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## Improving Self-Efficacy and Knowledge While Reducing Anxiety in High-Risk Breast Cancer Patients through Standardized Education

Shelley Miles

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IMPROVING SELF-EFFICACY AND KNOWLEDGE WHILE REDUCING  
ANXIETY IN HIGH-RISK BREAST CANCER PATIENTS  
THROUGH STANDARDIZED EDUCATION

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A doctoral project submitted in partial fulfillment  
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Doctor of Nursing Practice

School of Nursing  
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## **Doctoral Project Approval**

The Graduate College  
The University of Nevada, Las Vegas

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This doctoral project prepared by

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Improving Self-Efficacy and Knowledge While Reducing Anxiety in High-Risk Breast Cancer Patients through Standardized Education

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## Abstract

Breast cancer is the leading cause of death of women in the United States. Patients at high risk for developing cancer are more easily identified in today's world. Early identification might be due to strong family history or genetic mutations, such as *BRCA1* or *BRCA2*. Screening and risk reduction guidelines have been developed over recent years for these patients. Adherence to these guidelines continues to be a problem. The factors stemming from this problem include lack of knowledge about being high-risk, understanding the guidelines, and anxiety and depression about the perceived risk of developing breast cancer. These factors can cause a barrier and prevent patients from following through with their recommended screening or risk reduction strategy. The purpose of this Doctor of Nursing Practice (DNP) project was to determine if cancer risk education increases knowledge and self-efficacy and decreases anxiety and depression. Based on a literature review, the project was developed to evaluate the outcome variables of self-efficacy, knowledge, anxiety, and depression before and after a standardized educational intervention for high-risk cancer patients. Data collected were analyzed with a paired *t*-test and an increase in knowledge scores from the and post-survey answers were identified as being statistically significant ( $p = 0.04$ ). Although anxiety shows a clinical significance, there were no statistically significant changes in anxiety and depression.

*Keywords:* high-risk breast cancer, *BRCA1* and or *BRCA2*, risk reduction strategies, breast cancer screening, screening and risk reduction strategies adherence, anxiety, depression, education, knowledge, self-efficacy

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## Chapter I

### Introduction and Background

Breast cancer is one of the leading causes of death in women in the United States. Approximately one in eight (13%) will be diagnosed with invasive breast cancer in their lifetime, and one in 39 women (35%) will die from breast cancer (American Cancer Society, 2019). There are many factors in oncology that can determine if a patient is considered high-risk. The two most common areas considered are 1) does the patient have a family history of breast cancer and 2) what is the patient's genetic testing regarding breast cancer.

Knowing a patient's family history can play an essential role in helping a provider determine if the patient has an additional risk that might increase their chances of developing breast cancer. Studies have shown that women with a family history of breast cancer in a first-degree relative (parent, child, or sibling) are 1.5 times more likely to be diagnosed at a young age. This group is also more likely to be diagnosed with a more advanced stage of cancer (American Cancer Society, 2019). Being familiar with a patient's family history can assist providers on who needs to undergo further genetic testing.

Genetic testing has become a mainstay when looking at high-risk patients and their family history. Patients tested and found to be *BRCA1* and *BRCA2* mutation positive have a greater than 20% lifetime risk for developing breast cancer (Rosenthal et al., 2017). Expanded genetic panels have become more readily available to evaluate women who may not have a strong family history of breast cancer. Expanding beyond the *BRCA1/2* mutation significantly increases the number of women identified as having an increased risk. These women are also candidates for increased risk reduction measures such as screening by not just mammograms and breast MRIs (Rosenthal et al., 2017). These patients may also benefit from starting annual

screening earlier than the United States Preventative Services Task Force recommends. Other risk reduction recommendations may include prophylactic mastectomies and hysterectomies if they are also considered high risk for ovarian cancer.

The cost of treating breast cancer also plays a critical role in encouraging adherence to screening. Blumen et al. (2010) performed a retrospective claims analysis on newly diagnosed breast cancer patients. They found that the cost of treatment for one year for a Stage 1 cancer averages about \$60,637, whereas the yearly cost for a Stage IV cancer averages about \$134,682.00 (Blumen et al., 2016). This cost included all methods of treatment such as IV and oral therapy.

### **Problem and Significance**

Adherence to recommended screenings is crucial when patients have a known high risk or a genetic predisposition. A study performed by the National Cancer Institute suggested that most women at high risk for breast cancer do not adhere to the recommended mammography screening guidelines. Only 63% of women aged 50 and older receive their annual screening mammograms, and 13% of those have never been screened despite their high-risk status (Watson-Johnson et al., 2011). Patients with genetic mutations are also provided options termed risk reduction strategies. Recommendations usually include prophylactic mastectomies and increased surveillance.

Many factors influence adherence to getting a mammogram done on a routine basis. These factors can range from the mammogram experience itself (Tang et al., 2008) to its cost. Factors also include lack of knowledge about the need for screening and anxiety about having the recommended screening performed. The anxiety can be further defined based on the patient's perception of the risk of developing breast cancer. According to Katapodi et al. (2004), "studies



exploring perceived breast cancer risk suggest that lay women hold a different set of beliefs about breast cancer's causes, curability, and risk factors than health care experts."

Furthermore, since screening is an integral part of managing high-risk patients, the practitioner needs to know the exact barriers or barriers. Within the practice, advanced practice registered nurses have many roles. Two of the most critical roles are educator and facilitator (Vogel, 2003). By educating and facilitating, the advanced practice registered nurse can provide patients an increased awareness of their risk for developing breast cancer, provide education on reducing that risk, and facilitate compliance to the recommended screenings.

In addition, this author believes that patients would be more adherent to screening recommendations by patients knowing and understanding what it means to be at high risk for breast cancer either due to family history or a genetic mutation. Furthermore, if patients receive education about their risks and the rationale behind the screening recommendations, it may improve their adherence to recommendations. Also, patients' education about their risk could reduce their anxiety about the screening and results. Based on the National Comprehensive Cancer Network's guidelines, these screening recommendations include mammograms, self-breast exams, clinical breast exams, and surgical risk reduction strategies.

Primary care providers are usually the ones tasked with ordering mammograms, and they may not be up to date on the additional screenings required for high-risk patients. Advanced practice registered nurses can connect with patients making it easier to discuss concerns and fears about all health issues. Connecting more with the patients may help the patient understand the importance of screening and risk reduction strategies. The time spent talking with the patients could reduce breast cancer development by educating patients thoroughly about their risk.

## **Purpose Statement**

The purpose of this Doctor of Nursing Practice (DNP) project is to determine if cancer risk education increases knowledge and self-efficacy and decreases anxiety and depression.

## Chapter II

### Literature Review

For this chapter, an extensive literature review was performed by this author in the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Cochrane, PUBMED, and Scopus databases. Each database search used the same keywords either by themselves or in combination. The keywords used were “high-risk breast cancer,” “anxiety,” “education,” “*BRCA1*,” “*BRCA2*,” “risk reduction strategies,” “breast cancer screening,” “screening adherence,” and “risk reduction strategies adherence.” The following synonyms were also used to enhance the search: neoplasm, carcinoma, anxiety disorders, generalized anxiety, depression, knowledge, understanding, awareness, prevention strategies, clinical breast exam, self-breast exam, mastectomy, and mammogram. The keywords and synonyms were combined to narrow the search, and the results are available in appendix A.

Furthermore, while conducting this review, this author performed three separate searches. The first was aimed at looking at both adherence behaviors and barriers. The second search combined the keywords to look at patient anxiety, depression, knowledge level, and perceived risk for high-risk breast cancer (see Appendix A). Furthermore, although the search parameters were set to exclude grey papers they did include quality improvement plans. The third search used the keyword self-efficacy and the ones utilized for the first two searches. After the searches, it has become clear that the literature is abundant regarding screening adherence based on the knowledge level and risk perception for patients predisposed to developing breast cancer.

### Similarities and Dissimilarities

The literature was reviewed more closely for similarities and dissimilarities across multiple articles focusing on the first two searches. These articles focused on finding reasons for

determining why women did or did not adhere to screening recommendations and if knowledge about risk and anxiety related to risk perception played a part. Based on these articles, data was collected in three different ways. The studies by Antill et al. (2006), Bredart et al. (2011), Buchanan et al. (2017), Cabrera et al. (2010), Grimm et al. (2019), Lobb et al. (2006), Phillips et al. (2006), Price et al. (2010), Roussi et al. (2010), and Tinley et al. (2004) sent their participants self-reporting questionnaires or handed them out in the clinical setting. Telephone interviews were used to collect data by Hass et al. (2005), Issacs et al. (2002), Peshkin et al. (2002), Roussi et al. (2010), and Tang et al. (2009). Katapodi et al. (2003) conducted a meta-analytic review and evaluated data from 42 articles. Genetic testing results from 9641 participants were also studied. Furthermore, Drukteinis et al. (2013) looked at options beyond mammography for patients with dense breast tissue, which can cause abnormalities to be missed by the radiologist. In addition, two articles were expert opinion papers. The first focused on the oncology nurse's role in educating patients about their risk and need for recommended screening. In contrast, the second article by Sciaraffa et al. (2020) focused on the components needed to develop a successful risk assessment management program. These articles focused on determining why women did or did not adhere to screening recommendations.

### ***Similarities***

Some similarities across all articles included the questions asked of the participants. In thirteen articles, participants were asked to provide demographic statistics such as age, employment status, family income, education level, marital status, ethnicity, number of offspring, insurance status, mutation status, and family history. Perception of risk for developing breast cancer was also a data point collected in eighteen of the articles. Psychological factors and a recollection of what screening measures were recommended to the participants were also data

points reviewed in the literature. Knowledge, both general and specific to a mutation, was evaluated in fifteen articles.

### *Dissimilarities*

Dissimilarities between the articles were primarily seen with the type of participant being evaluated. The articles by Antill et al. (2006), Bredart et al. (2011), Cabrera et al. (2010), Haas et al. (2005), Lobb et al. (2006), Roussi et al. (2010), and Price et al., (2010) looked only at women with no personal history of cancer. Still, they had a moderate to high risk based on their genetic pedigree. Buchanan et al. (2017), Isaacs et al. (2002), Peshkin et al. (2002), Philips et al. (2006), and Tinley et al. (2004) all looked at participants that were unaffected carriers of the *BRCA1* or *BRCA2* gene. Green et al. (2004) included participants with a personal or family history of breast cancer. Grimm et al. (2019) looked specifically at a women's subjective estimate of breast cancer risk and frequency of breast cancer thoughts. The participants for Katapodi et al. (2003) and Rosenthal et al. (2016) were obtained either from previous research done in a literature review or a review of genetic testing by a specific laboratory.

There were also some dissimilarities in the screening practices that were evaluated. Seven out of the ten articles did include mammograms as the primary data point to determine adherence. Antill et al. (2006), Phillips et al. (2006), Price et al. (2010), and Tinley et al. (2004) also included breast self-exam (BSE) as a screening measure. Antill et al. (2006), Isaacs et al. (2002), Peshkin et al. (2002), Phillips et al. (2006), Price et al. (2010), and Tinley et al. (2004) all included the clinical breast exam (CBE) as a screening measure. Antill et al. (2006), Buchanan et al. (2017), and Price et al. (2010) looked at patterns of over-screening vs. under-screening in this high-risk population.

Phillips et al. (2006) mentioned the risk reduction measure of chemoprevention with Nolvadex (tamoxifen). This article is the only sample that included genetic counseling as a factor in evaluating screening adherence. Tinley et al. (2004) was the only article that looked at compliance based on a specific provider's intervention and recommendation, precisely the primary care provider.

The mammogram experience itself as a factor in adherence to screening for all populations was also considered by Tang et al. (2009). This article was included as it helps this author look at factors outside of the high risk for breast cancer as a reason for not getting screenings done. Rosenthal et al. (2016) was chosen to help define the most common genetic mutations for developing breast cancer beyond *BRCA1* and *BRCA2* now that expanded genetic panels are available to almost everyone. The meta-analysis done by Katapodi et al. (2003) was chosen as it looked at multiple sources of data that can help answer the question of screening adherence. The other articles were selected as they studied different sets of high-risk participants and looked at all the current significant screening recommendations individually.

### **Data Concerns**

There were some concerns with some of the data reviewed. It was noted that four of the articles all originated from a single study done in Australia. Participants were pulled from the Kathleen Cunningham Consortium for Research into Familial Cancer (kConFab) data. Even though the articles by Antill et al. (2006), Isaacs et al. (2002), Phillips et al. (2006), and Peshkin et al. (2002) were pulled from the same data pool, their parameters and findings varied across all the studies. This author is unsure of how much overlap there was in the participants across all four articles. The same can be said for the articles by Lobb et al., 2005 and 2006. The same

population pool was used in these articles, as were the same genetic counselors to provide the education.

### **Cancer Risk Education and Knowledge**

Most had similar results in the 15 articles that studied knowledge and cancer risk education. By educating the participants about their high-risk status and the implications, their knowledge level increased, leading to increased adherence to screening recommendations. There were some differences between how the education was provided. Cabrera et al. (2010), Green et al. (2004), Lobb et al. (2006), Price et al. (2007), Roussi et al. (2010), and Stalmeier et al. (2009) used genetic counseling for their educational intervention. In contrast, in 2005 and 2006, Lobb et al. looked at using a standardized communication tool during counseling sessions. Various tools were used across all of the studies to evaluate knowledge. The most utilized tools to assess knowledge were the Cassileth Information Styles Questionnaire and the Breast Cancer Genetics Knowledge questionnaire. Green et al. (2004) was the only study that used a computer-based educational tool and compared it to one-on-one genetic counseling. This study revealed that participants felt their knowledge improved significantly after viewing the tool.

### **Self-Efficacy**

The literature review also revealed that self-efficacy improved as knowledge was gained and anxiety lessened in most participants. Of the 18 studies that included self-efficacy, only the study done by Antill et al. (2006) showed no clinical significance in improving participant self-efficacy when education was provided regarding high-risk status. Cabrera et al. (2010) showed that their intervention with genetic counseling improved self-efficacy to the point that participants felt comfortable enough to pass the knowledge on to other family members to help them make more informed choices about undergoing screening. Green et al. (2004) found that

seeing a genetic counselor was most effective for improving self-efficacy, while Lobb et al. (2005) felt that genetic counseling sessions should be standardized for better self-efficacy. Overall improved self-efficacy was also shown to improve adherence to screening recommendations from the educational tool and genetic counseling session. Patients who were over-or under-screened stated that they would follow the recommended guidelines, and those who were not screened also made the same statements. The tools utilized to evaluate self-efficacy included the Life Event and Difficulty Scale, Cognitive-Social Health Information Processing Model (C-SHIP), Miller Behavioral Style Scale, and the Decision Evaluation Scale.

### **Anxiety**

Anxiety was found to be a significant factor for non-adherence to screening recommendations. In the 18 articles that studied anxiety, the participants' education significantly impacted reducing anxiety about being high-risk. Bredart et al. (2011) revealed that anxiety was higher in the older population, whereas Price et al. (2007) found that anxiety about high-risk was present in all age groups. This study also found that women unaffected by a relative having breast cancer had low anxiety levels (Price et al., 2007). Anxiety for women with a genetic mutation was higher in all the reviewed articles. The more frequently utilized tools for assessing anxiety were the Spielberg State Anxiety Index (STAI), Impact of Events Scale (IES), and Hospital Anxiety and Depression Scale (HADS).

### **Depression**

Depression should also be considered as another significant factor for non-adherence. Most articles focused on depression following a cancer diagnosis in the literature review, not just being at high risk. Listol et al. (2017) did focus on anxiety and depression symptoms in hereditary breast and ovarian cancer patients. This study evaluated using group-based patient



education courses to see if anxiety or depression symptoms changed from before the course to after (Listol, 2017). This study showed that women with a *BRCA* mutation felt alone with their concerns about being a mutation carrier. They wanted to discuss their challenges with peers and health professionals (Listol, 2017). In the four articles that studied depression in patients diagnosed with cancer, three were completed while patients actively underwent treatment. One evaluated depression symptoms following treatment up to five years. Nakamura et al. (2020) performed serial assessments of depression on both patients and providers for early-stage breast cancer.

In contrast, Weihs et al. (2018) used the National Institutes of Health (NIH) Stage model to design and test a single intervention to prevent depression in breast cancer patients at any stage in their diagnosis. Two international studies were also reviewed. The study by Kim et al. (2017) evaluated a nurse-led psychological program. It evaluated its effects on psychological distress and quality of life in patients with breast cancer undergoing chemotherapy and at high risk for depression in South Korea. In contrast, the study was done on the same group in Mexico by Doubova et al. (2020). It focused on the association of supportive care needs and quality patient-centered care for women with depression.

Furthermore, this study's findings revealed that up to 43.6% of women with breast cancer in Mexico reported substantial unmet supportive care needs and depression symptoms (Doubova et al., 2020). The studies revealed that depression is common at any stage in breast cancer, whether it is someone with a high-risk or undergoing treatment. Each of the studies showed improvement in depression following the study interventions.

### **Social Learning Theory**

An additional search was conducted to look for evidence to support the project's focus that increasing knowledge will decrease anxiety and improve self-efficacy. After the initial search revealed many theories based on the keywords, the search was narrowed to Bandura's Social Learning Theory. This theory looks at improving self-efficacy with improving knowledge. An article by Bandura, 1983, described how giving someone money can help overcome a fear of snakes. The learning theory was further broken down in articles by Cherry (2019), Elder et al. (1999), Horsburgh et al. (2018), Loveless (2021), and Rosenstock et al. (1988). These articles all discussed how increasing knowledge would decrease anxiety about perceived risk and improve self-efficacy, leading to better adherence to recommendations. Schwarzer et al. (1995) even developed a validated General Self-Efficacy Scale to evaluate someone's ability to respond to and control environmental demands and challenges.

### **Summary**

After reviewing all the evidence found in the referenced articles for the first two searches, there does seem to be a direct correlation between knowledge about a patient's high-risk status and their anxiety about their perception of their risk. These feelings can also lead to either poor adherence to screening as recommended or not screening due to anxiety and depression. By developing a program for these patients that focuses on their anxiety, depression, and knowledge deficits, we may achieve better screening adherence, potentially leading to earlier detection of breast cancer in this population.

## Chapter III

### Conceptual Framework

Albert Bandura's Social Learning Theory will guide this DNP project (Bandura, 1977). According to Elder et al. (1999), this theory emphasizes the interactions between a person's cognition and behavior. Bandura accomplishes this through self-efficacy and outcome expectancies (or response efficacy). Bandura states that "if people believe they can exercise control over the occurrence of events that can be injurious, they do not fear them" (Bandura, 1983). Bandura's theory moves beyond traditional behavioral theories, suggesting that all behaviors are learned through conditioning and cognitive theories and considers psychological influences such as attention and memory (Cherry, 2019).

Within the theory, there are five major guiding principles for learning. The first principle states that learning is not just a behavioral process responding to stimuli. Instead, the behavior is a cognitive process within the larger social environment (Loveless, 2021). The second principle of this theory is that learning behaviors need to be reinforced either by direct or vicarious reinforcement. Direct reinforcement uses punishments and rewards to increase or decrease the likeliness that a behavior will be repeated (Loveless, 2021). Vicarious reinforcement posits that instead of directly experiencing the consequence, the learner will learn by observing the outcome of others' actions (Loveless, 2021). The third principle is the importance of observation. While watching, learners observe an action's outcomes, including whether it is rewarded or punished (Loveless, 2021). Reinforcement does support learning with the fourth principle in this theory. The fourth principle indicates that learning results from multiple influences instead of any specific ones (Loveless, 2021). The final principle is that learners are active in their learning

process. They think about their behaviors, engage in their environment, and reciprocate with the influences that impact them (Loveless, 2021).

Because learning is a very complex process, Bandura's theory was utilized to support this project. Much of this project focused on reducing the anxiety about being a high-risk breast cancer patient. By providing education to improve knowledge and self-efficacy, the hope was that the patients whose perceived effects of changing lifestyles (incentives) will attempt to change if they believe that (a) their current lifestyles pose threats to any personally valued outcomes, such as health or appearance (environmental cues); (b) that certain behavioral changes will reduce the threats (outcome expectations); and (c) that they are personally capable of adopting the new behaviors (efficacy expectations) (Rosenstock et al., 1988).

Bandura's framework was applied to this project by evaluating a patient's knowledge and anxiety about being at increased for breast cancer before they undergo standardized education to improve their self-efficacy. The following steps were used in the educational tool using Bandura's theory. The first was to make sure the tool was attractive to the learner to hold their attention. To learn, one must pay attention, as any distraction will have a negative effect on observational learning (Cherry, 2019). Retention was the next step in learning. If patients cannot store the information provided, they may not be able to act on the recommendations made in an educational tool for their specific needs. The third step was reproduction. Once the patient has given their full attention to the educational tool and has retained the information, it is time for them to perform the behavior observed (Cherry, 2019). The participants would complete a post-survey to test how their knowledge and anxiety have changed following the educational intervention. For the last step, participants showed they are motivated to follow through with the

recommended screenings to help reduce their risk of developing high-risk breast cancer. This motivation will be evaluated on the post-survey questionnaire.

## Chapter IV

### **DNP Final Project**

This chapter describes the DNP final project. The project aimed to determine if cancer risk education increased knowledge and self-efficacy and decreased anxiety and depression. The chapter addresses the project's setting, the sample, project tasks, team members, outcomes and instrumentation, and the project timeline. The discussion includes the project sponsor, key stakeholders, the organizational assessment, resources and supports, risks and threats, and the project's financial plan.

### ***Design and Setting***

A pre-post evaluative design was utilized for this project. An educational intervention was provided between the assessments of the project's variables, including knowledge, self-efficacy, anxiety, and depression. The setting for this project was at a large cancer center in Southern Nevada. This DNP student is a provider for the general oncology division and works closely with the genetic counselor onsite.

### ***Population and Sample***

The population of interest were females at risk for breast cancer related to genetic factors. The sample included women referred to the genetic counselor for consultation due to potentially being at high risk for breast cancer, either due to a strong family history of breast cancer or a genetic mutation for breast cancer. A power analysis estimated that there should be at least 103 participants for this project, so the overall goal was to enroll 120 participants.

Inclusion criteria included females over 18 years of age, having either a family history of breast cancer or genetic mutation, having a genetic mutation (such as BRCA1/2), and ability to read and write in English.

### ***Project Tasks***

The project tasks included:

- Proposal Defense
- UNLV and project sites IRB approvals
- Development of educational intervention and assessments
- Pre-assessment of knowledge, self-efficacy, anxiety, and depression
- Implementation of an educational session with participants
- Post-assessment of knowledge, self-efficacy, anxiety, and depression
- Data analysis and program evaluation
- Prepare final documents detailing results, conclusions, and discussion

### ***Team***

The team for this project comprised the DNP student, the University's graduate advisory committee chair and members, the genetic counselor, and the Practice Manager at the cancer center.

### ***Procedures***

The schedule for the genetic counselor was reviewed weekly for the upcoming week. Once a patient was identified as meeting the inclusion criteria, they were contacted by the DNP student, where project information and consent were discussed. If the patient consented to participate in the project, the DNP student met them at their first visit to sign the consent and complete a demographics questionnaire (see Appendix G) and the three project assessments. Demographic data, including age, educational level, marital status, and ethnicity, were collected. Consenting participants completed the knowledge, self-efficacy, anxiety, and depression assessments before viewing an educational PowerPoint presentation (the project's intervention). The participants were given a printed copy of the educational slides and instructions on accessing

the video on the internet if they or any other family member wished to view it. The same pre-assessments and a brief program evaluation (post-survey) (see Appendix H) were completed at their follow-up visit with the genetic counselor, approximately three to four weeks after the initial appointment. This completed the patients' participation in this project. Participants also had the option to complete all the surveys and assessments with pen and paper if they were uncomfortable using the hand-held device. The instruments used to collect the above data included (a) Breast Cancer Knowledge Questionnaire 27, (b) DASS-21, and (c) Generalized Self-Efficacy Scale; these instruments are discussed below.

### ***Project Intervention, Instruments, and Outcome Variables***

At the initial visit, the participant viewed a short PowerPoint presentation (the intervention) discussing different aspects of breast cancer and breast cancer risk. The presentation included information on genes, genetic testing, and the genetic counselor's role. Also discussed in the presentation were the myths around developing breast cancer, criteria for establishing a high-risk patient, and lifestyle changes and screenings for risk reduction. At the follow-up visit with the genetic counselor, which was approximately three to four weeks after the initial appointment, the project leader met with the patient to complete the post-intervention assessments.

The study variables included breast cancer genetics knowledge, self-efficacy, anxiety, and depression. Three previously validated instruments were used in this project. The Breast Cancer Genetics Knowledge Questionnaire is a 27-item instrument that assesses breast cancer genetics knowledge (see Appendix D). Anxiety and depression were assessed using the 14-item Depression, Anxiety, and Stress Scale (DASS) (see Appendix E). Lastly, the General Self-Efficacy (GSE) scale was utilized (see Appendix F). This project's outcome goals were to



potentially see a change in knowledge, a change in anxiety and depression, and a change in self-efficacy regarding being at high risk for developing breast cancer.

### ***Timeline***

For this project, the proposal defense was completed in April 2021. Once the project proposal was completed and approved, the project was submitted to the University's IRB for approval. After the appropriate IRB approvals were obtained, data collection began. The goals were to start data collection in May 2021 and continue through December 2021. Data analysis began in January 2022. The project was completed and defended in the Spring of 2022.

### ***Resource Utilization***

Resources for this DNP project included a genetic counselor at a large cancer center in Southern Nevada who helped develop the PowerPoint intervention. In addition, the cancer center practice manager assisted with scheduling the high-risk patients and helping the DNP student with identifying potential study participants. The genetic clinic scheduler was also a team member who helped screen potential patients and notified the DNP student. The DNP student then reviewed the chart and contacted the patient to discuss the possibility of inclusion in the study before their arrival for their appointment.

### ***Data Analysis***

Descriptive statistics were used to describe the demographic data of the sample, including frequencies and percentages. The data were analyzed using the Statistical Package for Social Sciences (SPSS) software. A dependent paired *t*-test, with the significance level set to 0.05, determined if there was a statistical significance when comparing the outcome variables pre-and post-the intervention.

### ***Key Stakeholders***

Key stakeholders for this project included this DNP student, the University's graduate advisory committee chair and members, , the cancer center's clinical director, executive director of the cancer centers, and a medical oncologist and practice president for the cancer centers. Further stakeholders included the patients, families, and additional providers at the clinics.

### ***Organizational Assessment***

The cancer center is the most extensive oncology practice in Nevada. They have 25 medical oncologists, nine radiation oncologists, and 11 advanced practice providers across seven offices. Two of the advanced practice providers specialize in genetic counseling. There are very few genetic counselors in Nevada; therefore, the counselors at the cancer center have a robust practice.

### ***Resources and Support***

The educational video was developed in PowerPoint for ease of presentation and uploaded to the internet. All information was created with the genetic counselor to ensure that it was comprehensive. Educational materials and guidelines were generated from the National Comprehensive Cancer Network, Myriad Genetics Laboratories, Invitae Laboratories, and the genetic counselor's education tools currently provided to patients during their initial visit.

### ***Risks and Threats***

For this project, one of the most significant risks was the possibility of not having enough participants. Often, patients were scheduled to see the genetic counselor and not keep the appointment. A potential threat for this project was the patients. Experience has shown that once patients learn of a new medical issue, they immediately search the internet for information. Some of the information available is very good, but some are biased. This unclear information can

cause patients to have preconceived beliefs about their high-risk status and make it difficult if the ideas and education differ significantly from what they believe.

***Financial Plan***

No financial needs were anticipated for this project, and no costs were incurred.

## Chapter V

### Results

This chapter presents the results of this DNP Project, for which the purpose was to determine if cancer risk education changes knowledge, self-efficacy, anxiety, and depression. Results describing the participants' selection and demographics and the outcome variables of knowledge, self-efficacy, anxiety, and depression are included.

Participant selection was initiated on June 11, 2021. The schedules for the genetic counselor were reviewed daily from July 6, 2021, to December 14, 2021. The exclusion/inclusion criteria described in Chapter IV were utilized during the schedules' initial screening. Potential participants who met the inclusion criteria were contacted by phone the day before their genetic counseling appointment. The project process and goals were discussed during the phone call, and participant questions were answered. Potential participants were then given the option to agree to be included in the study or decline. Over the five months, 82 potential participants were identified. Of those 82 contacts, 31 agreed to participate in the project, completed the pre-survey, and viewed the educational intervention. Of those 31, 22 participants fulfilled the task by completing the post-survey questionnaires and composing this project's sample ( $N=22$ ). The other nine participants either did not attend their follow-up appointment or had a telehealth visit and did not complete the post-survey questionnaires.

#### *Participant Demographics*

Participants' age ranged from 21 – 67 years, with a mean of  $45.6 \pm 11.0$  years. All participants were female; most had some college education and were married, White, had no genetic counseling, and had their last mammogram in 2021 (Table 1).

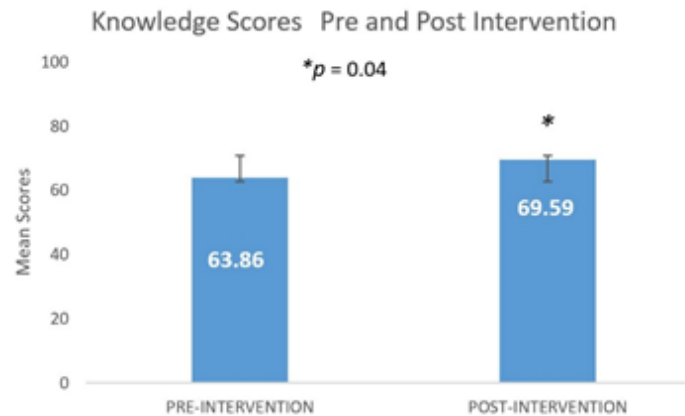
**Table 1: Participants' Demographic Characteristics (N= 22)**

Characteristic	Frequency	Percentage
Education		
High School Diploma	6	27.3
Associate Degree	5	22.7
Bachelor's Degree	3	13.6
Master's Degree or Higher	7	31.8
Prefer Not to Answer	1	4.5
Marital Status		
Single/Never Married	7	31.8
Married/Domestic Partner	14	63.6
Divorced	1	4.5
Ethnicity		
Black/African American	2	9.1
Asian/Pacific Islander	3	13.6
Hispanic/Latino	3	13.6
White/Non-Hispanic	14	63.6
Previous Genetic Counseling		
No	20	90.9
Yes	2	9.1
Last Mammogram		
Never	3	13.6
2020	1	4.5
2021	18	81.8

## Outcome Variables

The outcome variables for this project included knowledge and self-efficacy, anxiety, and depression. The goal of the project was to see changes in knowledge, self-efficacy, anxiety, and depression between the pre-and post-evaluation. Statistical differences pre and post-intervention were noted only in Knowledge ( $p = 0.04$ ) (Figure 1 and Table 2).

**Figure 1 Knowledge Scores ( $n=22$ )**



**Table 2: Paired Sample Statistics from participants in an educational intervention ( $n=22$ )**

Outcome Variable	Mean/SD Pre-Intervention	Mean/SD Post-Intervention	<i>p-value</i>
Knowledge	63.86±11.961	69.59±12.53	0.04
Self-efficacy	32.82±3.67	32.8±2.88	ns
Anxiety	6.45±6.442	5.18±4.30	ns
Depression	5.36±5.287	6.00±5.30	ns

**Table 3: Project Evaluation**

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<i>Evaluation Questions and Possible Responses</i>	Frequency	Percentage
<i>Do you feel that the education you received has helped with your understanding of your high-risk status?</i>		
Yes	21	95.4%
No	1	4.5%
	22	100.0%
<i>Do you feel that the new knowledge you have has helped reduce your anxiety about your high-risk status?</i>		
Yes	19	86.4%
No	3	13.6%
	22	100.0%
<i>Do you feel this will also help you in following the screening recommendations that were made?</i>		
Yes	22	100.0%
No	0	0.0%
	22	100.0%
<i>How many times did you watch the educational video at home?</i>		
0	12	54.5%
1	9	41.0%
2	1	4.5%
	22	100.0%
<i>Did anyone in your family view the video?</i>		
Yes	5	22.7%
No	17	77.3%
	22	100.0%

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## Chapter VI

### Discussion and Conclusion

Breast cancer continues to be a significant health concern for women in the United States. Genetics has become an essential part of managing those at high risk for developing breast cancer. Patients who are considered high-risk for breast cancer go through many emotions when they receive a recommendation for genetic counseling. These emotions can include decreased self-efficacy, anxiety, and depression when undergoing genetic counseling and testing due to a lack of knowledge. This Doctor of Nursing Practice project aimed to see if knowledge and self-efficacy could be improved and if anxiety and depression changed following an educational intervention regarding being at high risk of developing breast cancer.

This chapter presents a discussion of the results of this project related to the outcome variables and how these results related to the literature and other issues impacting this project. Variables, project barriers and limitations, project results and impact, project results and impact, sustainability, dissemination, and the project conclusion are also included.

#### *Variables*

Data analysis from a paired samples *t*-test revealed no significant difference in self-efficacy, depression, and anxiety pre-and post- the intervention. The self-efficacy scores were unchanged between the two assessment time frames, the depression scores slightly increased, and anxiety was improved, but not significantly.

This author speculates that this could be due to multiple factors. One could be that patients were experiencing these feelings about the initial genetic counseling visit where they would have to review family history and determine if they did indeed need to have genetic testing performed. At the follow-up visit, the participants were still experiencing their feelings



about the upcoming review and interpretation of the genetic testing results. The participants may have also been influenced by thinking about what additional surveillance they would have to undergo to monitor their high-risk status.

The anxiety scores did show a slight but not clinically significant improvement when comparing the pre-and post-intervention results. Data from the post-survey revealed that many participants recognized that the educational intervention helped with anxiety. It is hypothesized that this could be due to how the educational intervention explained the genetic counselor's role and the rationale for a visit better than what was presented by the referring provider when the genetic counseling referral was made. The variable with the most clinical and statistically significant change was knowledge. After viewing the educational PowerPoint intervention, the project participants showed that they learned some basic tenets of breast cancer genetics.

### ***Project Barriers and Limitations***

Two main barriers could have affected the outcome of this DNP project. One is the worldwide COVID-19 pandemic occurring during the project implementation phase. The Delta and Omicron variant surges affected this phase by making potential participants weary of being out in public and opting to cancel or reschedule their appointments. The Delta variant surge occurred during July and August of 2021, and the Omicron variant occurred during December of 2021. If potential project participants chose to keep their genetic counseling appointment, many opted for a telehealth visit, making them ineligible to participate in the study. The Delta and Omicron COVID-19 pandemic surge also impacted the number of participants who completed the project. Thirty-one participants were recruited and completed the pre-survey questionnaires, but only twenty-two were able to complete the entire project.

This project was also affected by time which caused the project to be underpowered. The goal of the project was 120 participants. With only eight months to implement the project, there was insufficient time to accrue enough participants to power the study which could have affected the results. The time limit allowed an accrual of only 22 participants. Other factors included vacation days taken by the genetic counselor during the implementation phase, which also influenced the time limitations and the number of potential project participants.

### ***Project Results and Impact***

A data analysis review shows that the project addressed the statistical change in the knowledge variable and a clinically significant improvement in anxiety. Since the self-efficacy and depression scores did not change, the project did not impact these potential problems experienced by the project participation population.

When preparing for this project, the literature review was extensive for the variables that would be involved. Overall, 18 articles evaluated during the literature review revealed a direct correlation between knowledge and anxiety about having a high-risk status. Eleven of the articles reviewed found a correlation between increasing knowledge and decreasing anxiety. A clinically significant correlation between knowledge and anxiety was seen in this project. Improving understanding about being high-risk for breast cancer would help improve self-efficacy and reduce anxiety and depression regarding their status.

The project results were not conclusive when evaluating the depression variables. According to a study done by Listol et al. (2017), patients with a BRCA mutation felt alone with their concerns, causing depressive symptoms. The literature review evaluated five articles, and all five found that depression is common in someone who has a high-risk status. Listol (2017), Nakamura et al. (2020), Weihs et al. (2018), Kim et al. (2017), and Doubova et al. (2020) all had

improvements in depression following their proposed educational intervention, while this project saw a slight change in the depression score. These results could have influenced the upcoming appointment for genetic testing results, and the study itself was limited by time and an underpowered study.

The literature review for self-efficacy included 18 articles where most of the findings revealed that self-efficacy improved, and anxiety decreased as participant knowledge was gained on a particular subject. The only article that did not show a clinical significance in improving self-efficacy following an educational intervention was Antill et al. (2006). These findings are similar to the findings of this project, where the self-efficacy scores were the same pre-and post-intervention. These findings could result from the participants feeling comfortable with their decision to see the genetic counselor and be evaluated.

The conceptual framework for this project is based on Albert Bandura's Social Learning Theory (Bandura, 1977). He believed that "if people believe they can exercise control over the occurrence of events that can be injurious, they will not fear them" (Bandura, 1983). With the significant change in the knowledge variable, this author would speculate that the previous statement is true. When the variables of self-efficacy, depression, and anxiety are added to the mix, it does not seem to hold as the only variable that had any change in the positive direction was anxiety. There was no change in self-efficacy and an adverse change in the depression scores. These variables might have resulted differently if the educational intervention was more detailed or based on a needs survey about genetic counseling education.

This author feels that the study impacted patient outcomes based on the clinical and statistically significant change seen in the knowledge variable. Having more information about genetic counseling, a purpose for genetic testing, and the interpretation of the results is helpful in

any situation regarding someone's health risks. This project has impacted if even one of the participants follows through with the recommended screenings to help monitor breast cancer development.

### ***Sustainability***

This project could easily be sustained and become part of the genetic counseling visit. The education intervention is a 10-minute PowerPoint presentation that covers topics in greater depth than generally discussed at the visit. Since most genetic counseling visits are scheduled for sixty minutes, the presentation could easily be incorporated. Also, the information in the PowerPoint might help generate more meaningful questions and discussions during the genetic counseling visit.

### ***Dissemination***

The data and results from this DNP project will be presented at the Western Institute of Nursing's 2022 Research Conference on April 8, 2022, during the morning poster session. During this time, this author will be available to discuss the aspects of the project and the outcomes with interested parties. The conference presentation may also generate interest for these other parties to utilize an educational intervention with their genetic counseling visits. Even though there is no plan for further scholarly activities in this area, this author plans to continue to put the knowledge gained for her DNP degree in place at her current practice. One of her initial focuses will be staff recruitment and retention.

### ***Conclusion***

Breast cancer continues to be a significant health concern for women in the United States. As we learn more about the genetics of the disease and how it can influence a woman's risk for developing cancer, we must provide education about that risk. Having a high risk for breast

cancer can cause decreased self-efficacy, depression, and anxiety. This project aimed to determine if the variables of self-efficacy, anxiety, depression, and knowledge would be affected by having participants view an educational PowerPoint about breast cancer genetics.

More research needs to be done in this arena as the understanding of cancer genetics grows and becomes more complicated for the layperson. Developing education resources and tools for this population is imperative for helping high-risk patients undergo genetic counseling. Research should then be focused on the best way to provide these educational resources and tools for this population to improve their understanding of their risk. In the long term, this could improve the patient's self-efficacy and significantly decrease their anxiety and depression about being high-risk, ensuring they are more compliant with the recommended screenings for monitoring.

## Appendix A

Search Tables

**Table 1A**

*CINAHL Search Table 1*

High Risk for Breast Cancer	BRCA1 and BRCA2	Risk Reduction Strategy	Cancer Screening	Risk Reduction Adherence	Cancer Screening Adherence	#1 and #2	#7 and #3	#7 and #4	#8 and #5	#9 and #6	#10 and #11
1668	1243	13	5550	24394	111	151	0	17	0	1662	1670

**Table 2A**

*Cochrane Search Table 1*

High Risk for Breast Cancer	BRCA1 and BRCA2	Risk Reduction Strategy	Cancer Screening	Risk Reduction Adherence	Cancer Screening Adherence	#1 and #2	#7 and #3	#7 and #4	#8 and #5	#9 and #6	#10 and #11
82	3	41	225	21	9	1	1	1	15	13	6

**Table 3A***PUBMED Search Table 1*

High Risk for Breast Cancer	BRCA1 and BRCA2	Risk Reduction Strategy	Cancer Screening	Risk Reduction Adherence	Cancer Screening Adherence	#1 and #2	#7 and #3	#7 and #4	#8 and #5	#9 and #6	#10 and #11
1067	213	341	2690	178	140	19	20	1121	1	21	0

**Table 4A***Scopus Search Table 1*

High Risk for Breast Cancer	BRCA1 and BRCA2	Risk Reduction Strategy	Cancer Screening	Risk Reduction Adherence	Cancer Screening Adherence	#1 and #2	#7 and #3	#7 and #4	#8 and #5	#9 and #6	#10 and #11
48796	1747	5631	240976	880	3004	3538	159	1807	2	28	1

**Table 5A***CINAHL Search Table 2*

Cancer	Anxiety	Education/Knowledge	#1, #2, and #3	#4 and Breast Cancer	#2, #3, and #5	#7 and high-risk/BRCA1/2
445415	101749	684183	1248	94334	345	23

**Table 6A***Cochrane Search Table 2*

Cancer	Anxiety	Education/Knowledge	#1, #2, and #3	#4 and Breast Cancer	#2, #3, and #5	#7 and high-risk/BRCA1/2
1023	529	636	20	149	8	3

**Table 7A***Scopus Search Table 2*

Cancer	Anxiety	Education/Knowledge	#1, #2, and #3	#4 and Breast Cancer	#2, #3, and #5	#7 and high-risk/BRCA1/2
1078527	115503	470041	2865	527068	867	172

**Table 8A***PUBMED Search Table 2*

Cancer	Anxiety	Education/Knowledge	#1, #2, and #3	#4 and Breast Cancer	#2, #3, and #5	#7 and high-risk/BRCA1/2
4258919	254212	1828690	3451	901	871	50



## Appendix B

**Table 1B**

*Evidence Table*

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
Antill et al. (2006). Screening behavior in women at increased familial risk for breast cancer. <i>Familial Cancer</i> , 5, 359 – 368.	Sample: N = 266 participants with no personal history of cancer but either high/moderate risk based on genetic pedigree  Setting: Multicenter study	Two sources: subjects answered a self-report questionnaire and data were collected from each subject's medical record.  Data collected regarding demographics, family history and risk assessment, surveillance recommendation, risk perception, and impact of events  Reviewed practices of	Fisher's exact test Blyth-Still-Casella Method  Mantel-Haenszel Chi-Square test  Monte Carlo Estimation	No significant differences for demographics  For breast self-exam no significant association between adherence and risk category (P = 0.57)  For clinical breast exam no significant difference between moderate and high-risk groups in adherence (P=0.62)  For mammography	4	Looked only at familial risk not any genetics  Did include all current guidelines for screening but no surgery options  Limited results since was a self-report to determine adherence  High risk defined at estimated lifetime risk of >50%  Moderate risk defined as >25%

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
		doing CBE, BSE, and mammogram		the results were mixed with most adherence seen in the older population and number of first-degree relatives affected by breast cancer		Also looked at over and under screening practices
Bredart et al. (2011). Anxiety and specific distress in women at intermediate and high risk of breast cancer before and after surveillance versus standard mammography. <i>Psycho-Oncology</i> , 21, 1185-1194.	Sample: N=1561 participants aged 20 – 70 with no clinical signs of breast cancer, no ongoing breast cancer treatment, no metastasis, no bilateral mastectomy, and differed in terms of objective breast cancer risk.  Setting: 21 centers in France experienced in	Subjects were mailed a self-reported questionnaire one week prior to MRI and a second self-report questionnaire 15 days to 3 months after MRI  Data collected included patient demographics, breast cancer-risk perception  Study focused on psychological outcomes of	Multiple regression analysis  Hierarchical multiple regressions	Demographic among all participants was not significantly different  The two groups (Mx and MRI) were significantly different: MRI was younger, higher level of education, higher risk perception, more frequent ultrasound and less frequent personal history of breast cancer	4	Overall anxiety over risk perception was higher in all populations. Older women had higher STAI-State anxiety scores.  MRI group: women with demonstrated genetic mutation, non-tested women with FDR with genetic mutation, women with a probability of genetic mutation of at

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
	breast MRI techniques	additional surveillance with MRI in women at high risk for breast cancer  Tools Used: STAI-State Anxiety  Impact of Event Scale		and more frequent abnormal surveillance results  Anxiety levels considered to be low to moderate  Mx group has significantly higher mean scores of STAI – State Anxiety and IES-Avoidance than the MRI group		least 40% or mutation of at least 80%  Mx group: personal history of pathologic breast lesions or breast cancer between 40 – 50, no FMH, with one FDR with breast cancer between 50 – 70, or could not do MRI
Buchanan et al. (2017). Adherence to recommended risk management among unaffected women with a <i>BRCA</i> mutation. <i>Journal of Genetic</i>	Sample: N = 97 unaffected <i>BRCA</i> mutation carriers that had genetic counseling at least one year prior to survey  Setting: Self-reported questionnaires	Cross-sectional, single group to assess adherence to current guidelines, factors associated with adherence and common reasons for performing and not performing	Descriptive statistics  Dichotomous variables  Bivariate and multivariate regression models	Adherence exceeded 50% with the rates greater than 75% in women over 40	6	Many factors influence adherence  Looked at behaviors in general  Better genetics knowledge seemed to help adherence

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
<i>Counseling, 26, 79-92.</i>		recommended risk management	Cox & Snell Method  Fisher's exact test			Their theory about the HBM was not proven  Limited due to design  Also looked at over and under screening practices
Cabrera et al. (2010). The impact of genetic counseling on knowledge and emotional response in Spanish population with family history of breast cancer. <i>Patient Education and Counseling, 78 (3), 382-388.</i>	Sample: N =212 participants with family history of breast cancer, over 18 years of age, and ability to read/write Spanish  Setting: Self-report questionnaires pre and post genetic counseling	Self -report questionnaires to review demographics, knowledge about breast cancer, psychological measures, subjective risk assessment, risk assessment, and quality of life  Tools Used: HADS, Cancer Worry Scale, EuroQuol 5, Tyrer-Cuzick	Descriptive Statistics  Chi-Square  McNemar's Test  ANOVA followed by post hoc Fisher's test  Paired <i>t</i> -test  Spearman's Correlation	Demographic analysis showed most participants were married and had children  Mean knowledge scores (risk perception, education) were significantly in all groups after receiving counseling when compared to pre-intervention scores.	4	Shows that intervention of genetic counseling seems to improve cognitive aspects  Some cultural impact on the lack of perception adjustment  Women felt after counseling felt that it could help their family members make

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
		risk assessment model	Repeated measures ANOVA	Cancer worry decreased significantly after counseling intervention in all groups  No improvement seen in perceived risk vs. estimated risk after counseling visit		better decisions about health care
Drukteinis et al. (2013). Beyond mammography: New frontiers in breast cancer screening. <i>American Journal of Medicine</i> , 126, (6), 472-479.	Setting: Reviewed current standard recommendations for breast screening versus new techniques	Reviewed mammography on patients with dense breast versus other imaging modalities  Looked at high risk patients	None	Although mammogram is gold standard, in women with dense breasts there may be false positives leading to increase biopsies leading to increase patient anxiety	6	Recommend that imaging be based individually and not just mammogram on all patients, if patient has dense breast should look at other options that best suit the individual
Green et al. (2004). Effect of a computer-based decision aid on	Sample: N = 211  Setting:	Randomized controlled trial conducted from May 2000 to September 2002	Descriptive statistics for all variables  <i>t</i> -test	Comparable demographics between both groups	1	Findings show that an interactive computer program was

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
<p>knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility. <i>Journal of the American Medical Association</i>, 292, (4), 442-452.</p>	<p>Outpatient clinics offering genetic counseling at 6 US medical centers</p>	<p>with 2 groups: low-risk and high-risk</p> <p>Objective to compare the effectiveness of a computer-based decision aid with standard genetic counseling for educating women about <i>BRCA1/2</i> testing</p>	<p>Repeated measures ANOVA</p> <p>Chi-square</p> <p>Fisher exact test</p> <p>Likert Scale</p>	<p>Knowledge scores increased for both groups after counseling but was higher in the computer group</p> <p>Perception of risk decreased significantly after either intervention</p> <p>Mean state anxiety scores were reduced by counseling</p>		<p>more effective than standard counseling for increasing knowledge.</p> <p>Counselors were more effective in reducing a woman's anxiety and facilitating more accurate risk perceptions than the computer program.</p> <p>Interactive computer program should be used a supplement only</p>
<p>Grimm et al. (2019). Frequency of breast cancer thoughts and lifetime risk estimates: A multi-</p>	<p>Sample: N = 2747</p> <p>Setting: Participants were from 5 medical centers</p>	<p>Survey performed before their mammogram to quantify women's personal estimate of breast cancer risk and</p>	<p>State Anxiety Scale</p> <p>Cronbach <math>\alpha</math></p> <p>Likert scale</p>	<p>Women reported up to six thoughts of cancer on average in prior month</p>	4	<p>Demographics played a large part in risk perception</p>

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
institutional survey of women undergoing screening mammography. <i>Journal of the American College of Radiology</i> , 16, (10), 1393-1400.		frequency of breast cancer thoughts in the prior month  Notified of 12% lifetime average risk and asked to estimate their personal risk both subjectively and objectively	Wilcoxon's rank-sum test  Spearman's correlation coefficients	More frequent if personal/family history, greater anxiety, and genetic testing  Women without risks factors had 1.4 thoughts per month which correlated to baseline anxiety		
Haas et al. (2005). Perceived risk of breast cancer among women of average and increased risk. <i>Journal of Women's Health</i> , 14, (9), 845-851.	Sample: N = 1619 women aged 40-74 years with no history of breast cancer identified through the San Francisco Mammography Registry  Setting: Phone interview from March 2002 to July 2003	Survey to examine factors associated with perception of breast cancer risk among women at average and high objective risk. Study collected demographics and used the Gail model to determine participants breast cancer risk (risk score of at least 1.67% were	Frequency distributions  Multivariate logistic regression models  c-statistic	Approximately 2/3 of participants had an average risk – these women accurately perceived their risk at 72% whereas the high-risk only had 43.1% accuracy  Younger women than older women were more likely to perceive they	4	As expected, those women with established risk factors, particularly an FDR with breast cancer, were more likely than women without to accurately perceive they were at an increased risk  Need to make sure there is understanding of risk to make

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
		considered high risk		were at perceived risk  Women with a family history regardless of risk were more likely to overestimate  Prior breast biopsy and h/o abnormal mammogram no associated with perception of risk		informed decisions about screening and options for risk reduction
Issacs et al. (2002). Breast and ovarian cancer screening practices in health women with a strong family history of breast or ovarian cancer. <i>Breast Cancer Research and Treatment</i> , 71, 103 – 112.	Sample: N = 216 females aged 30 and older who were unaffected with cancer and were either members of families with at least a 10% probability of carrying <i>BRCA1/2</i> or have a first degree or second degree relative with a documented	Data collected on demographic characteristics, clinical characteristics, and psychological factors  Also included practices of obtaining a clinical breast exam and mammogram	Likert Scale Descriptive statistics  Bivariate analysis  Multivariate analysis  Chi-square	Relatively low adherence rate to mammography in older women and no real significance in adherence with the other factors reviewed	4	5-year study Looked at all methods of screening  First study done in the US examining adherence to screening recommendations  Revealed that better education is needed overall



Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
	<i>BRCA1/2</i> mutation  Setting: Telephone Interviews					
Katapodi et al. (2003). Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: a meta-analytic review. <i>Preventative Medicine</i> , 38, 388-402.	Sample: N = 42 studies between 1985 – 2004	Meta-analysis looking at perceived risk to predict adoption of health-protective measures	Means and SDs  <i>t</i> tests  chi-square  <i>F</i> tests  <i>r</i> correlations  frequencies or proportions  <i>P</i> values  2x2 tables	Women do not have an accurate perception of their risk for breast cancer  Women with a positive family history perceive their risk to be higher  Only a few studies to look at demographics and perceived risk  A positive correlation between perceived risk and intensity of	1	Looked at how a patient's perceived risk belief factored into their adherence to screening  Recommended continuing development strategies to reduce risk and change perception of risk  Believes that relationship between perceived risk and screening behavior is complex

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
				<p>emotional response</p> <p>A positive association between perceived risk and adherence to mammography screening</p> <p>Women with HBOC perceived their risk to be higher</p>		
<p>Lobb et al. (2006). Development of a communication aid to facilitate risk communication in consultations with unaffected women from high risk breast cancer families: A pilot study. <i>Journal of Genetic</i></p>	<p>Sample: N = 27</p> <p>Setting: Self-report questionnaires 1 week prior to genetic counseling session and 2 weeks after</p>	<p>To determine if adding a standardized communication aid would increase knowledge and risk communication during a visit with a genetic counselor</p> <p>Data collected:</p>	<p>Descriptive Statistics</p> <p>Change scores</p> <p>Chi-square</p> <p>Student <i>t</i>-tests</p> <p>Mann-Whitney <i>U</i>-tests</p> <p>Repeated Measures ANOVA</p>	<p>Significant difference in knowledge scores between baseline and follow-up</p> <p>No significant difference between total knowledge scores between any groups</p>	4	<p>Only study to compare to previous RCT done by same author</p> <p>Also, only study to evaluate practitioner outcomes about the use of aid</p>

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
<p><i>Counseling, 15, (5), 393-405.</i></p>		<p>Demographics, breast cancer genetics knowledge, risk perception, breast cancer anxiety, general anxiety and depression, satisfaction with genetic counseling session, satisfaction with risk communication aid</p>		<p>No significant differences in the change scores in general anxiety or breast cancer specific anxiety</p> <p>Most women accurately estimated the population risk of breast cancer</p> <p>Majority of women were satisfied with the genetic counseling session</p> <p>Majority of women found aid extremely or very useful in understanding breast cancer genetics and in understanding their personal risk</p>		

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
Lobb et al. (2005). Differences in individual approaches: Communication in the familial breast cancer consultation and the effect on patient outcomes. <i>Journal of Genetic Counseling</i> , 14, (1), 43-53.	Sample: N = 150  Setting: Participants were from 10 familial cancer clinics seen between November 1998 – April 2000.	Data collected by self-reported questionnaire 2 weeks prior to and 4 weeks after genetic counseling  Participants stratified according to affected or unaffected women  Consultations were recorded to compare recommendations and education provided during the consultations  Measures included: demographics, objective risk, expectations, coping style, decision making preference	Descriptive Statistics  ANOVA  Kruskal-Wallis  Chi-square  Bonferroni Adjustment  Power Analysis	87% of women wanted as much information as possible  12% wanted only information needed to deal with immediate issues  1% wanted additional information only if it was good news  Decision-Making: 88% collaborative decision making 5% decision made by clinician 7% make their own decision No relationship for decision making based on age, education, or	1	Study that looks at the participants and the counseling session and how information and recommendations were provided  By combining both teaching and counseling might see an improvement in both knowledge and anxiety about perceived risk.  Need more consistency in consultations

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
		Tools used: Monitoring-Blunting Style Scale, Cassileth Information Styles Questionnaire, Impacts of Events Scale, HADS, Breast Cancer Genetics Knowledge		professional status  Monitoring: 56% high monitors 45% low monitors  Significant differences in styles of consultation and how data was delivered		
Manley Conto et al. (2001). Risk factors and health promotion in families of patients with breast cancer. <i>Clinical Journal of Oncology Nursing</i> , 6, (2), 1-5.	Sample: N = 0  Setting: Review of guidelines for high risk patients	Evaluated the role of the oncology nurse in health promotion regarding high risk and education	None	Reviewed the ability of oncology nurse to provide education about high risk and help promote adherence to screening recommendations such as SBE, CBE, mammography, and genetic	7	Expert opinion paper  Encourage the expert level oncology nurse to help promote health behaviors and provide guidance to help reduce anxiety

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
				counseling when warranted.		
Peshkin et al. (2002). Utilization of breast cancer screening in a clinically based sample of women after <i>BRCA1/2</i> testing. <i>Cancer Epidemiology, Biomarkers, &amp; Prevention, 11</i> , 1115 – 1118.	Sample: N = 107 women who self-referred for genetic counseling that were > 25 with no history of cancer or prophylactic mastectomy and had definitive <i>BRCA1/2</i> results  Setting: Telephone Interview	Patients were tested for <i>BRCA1/2</i> and then received counseling. They were then contacted via phone one, six, and 12 months after to ask whether they had undergone any surgery and if not had they obtained a CBE and mammogram	Chi-square	No significant difference for carriers/non-carriers based on demographics  Significant results predictor of obtaining a CBE after receipt of test results  No significant difference for mammography utilization	4	Hard to tell what statistics they used Showed different result for mammogram utilization in the older population than other studies  Question if guidelines for testing high risk women under 35 should be changed
Phillips et al. (2006). Risk-reducing surgery, screening, and chemoprevention practices of <i>BRCA1</i> and <i>BRCA2</i> mutation carriers: a prospective cohort study,	Sample: N = 142 unaffected female mutation carriers  Setting: Self-reporting questionnaire mailed to their home	Participants enrolled in kConFab study and had to be carriers of a pathogenic mutation in <i>BRCA1</i> or <i>BRCA2</i> , complete questionnaire at 3 years after study	Exact binomial confidence intervals (CIs)  Fisher's exact p-values  Linear logistic regression  Parsimonious models	59% of participants had attended an FCC  7% underwent Bilateral mastectomy  Only one underwent chemoprevention	4	Only study to include chemoprevention  Mention MRI as risk reduction measure  Noted that women who know and understood their

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
<i>Clinical Genetics</i> , 70, 198-206.		entry, and not have personal history of invasive cancer.  Data collected: demographics, mutation status, and risk management Also included practices of obtaining BSE, CBE, mammogram, risk management, and chemoprevention		23% undergoing annual breast exams  Only one had regular breast MRI  Women aware of their mutation status were 7 times more likely to undergo risk-reducing surgery and undertake all screening practices except BSE		mutation more likely to keep up with screenings  Had high response rate of 75% to mailed questionnaires  No reminder system available to keep women aware of screening needs  Included women that had undergone genetic counseling
Price, et al. (2010). Predictors of breast cancer screening behavior in women with a strong family history of the disease. <i>Breast</i>	Sample: N = 748 unaffected women with a strong family history of breast cancer.  Setting:	Data collected on self-reporting questionnaire included: demographics, cognitive representation of perceived risk, emotional representation,	Analysis of variance  chi-square  multi-nominal logistic regression	Screening practices statistics: 74% screened accordingly, 16% under-screened, 10% over-screened.	4	More strategies needed such as education to help reduce number of under screening and over screening  Perceived risk of developing breast

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
<i>Cancer Research and Treatment</i> , 124, 509-519.	Women participating in the kConFab Clinical Follow-up study and kConFab Psychosocial study were mailed self-reporting questionnaires	and concordance with screening guidelines Included practices of obtaining a CBE, doing BSE, and mammogram		Includes breakdown of each method with results showing same and based on age		cancer is a motivating factor in screening practices  Genetic counseling should also be offered to this high-risk group  Looked at factors that contribute to over and under screening
Price et al. (2007). Predictors of cancer worry in unaffected women from high risk breast cancer families: Risk perception is not the primary issue. <i>Journal of Genetic Counseling</i> , 16, 635 – 644.	Sample: N = 1744  Setting: Women aged 18 – 75 years participating in kConFab. Mailed information and self-report questionnaires	Data collected to evaluate cancer specific worry, perceived lifetime risk, demographics including family history and biological variables, psychosocial variables for anxiety  Tools Used:	Descriptive Statistics  Spearman's coefficient	Participants with FM and/or genetic testing had the strongest correlation with cancer worry or perceived risk  Levels of cancer worry are low in unaffected women  Women's anxiety or worry about	4	Cancer risk calculated using the Tyrer-Cuzick algorithm  Knowledge of mutation revealed to be a complex construct



Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
		Life Event and Difficulties Schedule, HADS, Life Orientation Test, Duke-UNC Life Orientation Test		breast cancer is influenced by a range of factors and if they have generalized anxiety  Not having family support also increase anxiety		
Rosenthal et al. (2016). Increased identification of candidates for high-risk breast cancer screening through expanded genetic testing. <i>Journal of the American College of Radiology</i> , 14, 4, 561-568.	Sample: N = 9641 women who had undergone expanded genetic testing  Setting: Data derived from clinical testing ordered at Myriad Genetic Laboratories for 194,1078 female patients between 9/2013 – 2/2016.	To quantify the impact of testing for genes beyond <i>BRCA1/BRCA2</i> and the extent to which mutation carriers in the genes would have been identified as candidates for enhanced screening based on family history alone	Claus Model to assess lifetime risk	<i>BRCA1/BRCA2</i> accounted for 59.1% of all PVs  38.8% PVs were in <i>ATM, CHEK2, or PALB2</i> Only 24.7% of all women with PVs found in any gene reached the >20% lifetime risk threshold	6	Looked specifically at genetic mutations to see if expanded screening is needed  Recommended that expanded screening is needed to find those women who need increased screening and would not have been identified

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
						based on family history alone
Roussi et al. (2010). Enhanced counselling for women undergoing BRCA1/2 testing: Impact on knowledge and psychosocial distress – results from a randomized clinical trial. <i>Psychology and Health, 25, (4), 401-415.</i>	Sample: N = 134  Setting: Participants were recruited from the Family Risk Assessment Program at Fox Chase Cancer Center between May 1998 – October 2000  Telephone contact followed by self-report questionnaire	Data collected at baseline included background variables: demographics, cancer history, trait, anxiety, and attentional style, and outcomes variables: knowledge intrusive ideation, and cancer-related worry  Knowledge re-assessed 1 week after intervention and 1 week following test result (if opted to have genetic testing done); intrusive ideation and cancer-related worry re-assessed 1-week	Linear regression analysis  Two-way interactions  Chi-square  Two-tailed <i>t</i> -tests  Descriptive statistics  Pearson's coefficient	Women who attended all sessions were more knowledgeable  Women who did not complete final questionnaires scored lower on trait anxiety at baseline  Those with less education tended to have more anxiety  Those in the EC group had lower levels of intrusive ideation 1-week post test result  Women in the EC group	4	Intervention and Control groups: EC – cognitive affective preparation  All participants met for pre-disclosure session  EC group met with Health educator after genetic counselling session  Educational aids along with counseling sessions improves experience overall

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
		<p>following disclosure of test results</p> <p>Tools used: State-Trait Anxiety Inventory, Miller Behavioral Style Scale, Impact of Events Scale</p>		<p>demonstrated greater knowledge consistent with hypothesis and literature</p> <p>No significant results regarding impact of intervention on cancer-related worry</p>		
<p>Sciaraffa et al. (2020). Breast cancer risk assessment and management programs: A practical guide. <i>The Breast Journal</i>, 26, 1556-1564.</p>	<p>Sample: N = 0</p> <p>Setting: None</p>	<p>Expert opinion on a Risk Assessment and Management Program for high risk patients</p>	<p>None</p>	<p>Described the components and information necessary to build a comprehensive program for management of high-risk breast patients: target population, referrals, marketing, administrative considerations roles and responsibilities,</p>	<p>7</p>	<p>Reviewed the GINA laws</p> <p>Table with all breast cancer risk assessment models – organized according to clinical decision-making</p> <p>Breaks the visit experience down into 3 parts: Information gathering, the</p>

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
				research opportunities, the visit experience, and follow-up plan		risk profile, and the risk management plan
Stalmeier et al. (2009). Concise evaluation of decision aids. <i>Patient Education and Counseling</i> , 74, (1), 104-109.	Sample: N = 390 participants that had <i>BRCA1/2</i> mutation  Setting: In the clinic and at home	2 Decision aids were used: 1) Brochure and video reviewed at home 2) 3 sessions with trained research assistant with an interval of 1-2 weeks  Data collected: Satisfaction with quality of information, subjective knowledge, amount of information, decision	Tools used: Decision Evaluation Scales, Center for Epidemiologic Studies Depression Scale, Spielberger State-Trait Anxiety Inventory, Impact of Event Scale  Likert Scale  ANOVA	Two different decision aids affected separate factors – The second had positive long-term effects but not short term  Short questionnaires are more desirable	4	Dutch study  Did not include patients that had metastatic disease, had undergone surgery, or had been treated for cancer less than one month before blood sampling

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
		evaluation scales, depression, anxiety, distress, general health, strength of preference, weighing pro and cons				
Tang et al. (2009). Women's mammography experience and its impact on screening adherence. <i>Psycho-Oncology</i> , 18, 727-734.	Sample: N = 397 women obtaining screening mammograms  Setting: Telephone interview	To analyze a women's mammography experience, examine the rates of repeat mammography, and to identify the significant predictors of repeat testing within 12 and 18 months of index mammogram. Data collected on satisfaction with clinical services, physical experience, psychological experience, and communication with clinic staff.	Logistic regression models  Likert Scale  Cronbach's alpha	Tang et al. (2009). Women's mammography experience and its impact on screening adherence. <i>Psycho-Oncology</i> , 18, 727-734.	Sample: N = 397 women obtaining screening mammograms  Setting: Telephone interview	To analyze a women's mammography experience, examine the rates of repeat mammography, and to identify the significant predictors of repeat testing within 12 and 18 months of index mammogram. Data collected on satisfaction with clinical services, physical experience, psychological experience, and communication with clinic staff.

Citation	Sampling/Setting	Research Design	Data Analysis	Findings	Level of Evidence	Comments
Tinley, et al. (2004). Screening adherence in <i>BRCA1/2</i> families is associated with primary care physician's behavior. <i>American Journal of Medical Genetics, 125A, 5-11.</i>	Sample: N = 112 women who tested positive for <i>BRCA1/2</i> and their female relatives who have not been tested but are known to have a 50% risk of having the mutation  Setting: Mailed self-reporting questionnaires	Data collected included screening behaviors over last 2 years, risk perception, cancer specific distress, adherence, determinants, specific barriers, and cancer history to provide an assessment of long-term breast cancer screening with adherence Looked at practice of obtaining CBE, SBE, and mammogram	Descriptive statistics  chi-square test of independence  Fisher's Exact test  Mantel Haenszel <i>P</i>  Breslow-Day  Wilcoxon Rank Sum  Wald Test	Tinley, et al. (2004). Screening adherence in <i>BRCA1/2</i> families is associated with primary care physician's behavior. <i>American Journal of Medical Genetics, 125A, 5-11.</i>	Sample: N = 112 women who tested positive for <i>BRCA1/2</i> and their female relatives who have not been tested but are known to have a 50% risk of having the mutation  Setting: Mailed self-reporting questionnaires	Data collected included screening behaviors over last 2 years, risk perception, cancer specific distress, adherence, determinants, specific barriers, and cancer history to provide an assessment of long-term breast cancer screening with adherence Looked at practice of obtaining CBE, SBE, and mammogram

## Appendix C

**Table 1C**

*Synthesis Table*

Study	Setting	Recommended Screening	Anxiety/Perceived Risk	Knowledge	Genetic Counseling	Genetic Mutation	Fm Hx	Education	Outcome
Antill et al.	Questionnaire	Mammo, CBE, SBE	X			X	X		No Clinical Significance
Bredart, et al.	Questionnaire	MRI	X			X	X		↑ Risk perception and ↑ screening adherence
Buchanan, et al.	Questionnaire	Mammo, CBE, SBE	X		X	X		X	↑adherence
Cabrera, et al.	Questionnaire		X	X	X		X	X	↑knowledge ↓ risk perception following intervention
Drukteinis, et al.	Data Review	Based on breast density				X	X		No Clinical Significance
Green, et al.	Outpatient Clinic – Interactive computer or one-on-one counseling			X	X	X		X	↑knowledge with computer ↓anxiety with one-on-one counseling
Grimm, et al.	Medical Center – pre/post questionnaire	Mammo	X	X				X	↑risk perception based on demographics

Study	Setting	Recommended Screening	Anxiety/Perceived Risk	Knowledge	Genetic Counseling	Genetic Mutation	Fm Hx	Education	Outcome
Haas, et al.	Telephone		X	X			X	X	↓knowledge ↑risk perception
Issacs, et al.	Telephone	Mammo, CBE	X			X	X		↑adherence
Katapodi, et al.	Meta-analysis	Mammo, CBE, SBE	X	X	X	X	X	X	↑adherence ↑knowledge ↓anxiety
Lobb, et al.	Questionnaire Pre/post genetic counseling		X	X	X	X	X	X	↑knowledge ↓anxiety Used standardized teaching tool
Lobb, et al.	Questionnaire Pre/post genetic counseling		X	X	X		X	X	↑knowledge ↓anxiety about perceived risk
Manley, et al.	Expert Opinion	Mammo, CBE, SBE	X	X		X	X	X	↑knowledge ↓anxiety about perceived risk
Peshkin, et al.	Telephone	Mammo, CBE	X	X		X			Unable to determine
Phillips, et al.	Questionnaire	Mammo, CBE, SBE, surgical risk management, chemoprevention		X	X	X		X	↑knowledge ↑screening adherence
Price, et al.	Questionnaire	Mammo, CBE, SBE	X	X			X	X	↑knowledge ↑screening adherence



Study	Setting	Recommended Screening	Anxiety/Perceived Risk	Knowledge	Genetic Counseling	Genetic Mutation	Fm Hx	Education	Outcome
									↓over screening
Price, et al.	Questionnaire		X	X	X		X		↑knowledge ↓perceived risk and anxiety
Rosenthal, et al.	Data Review				X	X			Recommends expanded screening to rule out all possible mutations
Roussi et al.	Telephone/Questionnaire		X	X	X		X	X	↑knowledge ↓anxiety
Sciaraffa, et al.	Expert Opinion								Described components to develop a RAMP
Stalmeier, et al.	Clinic/Home		X	X	X	X		X	↑knowledge ↓perceived risk and anxiety
Tang, et al.	Telephone	Mammo, CBE	X					X	Mammography experience ↑adherence with education
Tinley, et al.	Questionnaire	Mammo, CBE, SBE	X	X	X	X	X	X	↑knowledge ↓perceived risk and anxiety

## Appendix D

### Breast Cancer Genetics Knowledge Questionnaire - 27

	Please choose the correct answer	True	False
1.	50% of inherited genetic information (about breast cancer risk) is passed down from a person's mother.		
2.	25% of inherited genetic information (about breast cancer risk) is passed down from a person's father.		
3.	There is more than one gene that can increase the risk of breast cancer.		
4.	A woman who has sister with a breast cancer gene mutation has a 1 in 4 chance of having a gene mutation herself.		
5.	A father can pass down a breast cancer gene mutation to his own daughters.		
6.	One in 10 women has a breast cancer gene mutation.		
7.	All women who have a breast cancer gene mutation will get cancer.		
	If current available genetic tests were to indicate that a woman has a breast cancer gene mutation, she is at increased risk for:		
8.	Breast Cancer		
9.	Ovarian Cancer		
10.	Lung Cancer		
11.	Bladder Cancer		
	If a woman who already had breast cancer was found to have a breast cancer gene mutation, she is at increased risk for developing:		
12.	Another breast cancer		
13.	Ovarian Cancer		



27. Select the procedure that is NOT appropriate for the detection of ovarian cancer.
- a. ultrasound
  - b. pap smear
  - c. CA-125 blood test
  - d. pelvic exam
  - e. Do not know

## Appendix E

### DASS 21

Please read each statement and indicate how much the statement applied to you *over the past week*.

There are no right or wrong answers.

Do not spend too much time on any statement.

The rating scale is as follows:

- Did not apply to me at all – NEVER
- Applied to me to some degree, or some of the time – SOMETIMES
- Applied to me to a considerable degree, or a good part of the time – OFTEN
- Applied to me very much, or most of the time – ALMOST ALWAYS

Item	Never	Sometimes	Often	Almost always
I found it hard to wind down				
I was aware of dryness of the mouth				
I could not seem to experience any positive feeling at all				
I experienced breathing difficulty (for example, excessively rapid breathing, breathlessness in the absence of physical exertion)				
I found it difficult to work up the initiative to do things				
I tended to over-react to situations				

Item	Never	Sometimes	Often	Almost always
I experienced trembling (for example, in the hands)				
I felt that I was using a lot of nervous energy				
I was worried about situations in which I might panic and make a fool of myself				
I felt that I had nothing to look forward to				
I found myself getting agitated				
I found it difficult to relax				
I felt downhearted and blue				
I was tolerant of anything that kept me from getting on with what I was doing				
I felt I was close to panic				
I was unable to become enthusiastic about anything				
I felt that I was not worth much as a person				

Item	Never	Sometimes	Often	Almost always
I felt that I was rather touchy				
I was aware of the action of my heart in the absence of physical exertion (for example, sense of heart rate increase, heart missing a beat)				
I felt scared without any good reason				
I felt that life was meaningless				

## Appendix F

### Generalized Self-Efficacy Scale (GES)

	Item	Not at all true	Rarely true	Moderately true	Exactly true
1.	I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
2.	If someone opposes me, I can find means and ways to get what I want.	1	2	3	4
3.	It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
4.	I am confident that I could deal efficiently with unexpected events	1	2	3	4
5.	Thanks to my resourcefulness, I know how to handle unforeseen situations.	1	2	3	4
6.	I can solve most problems if I invest the necessary effort.	1	2	3	4
7.	I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
8.	When I am confronted with a problem, I can usually find several solutions.	1	2	3	4
9.	If I am in a bind, I can usually think of something to do.	1	2	3	4
10.	No matter what comes my way, I'm usually able to handle it.	1	2	3	4



## Appendix G

### Pre-Survey Questionnaire

1. Please enter your age: \_\_\_\_\_
2. Please select your education level:
  - High School Diploma
  - Associate degree
  - Bachelor's Degree
  - Master's Degree or higher
  - Prefer not to answer
3. Please select your marital status:
  - Single/never married
  - Married or domestic partnership
  - Separated
  - Divorced
  - Widowed
  - Prefer not to answer
4. Please select your ethnicity:
  - Black/African American
  - White/Non-Hispanic
  - Hispanic/Latino
  - Asian/Pacific Islander
  - Native American or American Indian
  - Prefer not to answer
5. Have you ever received genetic counseling before?
  - Yes
  - No
6. When was your last mammogram? \_\_\_\_\_

## Appendix H

### Post-Survey Questionnaire

1. Do you feel that the education you received has helped with your understanding of your high-risk status?
  - Yes
  - No
  
2. Do you feel that the new knowledge you have has helped reduce your anxiety about your high-risk status?
  - Yes
  - No
  
3. Do you feel this will also help you in following the screening recommendations that were made?
  - Yes
  - No
  
4. How many times did you watch the educational video at home? \_\_\_\_\_
  
5. Did anyone in your family view the video?
  - Yes
  - No

## Appendix I

### Determination of Exempt Status Letter



#### UNLV Biomedical IRB - Exempt Review Exempt Notice

**DATE:** June 11, 2021

**TO:** Jennifer Pfannes, DNP  
**FROM:** Office of Research Integrity - Human Subjects

**PROTOCOL TITLE:** [1752016-1] Improving Self-Efficacy and Knowledge While Reducing Anxiety in High-Risk Breast Cancer Patients through Standardized Education

**ACTION:** DETERMINATION OF EXEMPT STATUS  
**EXEMPT DATE:** June 11, 2021  
**REVIEW CATEGORY:** Exemption category # 2

Thank you for your submission of New Project materials for this protocol. This memorandum is notification that the protocol referenced above has been reviewed as indicated in Federal regulatory statutes 45CFR46.101(b) and deemed exempt.

We will retain a copy of this correspondence with our records.

**PLEASE NOTE:**

Upon final determination of exempt status, the research team is responsible for conducting the research as stated in the exempt application reviewed by the ORI - HS and/or the IRB which shall include using the most recently submitted Informed Consent/Assent Forms (Information Sheet) and recruitment materials.

If your project involves paying research participants, it is recommended to contact Carisa Shaffer, ORI Program Coordinator at (702) 895-2794 to ensure compliance with the Policy for Incentives for Human Research Subjects.

Any changes to the application may cause this protocol to require a different level of IRB review. Should any changes need to be made, please submit a **Modification Form**. When the above-referenced protocol has been completed, please submit a **Continuing Review/Progress Completion report** to notify ORI - HS of its closure.

If you have questions, please contact the Office of Research Integrity - Human Subjects at [IRB@unlv.edu](mailto:IRB@unlv.edu) or call 702-895-2794. Please include your protocol title and IRBNet ID in all correspondence.

Office of Research Integrity - Human Subjects  
4505 Maryland Parkway . Box 451047 . Las Vegas, Nevada 89154-1047  
(702) 895-2794 . FAX: (702) 895-0805 . [IRB@unlv.edu](mailto:IRB@unlv.edu)

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## Curriculum Vitae

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EDUCATION: Doctor of Nursing Practice Candidate, Expected Graduation in May, 2022  
University of Nevada, Las Vegas  
Master of Science in Nursing, Family Nurse Practitioner, May 2012  
University of Nevada, Las Vegas  
Bachelor of Science in Nursing, May 1994  
University of Texas at Arlington  
Associate of Arts, May 1992  
South Plains College, Levelland, Texas

LICENSE: Advanced Practice Registered Nurse, Nevada License # APRN001400  
Registered Nurse, Nevada License #RN43344

CERTIFICATIONS: Oncology Certified Nurse, 1999 – 2015  
Advanced Oncology Certified Clinical Nurse Practitioner, 2015 – present  
BCLS Certified, 1992 – present  
ONS Certified Oncology Chemotherapy and Biotherapy Trainer, 2007 – present  
Family Nurse Practitioner, ANCC Board Certified, 2012 - present

### NURSING

#### EXPERIENCE:

Comprehensive Cancer Centers of Nevada, Las Vegas, Nevada  
Advanced Practice Registered Nurse  
December 2020 -Present

- Operational Excellence Administrator
  - Oversees development of new value-based care programs
  - Provides support to the clinical management team on development of clinical standards
  - Provides education to providers and clinical staff

August 2019 – December 2020:

- Supervisor, Advanced Practice Providers
  - Manage staff of 14 Advanced Practice Providers
  - Program development to continue growth of program

July 2012 – August 2019:

- Advanced Practice Registered Nurse
  - Managed patients undergoing treatment for neoplastic and hematological disorders
  - Provide one-on-one chemotherapy education

- Manage Outpatient Coumadin Clinic

Manager, iKnowMed Implementation and Special Projects

February 2011 – July 2012

- Oversee the management of the practice's electronic health record
- Assist all practice staff with any HER issues/problems
- Educate new staff of how to utilize the system
- Develop and design workflow processes for offices relating to the EHR and government requirements
- Oversee special projects including
  - Meaningful Use
  - Annual Staff Competency Labs

Northwest Office Supervisor/Primary Nurse/Infusion Suite Nurse

January 2007 – February 2011

- Supervised the clinical staff for the office which included:
  - Staffing
  - Counseling
  - Being a resource
  - Managed clinic patients with the physician by:
    - Performing telephone triage
    - Prior authorizations
    - Port Access/Port Draw

October 2006 – January 2007

- Chemotherapy Infusion Suite Nurse
  - IV therapy skills
  - Verification of chemotherapy medications and dose
    - Management of infusions and ability to identify reactions and treat in a timely manner