empowered to make a choice that is right for them:

> At first I remember going to my mom's oncologist. He said I had to decide if I was having kids and have them. Then start having surgeries. I should get a mastectomy and a hysterectomy. At the time I wasn't even married to my boyfriend, now husband! (Participant 6)

Option discovery and research. What sources of information were available to you (e.g. medical professionals, internet research, word of mouth, etc.)? What did you learn and from which sources? What role, if any, did any organizations, your mate, family, friends, medical professionals, your employer, or others play? Participant 1 started researching:

> It was a combination of researching and the memories of seeing my sister on the ground with the pain of ovarian cancer which is something that no one should have to witness, and knowing that that could not be my life path. Also at the same time watching my friend go through breast cancer and losing her life...seeing how sick she was and knowing that those two paths could not be my path. Seeing the devastation, the battles, the chemotherapy, so it was a lot of learning. Also the fact that I had dense breasts which makes it difficult to identify breast disease on a mammogram. Many risk factors, including dense breast tissue, genetic predisposition, watching those cancer battles in front of me…I knew I did not want this sort of diagnosis and I did not want to go through chemotherapy. I had an appointment, including my husband, with an oncologist who handed me a list of all of my options that she sat and wrote down for us. My confidence grew as I continued my research. I think my self-efficacy started at 20% gradually building to 35% to 40%. That's when I started eating a lot of

chocolate and drinking a lot of wine. The options become very real. My husband and I left the appointment feeling like we had been run over by a truck. I moved up to 50% as I learned more. I decided that to save my own life I had to do it and I have to be here for my kids.

Participant 2 stated that she "was very confident after her thorough research and very confident with her doctors, informing her decision. I began with the social media and then followed up with my physicians." When Participant 3 was asked about research she responded:

I first started research then as I continued my research I would be able to come to some conclusion about what to do. My self-efficacy was at about 50%. I dove in and looked for other people who have been there before me, so I immediately went to this informative web site. Talking to other members allayed my fears, talking to me on the phone telling me that I could get through this. They assured me that they had been on this same path that I was on and they could make it through it. They successfully navigated all this and they were still ok made me feel confident that I too would be able to do this.

Participant 3 was directed to a genetic counselor:

Sources of information available to you? It was on the fringes of my awareness, but I didn't really know anything about it just seemed like this weird thing, like why would someone do something like that? And then my mom had cancer and she tested positive. Then I started learning more about it from her oncologist and then I made an appointment right away with a genetic counselor that was what was recommended to me, and my sisters. I went on line went to the American

Cancer Society. Although few of the participants reported being referred to a genetic counselor, this participant was and benefited from being referred to the informative brochures and on-line groups. This suggests that counseling may play a big part in decision making for women at high-risk of breast cancer, and should be explored in future research (Nekhyludov, Bower, & Altschuler, 2005). Participant 3 continued:

> I saw the genetic counselor early on and she gave me some brochures talked to me turned me on to a breast health awareness organization headquartered in south Florida which has a large web presence and community right away. It was overwhelming at first—so much to try and figure out. This web site was very helpful. I also found a handbook about breast reconstruction helpful. There was a dietician, and six experts. They included my family in this educational meeting. This was especially helpful to my husband, because he didn't understand it all. For him as all he could hear from me was emotion.

This reveals the emerging theme regarding value to the patient of treating the whole person and the whole family support system. This will be discussed in Chapter Five.

When asked about sources of information and their credibility and how to select best informed sources, Participant 4 warned, "People may want to hang on to something when doing research in a vulnerable state and need to insure that the sites they research are credible." Participant 5 used Internet research: "For research I mainly used Google, Facebook. Later, I went to a genetic counselor who said, 'You've done so much homework you could almost counsel someone else in it.'" This became an emerging theme and will be further discussed in Chapter Five.

"I gathered every bit of information I could get my hands on before I went in there." At this point Participant 5's self-efficacy was high and the more information she gathered, the more sure she became:

> Had more information than I could handle. One side you have to do this, another side of research saying you don't have to. They can't say what is best for me what I have to do for my life. Your life, your decision, you are the only person who can make the call.

When asked about the role of self-efficacy as Participant 5 began gathering information, she reported that her self-efficacy began to rise. "Getting past initial overwhelmed feelings, then finding answers, as answers came, giving me hope that this is the right thing to do. But although it will be difficult it will leave nothing but a positive result." Her self-reported self-efficacy at this point was 20%. She summarized her theory this way: "There may be roadblocks, but it would come to an end. Things that suck will end eventually and the sun will come up the next day."

When asked about the decision making process, Participant 5 said:

> At first I was gung ho—going to do this for me, my family, my future. Then I don't want to do this. Like the five steps of grief. Six weeks to get to acceptance this is what I'm doing for sure.

Participant 5 focused on the value of her research to inform her decision-making:

> The more knowledge I got the more I knew that I would get through it, and it would be the answer that I needed to do. The more information I got the more control I got because I could make those decisions evidence based decisions and I had control. I did have control. I didn't hold the scalpel but I had control.

The idea of having control is a theme that all participants in this study expressed. Participant 6 based her initial decision on the fact that she was so young believing that she had time to wait. She improved her health with diet and exercise. Then her aunt got breast cancer at 42 and died. Physicians recommended that she have close surveillance starting at 32. She decided on prophylactic mastectomy because she believed that if she could avoid it, what she saw her mother and her aunt go through, she would, in any way that she could:

> I went through a time when I thought that people who did this were absolutely crazy. Why would you cut perfectly healthy tissue off? It's not 100% chance. But then as I grew older and I had children I realized that I don't want to risk it. It's not worth it. I want to watch my boys grow up and I don't want to miss out…so yeah.

All participants who were mothers factored in protecting their children from the experiences that they had with their families, the idea of surviving to watch their children grow. Participant 6 did a lot of Internet research, beginning her research with a pamphlet from a major south Florida breast health advocacy organization headquartered in southern Florida. This organization has a broad presence on the Internet:

> I signed up with newsletter gave me information about a group that focuses on health destiny on the Internet. Once I decided to move forward in undergoing surgery it is sort of a support group for women and lots of information sharing. So far everyone has been so very helpful to me and that has made me feel good. A lot of the nurses and doctors said to me that if they were in her position they would do the same thing.

This data reveals that the support of the patient's health care decisions by health care providers can create a positive feeling for the patient.

All of the participants did research directly on the Internet, in addition to working with their health care providers. Some went to the library. Some asked family members to share their health histories. Most located reliable sources quickly and connected with numerous social networking sites for support and continue to do so.

Surgery. At the start of surgery Participant 2 felt very confident. She stated:

> Before the surgery I was at about 80% on the self-efficacy scale. After the surgery, it looked bad, so my self-efficacy dipped to like a 60. But that was the first week and I was like, "Oh my god, what am I going to look like?" I was really scared. Besides the looks, the feeling, I couldn't lift my arms, I couldn't do anything! And I cried and cried. Will I be able to comb my hair? I crawled to the bed and tried to do the exercises that they would tell me…It was really hard, and at that moment I would feel like a minus 10! I exercise, I work out, but I couldn't do anything. To only breathe it hurt so much the first week after the mastectomy, then I felt like a zero at self-efficacy. I recommend that you get some sort of help because you can't take care of yourself.

At surgery, Participant 3 was feeling scared:

> Going into the surgery, it was scary, but I felt like I could do it. I felt like I have worked on a process, and I was committed to it and it didn't matter if I was scared it was just going to happened so I might as well just go with it. Like being on a roller coaster when the bar comes down you are just in for the ride! I'd done a lot

of research and had a pretty high level of confidence that I would be OK. Thought I would be ok, so maybe my self-efficacy was in the 80% range.

As Participant 4 was going through surgery she felt, that her self-efficacy waivered:

> Some days I felt really empowered I can do this. There were days I felt not so strong. There were days at work where I would go out and sit in my car and thought how hard this was, especially leading up to the surgery, especially after I told them at work and the employers, began acting differently and work got difficult creating to campaign to discredit me and prepare to fire me. They were kicking me at a low point in my life, but I had no choice but to take it.

However, at surgery Participant 4 felt:

> Completely resolved. Day of first surgery I was amazingly calm. I was amazed at how calm I really was. I didn't know how it would be in there. I thought I would be hysterical I thought I'd cry myself into the operating room but I didn't. Very committed to the decision I'd made. My self-efficacy was at 100%.

When Participant 5 was asked about self-efficacy at surgery she responded that she:

> Felt stronger mentally not necessarily physically stronger, because I needed help, but it was the thing that my daughter who was 17 at the time said to me, "You are the toughest woman I know." If I didn't have children I would have held off. For me it was important for them grow up with a mom hopefully living many years. I didn't have the same ability growing up with my mother. I knew what I had to do. I did what I needed to do. I feel relief.

Healing and recovery. Participant 5 felt that throughout healing and recovery she sometimes had a little pain or had to change bras to relieve the pain. "It is not 100% but it comfortable enough." Participant 3 found healing to be thrilling:

> I was thrilled. It was hard. It was hard recovering from it. It hurts for a long time. But I was so relieved that it was over and I knew that every day would be a little bit better. Do something else now. My self-efficacy was at 100%. Now at healing. I got more out of this experience than I ever could have imagined. It has redirected my life in ways that are so gratifying to me. I discovered so much about myself that if I could go back and not have the mutations. I'm not sure that I would. I would have to give up so much that I've learned. And I don't think my husband wishes I had done it. My husband wishes we could go back and undo the whole thing and it's really hard on him, hard time coping with it. The things I'm doing now are things I couldn't have imagined beforehand.

This data may indicate an emerging theme regarding the role of caretakers in this experience. More on this will be seen in Chapter 5.

Participant 4 reflected on healing and recovery:

> Yeah. I had a lot of days during healing that were difficult. There were 20-30 days that I just didn't think that this was achievable. It went on for quite a long time I didn't think the results were what I'd hoped for. That I didn't think I'd ever get back to my old physical self.
>
> I never stopped to wonder if I did make the right decision for my health, but I wondered if I'd made the right decision mentally. There were also times, I'm single I wondered if I'd made the right decision …dating…its odd. I'm still

> uncomfortable with my body. And not exactly want to show off to people and it's an odd to explain to people that, No I didn't have cancer but I chose to remove my breasts anyway. And I have these two rather hard lumps of silicone on my chest and this is why I have them. Uncomfortable explaining it to people.

Participant 4 continued:

> At that point my self-efficacy is at 100%. I know that I made the right choice for myself. I have two girlfriends going through chemo right now and I see how sick they are. Interwoven with days that this wasn't the easiest thing. There are some prices I paid for it. Part of my job loss was attributed to the fact that I took so much time off for surgery.

When reflecting on her healing and recovery said Participant 4: "I had to have time to heal. At that time, I couldn't not get better." When addressing healing Participant 4 responded:

> The most important thing for me at that point was to get better. At that point I felt that, "You couldn't listen to the voice that said you couldn't do this." Completely focused on that. I tried to make getting better as easy as I could for myself. Didn't have a lot of people physically here to help me but I still tried to make it as easy as I could. Whether it was eating prepared foods and spending more money or sleeping most of the day then I slept. I didn't pressure myself. I listened to my body and if it wanted rest then I rested. I didn't push myself to do things except listen to what my doctor said. I was kind and gentle to myself. Some days that meant that I couldn't look at what my chest looked like, because that upset me but, ugh. Basically I didn't take off my surgical bra because it just upset me.

During healing, Participant 5 reflected on her experience:

> I've gathered and learned more than I can ever use and I use it to reach out to other people in the same situation, or approaching it to help them. I was scared out of my mind, I know exactly where they are and I feel like if anything a lot of this was learning to help others. This has been a learning thing, and answers the question, "Can I get through the crazy things in life?" and the answer yes, it is a life changing event.

Participant 6 said that she had a few:

> Wet and weepy days right after the surgery, when she was feeling some doubts. Then I got my period and figured out what that was all about. The drain sites hurt so bad. It was horrible. And I thought, "Why did I choose to do this to myself…it hurt so bad. I felt so stupid. But then I thought, yeah, and it got better. I feel nearly back to normal already.

Table 4

Coping Strategies Participants Utilized While Undertaking Risk Reducing Mastectomy

Participant Coping Strategies	1. Appraisal-focused: Assessment of risk, acceptance of status quo or distancing self from problem	2. Problem-focused: Directed behavior to reduce or eliminate a stressor, or adaptive behavior	3. Emotion-focused: Changing emotional reaction to a stressor (Weiten & Lloyd, 2008)
1. Diagnosis	"I felt in an overwhelmed state." "Used mental health techniques, such as determining if she had control, and if not allocating a brief amount of time to thinking about it and moving on to a new focus. While it can be debilitating when I think about it, I only allow certain periods for thinking about it and then I move on." "I have no control over the situation, besides choosing to do surgery or not. There is no reason to let it ruin my life. I try not to let it rule my life. They let the fear control their lives…which I can understand. When you are stressing…do you have control? Do something. If you have no control over the situation think about it for five minutes then say no more I'm not going to do this anymore. I'm not going to let it dominate my day and ruin my life. I've got to much more things to think about and live for…yeah. She also used mental health techniques, such as determining if she had control, and if not allocating a brief amount of time to thinking about it and moving on to a new focus. "While it can be debilitating when I think about it, I only allow certain periods for thinking about it and then I move on.	"Exercise, specifically running as a coping strategy. I'm a runner, my children are too, and it has been a huge coping mechanism. That's how I managed."	"Xanax, Wine, and Chocolate. I had to numb myself. I did that to cope."

Table 4 continues

Table 4 continued

Participant Coping Strategies	1. Appraisal-focused: Assessment of risk, acceptance of status quo or distancing self from problem	2. Problem-focused: Directed behavior to reduce or eliminate a stressor, or adaptive behavior	3. Emotion-focused: Changing emotional reaction to a stressor (Weiten & Lloyd, 2008)
2. Gathering Information and Option Discovery	"I felt in an overwhelmed state. reading a lot to get informed and that would help me cope with all of my worry and anxieties and everything. I learned a lot so I was able to explain anything that was happening to me. Ummm another way was talking with friends. Just spend time on the phone trying to express myself. Also I had a counselor, once."	"I relied on some friends, but I was really in research mode."	"I have a therapist…very helpful. The whole time. She is great. I highly recommend therapy, although a lot of people will think there is a stigma to it. It's nice to have someone who is objective."
Decision-Making	"I felt in an overwhelmed state."		"I felt in an overwhelmed state."
Surgery/ Surgeries	"Lying in bed crawled up in bed crying."		
Healing	Humor and creativity are two primary coping strategies. Coping strategies included, "Laughing." "I even used humor to cope, fairly early on in this process."	Went to the gym regularly	"Did not, and am not, going to allow anything to keep me down. Given me more reason to be an example to my children that anything you can throw at somebody you have the determination to get through it, give up, give in, or just keep going. At this point no way I would turn back. Intend to do a marathon next February. A long and hard year. My goal-keep going."
Recovery	Canine companion was a comfort to her as evidenced by her saying, "I have a dog who I love and she is a wonderful source of comfort she is great. Dog never jumped on my chest she was amazing. I don't know how she knew but she stayed with me."	"Step on the treadmill, even if I would walk half a mile, slowly, slowly, I would just walk, I would have a little more energy and that helped me a lot, tremendously. Exercise and to walk outside is my first coping mechanism. Resumed going to gym.	

Coping strategies. Coping strategies may be a part of adult learning (see Table 4). Did you use any coping strategies during these process? If so how and from where did you learn them? Why do you believe you could cope? (For example: fear, commitment, control, spirituality, family, resiliency etc.)? Participant 1 said:

> Oh yes. I'm not shy. I went straight to Xanax when I had to be there for my sister, seriously. I had to numb myself. I did that to cope. I drank wine and ate chocolate. I relied on some friends, but I was really in research mode. I felt in an overwhelmed state.

Most participants labeled some part of the experience overwhelming. Participant 2 went to the gym regularly prior to her diagnosis and has resumed going:

> Even after the surgery, I would go to the gym. Step on the treadmill, even if I would walk half a mile, slowly, slowly, I would just walk, I would have a little more energy and that helped me a lot, tremendously. Exercise and to walk outside is my first coping mechanism.

Participant 2 also shared:

> Reading a lot to get informed and that would help me cope with all of my worry and anxieties and everything. I learned a lot so I was able to explain anything that was happening to me. Ummm, another way was talking with friends. Just spend time on the phone trying to express myself. Also I had a counselor, once.

Humor and creativity are two primary coping strategies used by Participant 3. Her coping strategies include, "Laughing:"

> I use humor to cope, fairly early on in this process I was on line with a friend and we started writing limericks. I started a thread on a website. They were funny

> poems. The response was unbelievable. Over 300 limericks from all over the world and it was the first time we laughed about it and we were happy. We were online all the time. They were about surgery, about sex, and husbands, and kids and it was this bonding experience with all of these people who were going through this together to share it. Limericks are easy to write. They are just a little five line stupid little poem so even people who aren't real good with words could write a limerick.

This participant got the idea from a friend's therapist. One example follows:

> *"I've just had a genetic test*
>
> *And I'm feeling a little depressed*
>
> *It's not just because*
>
> *I'll have menopause*
>
> *But I wasn't quite done with my breasts."*

Participant 4 was not sure that she did the best job of coping. "Some days I don't think that I coped that well. Lying in bed crying is not a great coping strategy." Her canine companion was a comfort to her as evidenced by her saying:

> I have a dog who I love and she is a wonderful source of comfort she is great. Dog never jumped on my chest she was amazing. I don't know how she knew but she stayed with me. I have my sister who was going through the same thing. It's good to have somebody around. I have a therapist….very helpful. The whole time. She is great. I highly recommend therapy, although a lot of people will think there is a stigma to it. It's nice to have someone who is objective.

Participant 5 used exercise, specifically running, as a coping strategy. "I'm a runner, my children are too, and it has been a huge coping mechanism. That's how I managed." She went on to assert that she:

> Did not, and am not, going to allow anything to keep me down. Given me more reason to be an example to my children that anything you can throw at somebody you have the determination to get through it, give up, give in, or just keep going. At this point no way I would turn back. Intend to do a marathon next February. A long and hard year. My goal: keep going.

Participant 6 believes that her coping mechanism was:

> I have no control over the situation, besides choosing to do surgery or not. There is no reason to let it ruin my life. I try not to let it rule my life. I see so many people on the Internet and I feel terrible for them, it's as though it has taken over every aspect of their lives. They let the fear control their lives…which I can understand. When you are stressing…do you have control? Do something. If you have no control over the situation think about it for five minutes then say no more I'm not going to do this anymore. I'm not going to let it dominate my day and ruin my life. I've got to much more things to think about and live for…yeah.

She also used mental health techniques, such as determining if she had control, and if not allocating a brief amount of time to thinking about it and moving on to a new focus. "While it can be debilitating when I think about it, I only allow certain periods for thinking about it and then I move on."

Analysis suggests that coping strategies can be useful as women progress through the process of prophylactic mastectomy. These skills were learned and used by most

participants: talking to friends (n = 3), crawling up and crying (n = 2), exercise (n = 2), creative writing (n = 1), humor (1), writing limericks (n = 1), and taking Xanax (n = 1).

Disorienting dilemma. All participants agreed that this was a disorienting dilemma for them. Participant 1 responded, "To say it wasn't frightening would be silly because its heavy stuff. Yes." "Yes," agreed Participant 2:

> I was worried that I would never regain strength, that is one thing, and I didn't tell anybody that I was so limited, and I tried to keep it private, and to not show it to my kids that I didn't want them to see this. I always tried to be optimistic, but in this case that was really hard.

Participants were motivated to be positive regarding the situation not only for themselves but even more so for their families. Participant 3 asked, "Disorienting dilemma? Yeah." Participant 4 said:

> Yes. Of course this was a disorienting dilemma. I just find out, I'm mostly going to win the shit prize. You're probably going to get cancer, but you might not. And you can cut off your breasts and that will probably help you. But it might not. How else do you put that? Yes it was disorienting. Just horrible.

Participant 5 said:

> Yes it was. Initially it was overwhelming frightening, scare the pants off you. Again as I gathered more information and more knowledge I knew the overwhelming-ness dropped significantly two weeks before surgery were harder than recovery itself due to the mental and anxiety that goes along with it I found keeping myself busy staying active helped get me through those times. Support of people who had been through it before. This is the most difficult time. It

would have been 100 times harder without a support system. Everybody needs a buddy…absolutely.

Participant 6 agreed that this was a disorienting dilemma:

Of course! Who wants to hear that your genetics-that you are most likely going to get cancer? I can see how it could be debilitating for some people, but you've just got to push through. There is so much that life has to offer. This is just part of me, not all of me.

The researcher asked: "Did you experience self-examination? Were there feelings of guilt or shame?" "Not shame, because it was what it was," responded participant 1:

Guilt that I may have passed this on to my children. I may have unknowingly passed on something that may be a heavy burden in their life. I have some guilt that all of the surgeries and healing took away from them (her children) and me not being able to be mommy.

Participant 2 reported no feelings of guilt or shame:

No, no. I would feel guilty if I didn't tell everybody else that you can prevent this because I feel so good that after I did this, my sister, was able to prevent it. I would feel guilty if I didn't tell somebody.

Regarding body image, Participant 2 said, "Yes, somebody can tell that they are fake! But I don't care 'cause, they look very perky, (laughs…)." When asked this question Participant 3 said, "I don't recall any feelings of guilt or shame." Further she went on to say that as she progressed through the process she found herself to be more creative, "I'm more aware of themes in my life that I want to explore. The feeling…of

my writing is deeper. I am writing more serious material with humor in it. Added a lot of creative depth to my output." Presently she is writing a play on a related topic:

> Creating writing a play about five people who have who have to make a decision that will affect the course of their lives your life, and they can't know whether it's the right decision or not and they have to make it on a leap of faith and also know that once you know that once you have made your choice, that all the other there is no way to know what was down that other path. I will never know if I would have gotten breast cancer. Somehow you've got to come to peace with that not knowing. As well as knowing the outcome off the path that you have chosen. So that kind of awareness informs my work now.

She finds that she exploring themes of interest and digging deeper into them after this experience.

When Participant 4 was asked about this she responded, "I never felt guilty or shameful." Participant 5 responded:

> No shame. This was more of a pep talk. We are going to throw this out at you, and I said I'm going do this, there was no shame there I was just gung ho about getting it done and taking care of what I needed to take care of. For myself and my children. I never had any shame whatsoever. It never even crossed my mind.

The researcher asked, "Did you question sociocultural assumptions regarding this?" When asked about sociocultural assumptions regarding this issue, all participants gave emphatic answers. When Participant 3 was asked about sociocultural assumptions she was concerned about incorrect information getting to the public via uninformed sources. She said:

I am opposed to all that. Once I looked at the statistics and thought it through when the outside world intruded with their ill-informed opinions I am compelled to fight back and let people know the truth…Angelina Jolie, "Why did she mutilate herself, why didn't she have extra mammograms?" They just infuriated me. I felt I had to educate and let people know. They were ignorant. So I went on Facebook and Huffington Post to educate people. I was very confident that I had made the right decision for myself.

Participant 4 said:

Absolutely, no question about it, at work, I can't tell you how many times I got, "Oh well at least you get a big boob job out of this." "Doesn't it seem a bit drastic to cut off your boobs? You don't know that you're going to get cancer?" or, then there was the, "Medicine changes their mind on things all of the time, what if you do this now and then next year they change their mind?" There were people always judging what I was doing. There's a lot of that. And the ever popular, "You just need to eat healthily, and exercise and that prevents most cancers."

Regarding sociocultural assumptions Participant 5 responded:

They sort of angered me. First of all, no person can speak for me but me. And it is my decision, it is my life and I certainly would never accept judgment from them. One person (a country star) (she sings my "go to" running song) gives her opinion on prophylactic mastectomy, it is to not do it, and that just angered me. If I ever had a face to face…take a hike.

The researcher asked: "Did you realize that this discontent has been shared with others who have overcome or coped, and if so when?" Participant 1 found that:

> The resources were very limited. I felt that there were others when I got into the social media and Facebook groups. After attending a conference I realized that there were five or six hundred people there all have family histories and are at high-risk of breast cancer. Facebook has over 4,000 women, oh my gosh. That's a lot of women! That's when I figured it out that there were others.

Participant 2 realized after her mastectomy that there were educational organizations of people who had been through the same experience:

> My physician gave me a brochure on my final post-surgery visit about an organization that specializes in addressing high risk of breast cancer. I went to the conference and found many people with the same problem. Before that I was in "survival" mode. Afterwards it took me a long time to look around me to see that there were a lot of people around me just like me. I just knew that I wanted to get out of this and not have happen what I saw happen to my mommy and my aunts. I don't want my kids to go through the same thing that I went through when I was just a young girl. I was 13, I was very young. Back then it was just radiation and surgery, radiation and surgery, and I remember watching those four years, my mom go through that. That is a history that I didn't want to repeat.

The theme of survival as primary motivator and saving one's children from the suffering of watching a loved one lost were the two most resounding themes discovered in this research. When asked about this, Participant 4 said, "I realized that right away.

As I began my research. I got involved with a major breast cancer awareness organization in Florida on the web." Participant 5 advocated a buddy system:

> Yes. I think it's vital that anyone going through this be introduced, be led by someone who has gone through it. Sure you could do it without, but there are questions that you may come up with at 3 am that the only person who can answer it is somebody who has been there and likely they are the only ones who would answer the phone…I've found that with the Facebook group that I am still active with-24/7 support group people who have been exactly right there.

The researcher asked: Did you explore options for new roles, relationships or actions? If so please explain. Participant 3 had some concerns about the future of her private life:

> I was really worried about sex and what would happen to intimacy after all this was done? And that was one of my biggest fears going in into it that I didn't know if I was going to learn who I was as a non-sexual person. If that's how things went. That's always been a chord in my identity. And that was one of the things I had to leap on I didn't know what was going to happen but I had to do it anyway.
>
> It's OK. I don't have regrets. And I guess. Some ways it's freed me up to think about something else. Before I was a cabaret performer, the glitter evening gowns, I had this sexy persona on stage and I you now didn't want to suddenly be "mastectomy girl" and lose this prevention of myself as a sexy person. And I am a less sexy person than I was before all this. I am still a

somewhat sexy person and I am coming to peace with that. And there are things I miss.

I had a beautiful reconstruction. My breasts look great. But they are not. They are cold. They have no feeling. I'm sorry about that. I still have a sex life. My creative work has been exciting to me. Growing older there are losses along the way. And gains…

Participant 4 is finding dating difficult:

I think that dating is weird and awkward. I haven't had a real relationship since. It's a process. I have another surgery coming up but I'm not scared about it, because I know what it's going to be like. I think that once I became more educated about this that I became more confident. It's always a scary situation when you don't know what's going to happen. As you know what it's going to be like I become more confident about it. I know what it will feel like, and how long I'll be out of commission. I know what to expect.

On the topic of empowering experiences Participant 4 shared that:

Overall this has not been a particularly empowering experience for me. I actually think this has had the opposite experience on me. I've found this to be an incredibly overall challenging situation. The last several things have been challenging, losing my brother to cancer, seeing my sister diagnosed with breast cancer, seeing my mother diagnosed with breast cancer. The last few years have not been particularly empowering.

Participant 5 wanted to keep her health choices private to avoid negative judgment:

I wanted few people to know what was going on because I didn't want them to see or feel anything different about me. Not regarding the decision but along the lines of thinking less of me as a woman because I've had this major life changing surgery. The fewer people who knew the better because I want to be tomorrow who I was a year ago. I know I've had changes and I have the scars to prove it, and will for the rest of my life but I don't want what other people see as me to be any different. Unless it is of a strong person with determination that's fine. While the body image thing is not as important to me personally what other people think of me unfortunately is. I've always been a caring person and it was very, very difficult for me to accept help. From anybody and that was another reason I didn't want anybody to know I didn't want anybody to have to help me. That is my role, I am supposed to help them. It was hard, but it got to a point sometimes where it was so difficult that I had to accept help and that was humbling and that changed me significantly because I now know that it is OK to accept help. If people are willing to give it they don't want anything in return. And it's OK to accept it because at some point everyone will need it.

The researcher asked: "Did you plan a course of action?" Participant 5 researched and created a clear and concise action plan:

Absolutely, yes. Down to the nittty-gritty…excel worksheet…this is going to be what you do at this time…detail and numbers oriented…everything. I insured that the important things that needed to be taken care of in the long run were taken care of. The expectations. In none of this did I place expectations on anything because I believe that expectations only provide disappointment. I had hope and I

had hopes of the way things would go but I was prepared to accept anything the way it came and place no expectations on what the outcome would be. I tried to prepare for anything. If I have to do it again I will.

The researcher asked: "Did you have the needed knowledge and skills for implementing these plans, have you acquired them?" Participant 5 was fully prepared to implement her action plan. "Yes. I had everything ready set and tried to prepare for any and everything."

The researcher asked: "Did you build confidence and self-confidence in the new roles and relationships?"

Participant 5 built confidence through this process:

Yes. It's not anything I would advertise or I would brag about or anything. I try to I think humility is important and I would not brag to anybody but I am the strongest I've ever been in my entire life, and I'm glad I got to go through this, because believe it or not, it made my life better. It has shown me that there is so much that I have to live for and to work for and its put a whole new light on my life. It was hard, no doubt, um, but, I'm glad it happened. I'm glad it's over for the most part but it was a learning experience and I'm stronger and I'm glad I got to go through it.

The researcher asked: "What is the most valuable thing that you have learned from this experience?" Participant 1 believes that:

It is a combination of trusting your own gut instinct, and getting the accurate knowledge. What's right for one person is not right for another. You have to go with your gut and your own family history of what you are comfortable with and

> get the knowledge of how you can best manage your risk and basically what's best for your health.

Participant 2 wants others to know that:

> They need to get informed about everything that is going to happen in that process. Then get ready for it. Because you have to plan on it. Just make sure that the hospital that you choose that they have a very good support staff because you need them. I had a nurse and she taught me how to recover from this. I speak with other ladies and they never even had any help in regaining strength.

Participant 2 believes that "the whole experience has changed her and made her a better person: "It is amazing when you lose something and then you regain it. I appreciate everyday what I regained." Participant 3 responded that she wanted to share that, for her:

> When I first found out, it seemed like a curse. But it is also an incredible gift because you have the power to change your future and so many women don't get that chance and they are just blindsided by cancer and how lucky are we that we can act before it's too late.

Participant 4 wants people to know that:

> You can do this. It is doable; you can do this and get through it. It seems really overwhelming at first but it is absolutely doable. Yeah. I'm not superwoman. I didn't have armies of help, I didn't have people waiting on me hand and foot, and I didn't have any sort of cleaning crews. I'm just a regular, ordinary woman with a job and I did it. You can do it. You can live through the pain and everything.

> You can do it. I'm just a regular person, I'm not anything superwoman and I did it, you can do it.

Participant 5 wanted to share that:

> That it has to be your decision within you. And when you make that decision support is vital and I think more than anything the learning experience was…it ok to accept help its ok to not be strong 24/7 and that no matter what it will get better, it has to, it may get worse before it gets better but it will get better and you can do it and for the most part you don't have any choice but to do it so you might as well just get out there and do it.

In a quick flash back, Participant 2 added, "After all off of this, these surgeries, it was very hard, but, we did it and I'm happy."

Self-efficacy

Self-efficacy played a role in health care decisions for all research participants. Self-reported self-efficacy increased throughout the process (see Table 5).

Table 5

Self-scored Self-efficacy as Participants Went Through the Stages of Prophylactic Mastectomy

	Participant 1	Participant 2	Participant 3	Participant 4	Participant 5	Participant 6
Diagnosis	20%	90%	50%	30%	0%	100%
Option Discovery	20%-60%	90%	50%	70%	20%	70%
Decision Making	90%	90%	70%	100%	70%	100%
Surgery/ies	100%	80%-60%	80%	100%	100%	100%
Healing	100%	90%	100%	100%	100%	100%
Recovery	100%	90%	100%	100%	100%	100%

Note. Likert-type scale 1-100 increments of 10 being low 100 being high.

Chapter Summary

Transformational learning and self-efficacy play a role in the progress through the stages of undertaking prophylactic mastectomy for those participants studied, from diagnosis through recovery. All participants reported incredible transformations in their lives as they progressed through this process. Five of six have been compelled and actively provide education and assistance to others at high risk. Participants utilized a broad variety of preexisting coping skills from positive affirmations to training for a marathon. The role of transformational learning and self-efficacy is unique to each participant, as is their interpretation and representation of it.

Next, Chapter 5 will discuss the findings, connecting them to the reviewed literature. Suggestions for best practitioner and educator practices will be included. A

summary of the research will follow and the chapter will conclude with suggestions for future research.

V. DISCUSSION

Chapter five discusses the findings and connections between newly gathered data and related reviewed research. This study is meaningful to those at risk for inherited disease who may benefit from knowledge of first-person experiences from the perspective of the women at risk. This study examined the experiences of six women who have undergone prophylactic mastectomy to gather first-person experiences to assist newly diagnosed women by providing information to help guide their decisions.

Information gathered from this study has added to the body of knowledge to assist newly diagnosed women to make informed decisions regarding their health care. Further, this information informs health care providers of the patient's perspective, enabling them to provide improved patient centered health care. Finally this information can assist educators and curriculum developers in creating and improving programs and protocols to assist women through this process. The research included investigation through the stages of: (a) diagnosis, (b) information gathering and option discovery, (c) decision-making (d) surgeries, (e) healing, and (f) recovery. The focus of this study has been on transformational learning and self-efficacy.

Analysis of the findings are organized according to the overarching research questions investigating the role (if any) of transformational learning and self-efficacy as they pertain to prophylactic mastectomy. The researcher asked: What is the Role of Adult Learning in Prophylactic Mastectomy?

Adult Learning

Research reveals that adult learning does play a role in the process of undertaking prophylactic mastectomy. Adult Learning as theorized by Knowles et al. (2011) would support the experiences reported by our participants. All participants discovered the need to know and gather information and the belief that they could. They brought their own unique life experience, their readiness, orientation and motivation to learn. Each was self-directed, goal and relevancy oriented, and each brought a pragmatic practical perspective. The participants liked to be respected as evidenced by numerous comments about how they felt when physicians and nurses engaged them positively including the comment by Participant 6: "I felt good when physicians and nurses both reported that if they were in her place they would do the same thing."

During analysis, the following findings emerged as the participants revealed their experiences through the process from diagnosis through healing:

1. The all possessed the courage/fear to not go through the experience that they had observed (six out of six of the participants).
2. They had seen firsthand the ravages of treatments in one or more first-degree relatives (six out of six of the participants).
3. The all were primary caregivers to one or more survivors, or lost family members while under their care (six out of six of the participants).
4. All participants who observed the ravages of cancer therapy on their loved ones wanted to avoid it if possible. They wanted to avoid doing the same thing (six out of six of the participants).

5. Those with children (four out of six of the participants) wanted to protect their children from seeing what they had seen. They also wanted to be able to watch their children grow up.
6. They wanted to survive, thrive, and become examples of strength for those around them (six out of six of the participants).
7. They worried about their body image and "sexiness" after mastectomy (two out of six of the participants).
8. They wanted privacy to avoid negative judgment regarding their decision (four out of six of the participants).
9. Most came through the experience feeling stronger than ever (five out of six of the participants).
10. Most believed that the experience made their lives better, as reported by P-5: "I have so much I have to live for and to work for.
11. The Internet, specifically social media, had created a real, supportive information sharing system that was inclusive and helpful (six out of six of the participants). One participant noted: "I am closer to my on-line family regarding exchanges on this issue than to her sisters and mother."
12. They all want to give back (six out of six of the participants).
13. A sense of control was gained through research, and reflection (six out of six of the participants).

Transformative Learning

"Learning is understood as the process of using a prior interpretation to construe a new or a revised interpretation of the meaning of one's experience in order to guide

future action" (Mezirow, 1996, p. 162). Adults are life-long learners, learning by experience, observation, or study. As individuals faced the challenge of prophylactic mastectomy their self-efficacy increased. Phases of this were supported by this research. Mezirow's (1996) 10 phases of transformative learning and the significant concepts of disorienting dilemma, meaning schemes, meaning perspectives, perspective transformation, frame of reference, levels of learning processes, habits of mind, and critical self-reflection can be found in Table 2.

Participants followed phases of transformational learning, but not all participants went through all steps. One example of this is that all participants agreed that although they had practiced self-reflection that none felt guilt or shame for themselves, but mothers felt guilt at possibly passing on genetic mutation or family vulnerability to their children.

Coping Skills in Adult Learning

The ability to develop coping strategies or skills is another component of adult learning. Coping is defined as expending conscious effort to solve personal and interpersonal problems, and seeking to master, minimize, or tolerate stress or conflict (Lazarus & Folkman, 1984; Weiten & Lloyd, 2008). Psychologists Weiten and Lloyd have provided a useful summary of three broad types of coping strategies:

1. Appraisal-focused: Assessment of risk, acceptance of status quo or distancing self from problem
2. Problem-focused: Directed behavior to reduce or eliminate a stressor, adaptive behavior
3. Emotion-focused: Changing emotional reaction to a stressor

In the case of coping with a diagnosis of high-risk of breast cancer, appraisal-focused coping strategy may be useful for those able to live with the uncertainty of being at high-risk. Those who use problem-focused strategies attempt to address the cause of their problem. They often do so by researching information on the problem. Problem-focused coping is aimed at changing or eliminating the source of stress. Those who use emotion-focused strategies, focus on releasing emotions, distracting themselves, meditating, or using systematic relaxation procedures. Emotion-focused coping is oriented toward managing the emotions that accompany stress (Brannon & Feist, 2009). Most people use a mixture of these three strategies to cope.

Participants reported using all three strategies. They ranged from "curling up in a ball and crying" to envisioning positive outcomes and repeating healthy affirmations, to training for a marathon. Participants utilized a broad range of coping methods. Each participant used numerous coping methods.

Self-efficacy

Self-efficacy is defined as the degree to which an individual believes that he or she will be able to achieve their objectives (Bandura, 1977). Analysis reveals that self-efficacy does play a role in the process of undertaking prophylactic mastectomy. Self-efficacy generally increased as revealed by the self-reported, remembered, self-efficacy percentages. However in all cases, the accompanying narrative tells a story with much wavering, of much lower self-efficacy, particularly the week prior to surgery and five to 20 days after surgery. This information can guide women, health care providers, and educational leaders regarding the need for support at these identified vulnerable times. The trend was revealed in Table 5.

Grounded theory

Grounded Theory is a systematic methodology in the social sciences involving the construction of theory through the analysis of data. According to data results from this study, self-efficacy increased as participants went through the stages of prophylactic mastectomy. This builds the theory that as an individual faces and over-comes a disorienting event successfully that their self-efficacy grows. This supports the adage that "if you think you can, or you think you can't, you are probably right."

Coping Strategies

Coping is defined as expending conscious effort to solve personal and interpersonal problems, and seeking to master, minimize or tolerate stress or conflict (Lazarus & Folkman, 1984; Weiten & Lloyd, 2008). Data analysis suggests that coping skills are important for women undertaking this process. Most women used coping skills already in place, such as exercising at the gym, running, creative writing. These skills were learned and used by most participants at the rate that their physical challenges allowed. No participant mentioned being taught, deep breathing, affirmations or yoga as having been introduced by any health care provider. This may be a cue to introduce those women who may not have regular healthy coping strategies established and incorporate new ones (see Table 6).

Lessons Learned

Participants were enthusiastic and passionate about sharing their experience with other women with the intention of benefit them, their health care providers and those who develop programs for patients at high risk. All participants shared this exact sentiment but in these, their own, words:

> When I saw my sister groaning in pain on the ground…no one should have to witness this. Then when I watched my friend go through it and lose her life, I realized that those two paths could not by my path. It was then that I knew I would have to give back to educate others regarding their risk of breast disease.

Participant 2 wants others to know that:

> They need to get informed about everything that is going to happen in that process. Then get ready for it. Because you have to plan on it. Just make sure that the hospital that you choose that they have a very good support staff because you need them. I had a nurse and she taught me how to recover from this. I speak with other ladies and they never even had any help in regaining strength.

Participant 2 believes that, "the whole experience has changed her and made her a better person. It is amazing when you lose something and then you regain it. I appreciate everyday what I regained." Participant 3 shared:

> When I first found out it seemed like a curse. But it is also an incredible gift because you have the power to change your future and so many women don't get that chance and they are just blindsided by cancer and how lucky are we that we can act before it's too late.

Participant 4 shared:

> That you can do this. It is doable you can do this and get through it. It seems really overwhelming at first but it is absolutely doable. Yeah. I'm not superwoman. I didn't have armies of help, I didn't have people waiting on me hand and foot, I didn't have any sort of cleaning crews. I'm just a regular, ordinary woman with a job and I did it. You can do it. You can live through the

pain and everything. You can do it. I'm just a regular person, I'm not anything superwoman and I did it, you can do it.

Participant 5 shared:

That it has to be your decision within you. And when you make that decision support is vital and I think more than anything the learning experience was…it ok to accept help, its ok to not be strong 24/7, and that no matter what it will get better, it has to, it may get worse before it gets better but it will get better and you can do it and for the most part you don't have any choice but to do it so you might as well just get out there and do it.

Suggested Best Practices for Health Care Providers and Educational Leaders

1. Early genetic testing, (a genetic risk chart), for everyone, can be effective in increasing early high-risk detection.
2. The week prior to and five through 20 days post-surgery seem to be times when women could most use support.
3. Attention should be paid to place and time of sharing initial diagnosis. An office visit with a family member loved may be good protocol.
4. Using patient focused care provided by first person accounts such as those provided by this research should form a basis for compassionate care by all health care providers from those who answer the phone to those inform patients of their results, those who change their sheets, and their nurses physicians assistants, physicians and specialists.
5. Professionals at every level should be trained with a view toward compassionate patient focused care including experiential learning and Continuing education units or continuing medical education units to insure that they patient needs are addressed focusing on the patient need not hospital or professional protocol.
6. Those who develop health care curriculum should be made aware of patient perspective in the case of breast cancer patients and all others and should implement into every component of teaching the perspective of the patient as gained from research directly from the first-person experiences of the patient as garnered from research such as this.

Recommendations for Future Research

This valuable research should be duplicated with a larger sample size. Including input from spouses, mates, or family members also would add insight. Families need to be informed, but also given the opportunity to be involved in the treatment process. Transformational learning as it applies to health changes could be studied in depth in areas beyond breast health and beyond proactive health care.

This research can be expanded to included health care workers, recognizing their contribution to the healing process from answering the phone to office environment, to room décor. Further training and curriculum development for all health care givers from certified nursing assistants to physicians in specialties would benefit from the perspective of the patient. Hands on experiential curriculum should be developed to enable caregivers to "walk in the shoes" of those they are caring for. Results would improve patient outcome and minimize in some cases patient recidivism. This study has also confirmed the value of the Internet as a learning tool for patients, and that transformational learning can be taught and modeled at every level of patient care.

Summary

Universally overwhelmed at diagnosis, these participants, after going through a processing period, dove deeply into research using Internet informational sites and social media. They also collected brochures, books, and consulted with physicians, genetic counselors, family, and friends. As they became better informed, their confidence regarding their decision-making increased. By the date of initial surgery, most were very confident that they would achieve their goals. Post-surgery was a vulnerable time for these participants. From four days post-surgery through three weeks post-surgery most

reported feelings of grief, loss, sadness, foolishness, and sorrow. Surprisingly self-reported efficacy percentages were consistently high. During recovery and healing percentages remained high and self-described narratives of their experiences coincided with these percentage representations.

It has been the experience of this researcher that discovering being at high-risk of breast cancer is a very disorienting event. Watching those around you succumb to this painstaking death, either with or without therapy, is a strong motivating factor in undertaking prophylactic mastectomy. This researcher strongly recommends that all women diagnosed with a high-risk of breast cancer research thoroughly the options available to them, select the one that is most suitable, and then close the book on this concern and move forward with their lives, sharing any garnered knowledge with others at risk.

APPENDICES

Appendix A. IRB Approved Recruitment Flyer

Faith Gordon

Recruitment Flyer

Department of Educational Leadership

Florida Atlantic University

PARTICIPANTS NEEDED FOR
RESEARCH ON PROPHYLACTIC MASTECTOMY

We are looking for volunteers to take part in a study of
Prophylactic Mastectomy.

As a participant in this study, your participation will involve one face to face meeting of about 60 minutes of your time and a follow up e-mail.

In appreciation for your time, you will receive:

The sincere appreciation of the researchers and beneficiaries of your experience.
For more information about this study, or to volunteer for this study.

Please contact: Faith Gordon
Department of Educational Leadership
Florida Atlantic University
561-310-0634
Email: fgordon6@fau.edu

Appendix B. IRB Approved Consent Form

ADULT CONSENT FORM

1**) Title of Research:** Transformational Learning and Self Efficacy: An Investigation into their Role in Prophylactic Mastectomy

2) Investigator (s): PI: Dr. Valerie Bryan/Co-PI: Faith E. Gordon

3) Purpose: For all women it is important to be informed regarding all current treatment options that are available to prevent breast cancer. For women in high-risk categories of breast cancer it is even more important that they are informed. The purpose of this study is to examine the experiences of six women who have undergone prophylactic mastectomy to gather firsthand experiences to assist newly diagnosed women with information upon to guide their decisions. Information gathered from this study will add to the body of knowledge to assist newly diagnosed women to make informed decisions regarding their health care. Further, this information will inform health care providers of the patient's perspective, enabling them to provide improved patient centered health care, and finally this information will assist educators and curriculum developers to create and improve programs and protocols to assist women through this process.

The research will include investigation through the stages of (a) diagnosis, (b) information gathering and option discovery, (c) decision-making (d) surgeries, (e) healing and recovery. The focus of this study will be on transformational learning and self-efficacy.

4) Procedures: This study has six participants. All are adult women between the ages of 18 and 90. All have been diagnosed at high-risk of breast cancer and have undergone prophylactic mastectomy. This research has three data collection methods. The first is a guided open-ended interview. The second is a brief survey on self-efficacy, and the third is your autobiography. You are asked to participate in a guided 60 minute interview and complete a brief survey. This interview will be audio recorded. When the interview is complete it will be e-mailed to the transcriber. Any and all identifiers will be removed. The transcript will be e-mailed back to me and I will e-mail a copy to you. If you wish to make any additions or changes, please do so and return it to me at: faithgordon121@hotmail.com within five days. By participating in this research you grant permission for the researcher to use direct quotations from your interview, anonymously without identifying information in the final research product. The information is for dissertation use.

Your participation is voluntary; refusal to participate will involve no penalty or loss of benefits to which you might otherwise be entitle, and you may discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

5) Risks: You will be asked to recall and talk about feelings and memories that may be associated with powerful emotions. This may be uncomfortable or disorienting. If, as a part of this study you experience psychological discomfort or stress there will be psychological counseling available at (866) 288-7475. In addition, you have a right to discontinue participation at any time of unanticipated stress occurs.

Initials_____

Approved on:	10/14/2014
Expires on:	10/13/2015

Institutional Review Board

6) Benefits: We do not know if you will receive any direct benefits by taking part in this study. However, this research will contribute to a greater understanding of the role of adult and transformational learning and self-efficacy play in the proactive health care choice of undertaking prophylactic mastectomy. Knowledge gained will provide newly diagnosed women with information to help them make informed decisions. It may also assist health care providers and educators to improve protocols, training, and curriculum development.

7) Data Storage:

Any information collected about you will be kept confidential and secure and only the people working with the study will see your data, unless required by law. You and any individuals named will be given pseudonyms. Locations will be general and organizations will be given generic names. Data will be kept for 2 years in a locked file drawer and on a password-protected computer in the researcher's home office. After 2 years paper copies will be destroyed by shredding and electronic data will be deleted. We may publish what we learn from this study. If we do, we will not let anyone know your name/identify unless you give us permission.

8) Contact Information:

- If you have questions about the study, you should call the principal investigator(s) Dr. Valerie Bryan at (561) 799-8639.
- In you have questions about your rights as a research participant, or experience problems, contact the Florida Atlantic University Division of Research at (561) 297-0777 or send an e-mail to fau.research@fau.edu

9) Consent Statement:

*I have read or had read to me the preceding information describing this study. All my questions have been answered to my satisfaction. I am 18 years or older and freely consent to participate. I understand that I am free to withdraw from the study at any time without penalty. I have received a copy of this consent form.

I agree _____ I do not agree _____ to be audiotaped/videotaped.

I agree _____ I do not agree _____ to use my direct quotes for this research.

Signature of Participant: _____ Date_____

Printed Name of Participant: First Name _____ Last Name _____

Signature of Co-Investigator: _____ Date _____

Appendix C. Interview Protocol and Adapted Survey

Interview #_____

Date_____

Research Participant Interview Questions

(Guided Interview-Open Ended Format)

Definition of Terms:

Prophylactic Mastectomy is defined as the surgical removal of one or both breasts to reduce the risk of breast cancer in those at high risk of developing the disease.

Transformational Learning: "Learning is understood as the process of using a prior interpretation to construe a new or a revised interpretation of the meaning of one's experience in order to guide future action" (Mezirow, 1996, p. 162). Adults are life-long learners, learning by experience, observation or study.

Self-efficacy is defined for this study as the degree to which an individual believes that he or she will be able to achieve their objectives (Bandura, 1977).

Coping: Coping is defined as expending conscious effort to solve personal and interpersonal problems, and seeking to master, minimize or tolerate stress or conflict (Lazarus & Folkman, 1984; Weiten & Lloyd, 2008).

Before we begin, I'd like you to take a moment to silently reflect on your experiences as you went through the process of being diagnosed at high-risk of breast cancer, and then moving through the process of Diagnosis, Gathering Information and Option Discovery, Decision Making, Surgeries, Healing and Recovery? Please consider your emotional, social, physical and intellectual states.

1. What were you doing before being diagnosed? (e.g., working, traveling, attending school, raising a family, training for a marathon) (Break the ice question.)
2. First let's talk about the role of transformational learning. What was the role of transformational learning as you progressed through the stages: diagnosis, gathering information and option discovery, decision making, surgeries, healing, and recovery?
3. What sources of information were available to you (e.g. medical professionals, internet research, word of mouth, etc.)? What did you learn and from which sources? What role, if any, did any organizations, your mate, family, friends, medical professionals, your employer, or others play?
4. Coping strategies may be a part of adult learning. Did you use any coping strategies during these process? If so how and from where did you learn them? Why do you believe you could cope? (For example: fear, commitment, control, spirituality, family, resiliency etc.)?
5. Now I'd like you to think about self-efficacy. What was the role of self-efficacy, as you progressed through the stages of diagnosis, gathering information and option discovery, decision making, surgeries, healing, recovery?
6. In what way, if any do you think that this experience has changed or transformed you? If so, how so?
7. Following the stages of transformational learning now:

(a) Was this a disorienting dilemma (a frightening life experience) for you? How so?

(b) Did you experience self-examination? Were there feelings of guilt or shame?

(c) Did you question sociocultural assumptions regarding this?

(d) Did you realize that this discontent has been shared with others who have overcome or coped, and if so when?

(e) Did you explore options for new roles, relationships or actions? If so please explain.

(f) Did you plan a course of action?

(g) Did you have the needed knowledge and skills for implementing these plans, have you acquired them?

(h) Did you try on new roles?

(i) Did you build confidence and self-confidence in the new roles and relationships?

(j) How did you reintegrate your transformed perspective in your life?

8. What is the most valuable thing that you have learned from this experience?

Appraisal Inventory of Self-Efficacy in Proactive Health Care (SEPHC)

(Adapted from Bandura 1977)

This scale is a measure of your own perceived self-efficacy over time as you progressed through the process of Diagnosis, Gathering Information and Option Discovery, Decision Making, Surgeries, Healing and finally, Recovery. Self-efficacy is the belief that you can achieve your goal.

The Scale below lists these milestones. In the column, rate how confident you were that you could achieve your goals at that time. Rate your degree of confidence by recording a number from 0-100 using the scale given below:

0 10 20 30 40 50 60 70 80 90 100

Can't Achieve Moderately Certain Highly Certain

My Goal I Can Achieve My Goal I Can Achieve My Goal

Stage in Process Confidence Level

1. At Diagnosis
2. While Gathering Information and Option Discovery
3. During Surgery/Surgeries
4. While Healing
5. At Recovery

Demographic Information	
Age	Children
Educational Level/Work Outside Home	Date of Diagnosis/Age at Diagnosis
Marital Status	Date of Surgery(ies)

THANK YOU for your participation in this study. Your unique insights and contributions will add invaluable insight into the experience of undertaking prophylactic mastectomy to minimize the lifetime risk of breast cancer. Keep in mind that I will be forwarding a copy of your transcribed responses. Please review it and return it with any additions or changes within five days.

Appendix D. Letter of Cooperation

FORCE
Facing Our Risk of Cancer
EMPOWERED

April 25, 2013

To: Faith Gordon
180 Satinwood Lane
Palm Beach Gardens, Florida
33410

From: Sue Friedman
FORCE

To Whom It May Concern:

I am pleased to write this letter of support and cooperation for your research project Prophylactic Mastectomy, The Role of Adult Learning, Self Efficacy. I believe that findings from this research may well add to our growing wealth of knowledge, enabling us to even better serve our members.

To assist in this research, FORCE will help in the recruitment of ten (10) individuals, from the local area, who meet the research criteria and who are willing to participate in this research.

I believe that this research project is important, feasible and consistent with the goals of FORCE.

Sincerely yours,

Sue Friedman, DVM
Executive Director

www.facingourrisk.org

Appendix E. Permission of Albert Bandura to Adapt his Self-efficacy Scale

Albert Bandura

08/02/2013

To: 'faith gordon'
Yes, you have permission. Please see attached! Albert Bandura

Albert Bandura

bandura@stanford.edu

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