2017

FACTORS INFLUENCING PREFERENCE FOR SURGICAL CHOICE AMONG WOMEN WITH EARLY STAGE BREAST CANCER

Susan G. Yackzan
University of Kentucky, susan.yackzan@uky.edu
Author ORCID Identifier:
https://orcid.org/0000-0001-5664-0814
Digital Object Identifier: https://doi.org/10.13023/ETD.2017.501

STUDENT AGREEMENT:

I represent that my thesis or dissertation and abstract are my original work. Proper attribution has been given to all outside sources. I understand that I am solely responsible for obtaining any needed copyright permissions. I have obtained needed written permission statement(s) from the owner(s) of each third-party copyrighted matter to be included in my work, allowing electronic distribution (if such use is not permitted by the fair use doctrine) which will be submitted to UKnowledge as Additional File.

I hereby grant to The University of Kentucky and its agents the irrevocable, non-exclusive, and royalty-free license to archive and make accessible my work in whole or in part in all forms of media, now or hereafter known. I agree that the document mentioned above may be made available immediately for worldwide access unless an embargo applies.

I retain all other ownership rights to the copyright of my work. I also retain the right to use in future works (such as articles or books) all or part of my work. I understand that I am free to register the copyright to my work.

REVIEW, APPROVAL AND ACCEPTANCE

The document mentioned above has been reviewed and accepted by the student's advisor, on behalf of the advisory committee, and by the Director of Graduate Studies (DGS), on behalf of the program; we verify that this is the final, approved version of the student's thesis including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Susan G. Yackzan, Student

Dr. Dorothy A. Brockopp, Major Professor

Dr. Debra Moser, Director of Graduate Studies

FACTORS INFLUENCING PREFERENCE FOR SURGICAL CHOICE AMONG WOMEN WITH EARLY STAGE BREAST CANCER

DISSERTATION

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Nursing at the University of Kentucky

By
Susan Germann Yackzan

Lexington, Kentucky

Director: Dr. Dorothy A. Brockopp, Professor of Nursing

Lexington, Kentucky

2017

ABSTRACT OF DISSERTATION

FACTORS INFLUENCING PREFERENCE FOR SURGICAL CHOICE AMONG WOMEN WITH EARLY STAGE BREAST CANCER

Breast cancer is the most common cancer among women in the United States with over 60% of cases diagnosed as early stage disease. For those women without prohibiting clinical or cosmetic concerns, a choice between breast-conserving surgery and mastectomy can be made. Either choice confers equivalent survival. The decision-making process also involves consideration of recurrence risk as well as management of the unaffected, contralateral breast for both future surveillance and risk reduction. In recent years, increasing rates of mastectomy with contralateral prophylactic mastectomy have been reported among women with unilateral, early stage breast cancer. If eligible for a choice among surgical options, a woman's decision becomes one of personal preference. The decision-making process is complex and involves consideration of potential benefits and harms with each option.

The purpose of this dissertation was to: 1) analyze the psychometric properties of the Anxiety Subscale of the Depression Anxiety Stress Scale, 2) critically review Decisional Conflict Scales and 3) prospectively identify demographic, clinical, cognitive and affective factors influencing a woman's decision to choose either breast conserving surgery or mastectomy with contralateral prophylactic mastectomy and to identify self-reported sources of information in the surgical decision-making process.

Three manuscripts make up the dissertation. A secondary data analysis was conducted to test the psychometric properties of the Anxiety Subscale of the Depression Anxiety Stress Scale (DASS). The results of this analysis supported the reliability and validity of the DASS anxiety subscale. A critical review of decisional conflict measures for use with early stage breast cancer patients making surgical treatment decisions was conducted. The results of this review supported the use of Decisional Conflict Scales from a clinical and research perspective. Existing Decisional Conflict Scales show moderate to acceptable reliability.

The first two manuscripts provided background and support for the use of scales included in the research study described in the third manuscript. This study was a prospective, exploratory, cross-sectional, mixed-methods study describing factors influencing preference for surgical choice among women with early stage breast cancer. A sample of 78 participants enrolled in the study, 47 who chose breast conserving surgery and 31 who chose mastectomy with contralateral prophylactic mastectomy.

Differences were tested between the groups. Women who chose mastectomy with contralateral prophylactic mastectomy were younger, more likely to work full or part-time, had larger tumors and participated in preoperative genetic counselling. Women who chose breast conserving surgery were more likely to have participated in preoperative breast magnetic resonance imaging. Overall, women choosing either surgery were not experiencing severe levels of distress, depression, anxiety or stress although there were individual variations. Women choosing mastectomy with contralateral prophylactic mastectomy were more anxious and had more frequent intrusive thoughts about the diagnosis. They also had less decisional conflict as compared to women choosing breast conserving surgery. Information sources were similar but the most influential information source differed among the two groups. In both groups, intention for surgical choice was matched by the final decision. There are many factors influencing surgical choice among women with early stage breast cancer. Previous work has focused on clinical, demographic and diagnostic processes influencing the decision. With this study, evidence regarding the influence of cognitive and affective factors is described.

KEYWORDS: Early stage breast cancer
Breast conserving surgery
Mastectomy with contralateral prophylactic mastectomy
Decisional conflict
Anxiety

Susan G. Yackzan

November 27, 2017
Date

FACTORS INFLUENCING PREFERENCE FOR SURGICAL CHOICE AMONG WOMEN WITH EARLY STAGE BREAST CANCER

By
Susan Germann Yackzan

Dorothy Brockopp, PhD, RN, FAAN

Director of Dissertation

Debra Moser, PhD, RN, FAHA, FAAN

Director of Graduate Studies

11/27/17

DEDICATION

This dissertation is dedicated to my parents, Gloria Ryan Germann and Thomas Germann, who provided opportunity and unwavering support toward my education.

ACKNOWLEDGEMENTS

I would like to take the opportunity to acknowledge the support of some very special people. First, I would like to acknowledge the time, expertise and advice of my doctoral committee consisting of Dr. Sherry Warden, Dr. Terry Lennie, Dr. Michael Andrykowski and the Chair of the committee, Dr. Dorothy Brockopp. I consider myself very fortunate for the opportunity to learn from them.

To my work family at Baptist Health Lexington, I acknowledge the unfailing support of so many. The administrative team of Bill Sisson, Karen Hill, Kay Ross, Amanda Henson & Greg Bodager provide an environment that fosters personal and professional growth. My colleagues in the research office, Dr. Dorothy Brockopp, Drew Bugajski, Alex Lengerich and Dr. Claire Davies, offered commiseration, advice and edits. My amazing group of colleagues in Outpatient Oncology and the Oncology Pathway provided professional and personal support. To Jenny Durr and Stacy Stanifer especially, I am deeply indebted for years of friendship and encouragement. The Oncology Nurse Navigators, Sara Beth Barker, Alena Glass, Suzanne Coulter and especially Peggy Wheeler, screened and enrolled patients in my study. They are colleagues and friends and this wouldn't have been possible without their help.

Thank you to my sisters and my parents who offered support and opportunity for so many years. My father died of cancer 25 years ago. He did not get the opportunity to go to college but he worked three jobs to get me there and was always proud of my academic and professional accomplishments.

Thank you to my husband, Joe Yackzan and my three sons, Daniel, Andrew and David, who put up with me and all of the reading and writing papers and the stress. They

never failed to tell me it would be OK and that I could do this thing. And I would be remiss to fail to acknowledge my patients over these many years of oncology nursing for whom it is my privilege to care, and from whom I learn about living.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE:

Introduction

1.1. Breast Cancer and Surgical Treatment

Breast cancer continues to be the cancer of highest incidence among women in the United States with 252,710 new cases projected in 2017 (Siegel, Miller, & Jemal, 2017). Declining mortality rates due to early detection and treatment advances have been noted since the 1990's yet breast cancer remains the second leading cause of cancer-related death among women (DeSantis, Ma, Bryan, & Jemal, 2014). The majority of breast cancer cases present as localized or early-stage disease, including non-invasive, Stage 0 (in situ) and invasive, Stage I and II carcinomas. Early stage breast cancers exhibit overall 5-year survival rates of 99% (Siegel et al., 2017).

For most women with unilateral early stage breast cancer, decision making among surgical treatment options for the affected breast involves a choice between breast-conserving surgery and mastectomy. With the addition of radiation therapy post-breast conserving surgery, either choice confers equivalent survival according to stage of disease (Early Breast Cancer Trialists' Group, 2011; Wong et al., 2017). Consideration is also given to management of the unaffected, contralateral breast. In an average-risk population (i.e. those without inherited genetic predisposition or history of breast radiation exposure), risk of a contralateral breast cancer is low overall but increased as compared to women with no history of breast cancer. The annual increased risk estimate is in the range of 0.1-0.6% and 0.7-1.8% for women with ductal carcinoma in situ and invasive carcinoma respectively (Boughey et al., 2016; Early Breast Cancer Trialists' Group, 2011; Gao, Fisher, & Emami, 2003; Mamtani & Morrow, 2017; Quan, Pommier,

& Pommier, 2008; Tuttle et al., 2009) Options for managing risk of a contralateral breast cancer include a schedule of screening and early detection measures such as breast imaging, chemoprevention with endocrine therapy agents, or contralateral prophylactic mastectomy. In recent years, a significant trend in choosing contralateral prophylactic mastectomy has been identified in women with ductal carcinoma in situ and invasive, unilateral, early stage breast cancer (Jones et al., 2009; Pesce, Liederbach, Czechura, Winchester, & Yao, 2014; Tuttle, Habermann, Grund, Morris, & Virnig, 2007; Tuttle et al., 2009). The use of contralateral prophylactic mastectomy is an aggressive approach from the perspective of the medical community, involving removal of a presumptively normal organ for reduction of a seemingly low risk and without sufficient evidence of a survival advantage.

1.2. Predictors of Surgical Choice

The breast cancer surgical decision-making process for a woman with early stage, unilateral breast cancer is complex. The decision involves consideration of potential benefits and harms with each option, as well as decisions about future surveillance and risk. Options vary in regard to outcome, procedure, extent of surgery and recommended follow-up. Decisions are preceded by recommendations from health care practitioners from both disease and cosmetic perspective, opinions of family and significant others, and personal choice including the influence of cognitive and affective factors. Ultimately, the decision becomes one of personal preference in a decision-making process which is poorly understood.

To date, most research into surgical decision making has been retrospective in nature, using demographic and clinic information collected in large databases to evaluate

predictors of surgical decision making. Factors such as age, ethnicity, and level of education are examples of analysed variables as are clinical features such as tumor size and receptor status. There is some evidence to suggest that distress, anxiety, uncertainty, quality of life or worry about recurrence may be associated with surgical preference (Goel, Sawka, Thiel, Gort, & O'Connor, 2001; Graves et al., 2007; Hawley et al., 2014; Pedersen, Sawatzky, & Hack, 2010). There is a prevalent assumption in the more recent medical literature suggesting women choosing mastectomy with CPM are not well-informed about true local recurrence risk, contralateral breast cancer risk and survival outcomes. Their surgical choice is described as an overestimation of risk and misunderstanding about any survival advantage from that choice (Moffat & Yakoub, 2016). The medical community is called upon to develop research initiatives, decision aids and supportive resources to assist women in this shared decision-making process (Burke, Portschy, & Tuttle, 2015; Rosenberg et al., 2013).

1.3. Decision-Making

Regarding medical decision-making in general, a theory-practice gap has been identified (Reyna, 2008). Decision aid and support interventions tested in practice are not consistently based in identified theory, including many of the interventions which have been the subject of randomized controlled trials (Durand, Stiel, Boivin, & Elwyn, 2008) . When applied, theoretical frameworks are often designed for normative decision-making and are primarily focused on the cognitive domain. The affective domain and individual characteristics in decision-making are often absent in theoretical frameworks in this subject area (Durand et al., 2008; Elwyn, Stiel, Durand, & Boivin, 2011; Pierce,

1993). Research in the field is needed in order to inform the development of support and counseling resources.

1.4. Summary of Subsequent Chapters

Chapter Two is a report on the psychometric properties of the Anxiety Subscale of the Depression Anxiety Stress Scale in women undergoing a diagnostic mammogram. It is a secondary analysis of existing data from a prospective study. Reliability and validity of the Depression Anxiety Stress Scale anxiety subscale was tested in 2672 women who had been recalled for false-positive mammograms. Internal consistency testing included Cronbach coefficient alpha and the split-half technique to determine reliability. Construct validity was assessed and factor analysis was conducted. The results of this analysis support the use of the DASS anxiety subscale as a reliable and valid measure of anxiety among women undergoing a diagnostic mammogram.

Chapter Three is a critical review of decisional conflict measures. The purpose of the analysis is to evaluate available decisional conflict scales for potential utilization at the time of surgical decision making among women with early stage breast cancer. Measurement of decisional conflict may promote the opportunity for high-quality surgical decision making. Decisional conflict scales may also be utilized for research with this population and in this setting. A review of the decisional conflict scale literature was undertaken. Two scales were identified: the Decisional Conflict Scale and the Sure of myself, Understand information, Risk-benefit ratio, Encouragement (SURE) screening test. Psychometric properties of each scale were researched and summarized. The 16 item Decisional Conflict Scale is the standard, most widely accepted and tested decisional conflict scale. The four item SURE scale is shorter and easier to use in a

clinical setting. This analysis supported the use of decisional conflict scales with women making surgical treatment decisions for breast cancer.

Chapter Four presents a prospective, exploratory, cross-sectional, mixed-methods study examining factors influencing preference for surgical choice among women with early stage breast cancer. Women were eligible to participate if they were newly diagnosed with unilateral, early stage breast cancer (defined as Stage 0, I or II) and if they were eligible to choose between the surgical options of breast conserving surgery or mastectomy with or without contralateral prophylactic mastectomy. Analysis was limited to those women who chose either breast conserving surgery or mastectomy with contralateral prophylactic mastectomy; women choosing unilateral mastectomy were excluded from analysis. A total of 78 women were included in this analysis, 47 in the breast conserving surgery group and 31 in the bilateral mastectomy group. Differences in demographic, diagnostic, clinical, cognitive and affective variables were tested between the groups. Information sources were assessed by participant self-report. This study demonstrated differences between the two groups. Women who chose mastectomy with contralateral prophylactic mastectomy were younger, more likely to work full or part-time, had larger tumors, participated in preoperative genetic counselling, had higher anxiety and breast cancer-specific distress. Women who chose breast conserving surgery had higher decisional conflict. Information sources were similar between the two groups but there were differences between the groups in the information source identified as the most influential.

CHAPTER TWO:

Psychometric Evaluation of the Anxiety Subscale of the Depression Anxiety Stress Scale (DASS) in Women Recalled for False-Positive Mammograms

2.1. Background

Among women in the United States, breast cancer is the most common cancer and the second leading cause of cancer-related mortality. Over 252,710 new cases of invasive breast cancers and 40,610 deaths due to breast cancer were expected in 2017 (Siegel et al., 2017). Breast cancer screening using mammography has significantly altered the diagnosis and prognosis of breast cancer, allowing for diagnosis in earlier stages when cancers are small and may be non-invasive (American Cancer Society, 2013; Smith, Duffy, & Tabar, 2012). The five year survival rate for these localized, early-stage breast cancers is 99%, as compared to a five year survival rate of 85% for regional, and 26% for metastatic disease (Siegel et al., 2017) .

Cancer screening examinations including mammography are conducted on a healthy population of at-risk individuals. As is the case with any screening activity, potential benefits of screening a well population must be balanced against any potential harms of the examination. Across all age groups, breast cancer screening with mammography exhibits 86.9% sensitivity and 88.9% specificity. Sensitivity is highest (88.5%) in older women with less dense breast tissue and lowest (73.4%) in women between the ages of 40 and 44 (Breast Cancer Surveillance Consortium). An abnormal screening exam results in follow-up or recall to a diagnostic phase consisting of additional and focused mammography imaging which may include ultrasound, biopsy and the use of other specific imaging technologies. In the United States, the average

recall rate from screening mammography is 9.6%, ranging from 16.3% in women under 40 to 6.9% in women over 80. The majority of women recalled for diagnostic mammograms will not have cancer, resulting in what is referred to as a false positive recall (Breast Cancer Surveillance Consortium). One of the potential harms of false positive recall is anxiety.

Heightened anxiety in women recalled for false positive mammograms has been reported. The prevalence and severity of anxiety varies and is difficult to predict. Research has been conducted using different measures and methods (Nelson et al., 2016). In women with heightened anxiety, when contrasted with their baseline status or compared to women who were not recalled from screening exams, short-term anxiety has been found to be increased, with declining anxiety levels after negative results were communicated (Brewer, Salz, & Lillie, 2007; Ekeberg, Skjauff, & Karesen, 2001; Nelson et al., 2016; Schou Bredal, Karesen, Skaane, Engelstad, & Ekeberg, 2013). Long-term anxiety may persist in some women for weeks, months and years after a false positive mammogram (Bolejko, Hagell, Wann-Hansson, & Zackrisson, 2015; Brett & Austoker, 2001; Brodersen & Siersma, 2013; Gotzsche & Jorgensen, 2013; Hafslund, Espehaug, & Nortvedt, 2012; Nelson et al., 2016). Recognition of subsets of women with elevated anxiety in this population is recognized. Possible rationale may include the existence of baseline or state anxiety as well as the combined effects of conditions such as depression, decreased quality of life and diminished sense of well-being. Some women undergo more imaging and procedures during this phase than others and anxiety levels may differ accordingly. In addition, interventions on the part of healthcare providers such as

communication, education, counselling and support may have an effect (Bolejko et al., 2015; Nelson et al., 2016).

Measurement of anxiety in this population is inconsistent in method. Single question items, visual analog/numeric rating scales and standardized anxiety scales and subscales such as the State Trait Anxiety Inventory, Consequences of Screening in Breast Cancer, Hospital Anxiety and Depression Scale, Impact of Events Scale, General Health Questionnaire, and the Psychosocial Consequences Questionnaire have been used to measure anxiety (Brett, Bankhead, Henderson, Watson, & Austoker, 2005; Brewer et al., 2007; Montgomery & McCrone, 2010; Nelson et al., 2016; Watson, Henderson, Brett, Bankhead, & Austoker, 2005). There is a wide variation in the timepoints at which anxiety has been assessed including the time of recall and in the days, weeks, months and years after a false-positive exam (Brett et al., 2005; Brewer et al., 2007; Brodersen & Siersma, 2013; Gotzsche & Jorgensen, 2013; Nelson et al., 2016).

Despite evidence of anxiety among women recalled for false positive mammograms, no consistent method or practice standard for measurement exists. A scale that is reliable and valid, concise and implementable in practice for use in this population could give caregivers a means to effectively diagnose anxiety. To date, use of the DASS anxiety subscale in this population has not been reported. The purpose of this study is to evaluate the psychometric properties of the DASS anxiety subscale in the assessment of anxiety in women recalled for false positive mammograms. The specific aims of this study were 1) to determine the reliability of the DASS anxiety subscale when used with women recalled for false-positive mammograms and 2) to evaluate construct and factorial validity of the DASS anxiety subscale. Internal consistency testing included

Cronbach coefficient alpha and the split-half technique to determine reliability. Construct validity was assessed using hypothesis testing. Factorial validity was examined through factor analysis. The hypothesis tested was that of a negative correlation between psychological well-being and anxiety (Winefield, Gill, Taylor, & Pikington, 2012).

2.2. Methods

2.2.1 Study design.

A secondary analysis of data from a descriptive, explanatory study examining the psychological well-being of women undergoing diagnostic mammograms was conducted. Subjects who were subsequently diagnosed with cancer were excluded from this analysis in order to limit the sample to women recalled for a false-positive mammogram.

2.2.2 Samples and setting.

The original study was conducted in a breast imaging department of a 391-bed Magnet®-designated hospital in the south eastern region of the United States. For all participants in the study, data were collected during the diagnostic mammogram visit in the healthcare setting and before results of the exam were known. Women were eligible to participate if they were age 18 or older, able to read, write and understand English, undergoing a diagnostic mammogram and if they provided consent to participate. Women who had a prior personal history of cancer or were unable to complete the questionnaires without assistance were excluded.

The convenience sample of women included 2973 total participants, 2928 of whom were healthy and 45 of whom were subsequently diagnosed with breast cancer. After removing those with breast cancer (n=45) and those with missing data, a total of

2672 women recalled for a false positive mammogram remained and were included in this analysis.

2.2.3 Procedure.

This study was approved by the study site's Institutional Review Board. Potential participants included all women undergoing diagnostic mammograms during the study period. A research assistant introduced the study and invited women to participate as they were waiting to be called for their diagnostic mammogram. Those who agreed to participate, met criteria for inclusion and completed informed consent were enrolled in the study. Women were provided a study packet of printed questionnaires to complete and return before leaving the breast imaging department. Completion of the study packet took approximately 20 minutes.

2.3. Variables and Measures

2.3.1 Demographics.

Demographic data were collected with a self-report questionnaire. Participants were asked to report variables including age, race/ethnicity, marital status, level of education, employment status, income level, primary wage earner status (yes/no), religious affiliation and family history of cancer (yes/no/adopted).

2.3.2 Anxiety Subscale of the Depression Anxiety Stress Scale.

Anxiety was assessed using the Depression Anxiety Stress Scale (DASS). The DASS consists of 42 items. Respondents are asked to identify and answer on a four-point scale ranging from 0 (did not apply to me at all) to 3 (applied to me very much or most of the time). Participants are asked to include experiences from the preceding week when responding. Fourteen items of the DASS pertain to depression, 14 to anxiety and 14 to

stress and items for each of these three subscales are interspersed among the other subscale items. Higher scores represent higher depression, anxiety and stress on the representative subscale.

Prior studies with the DASS have established good reliability and validity in both clinical and non-clinical populations. Cronbach alpha in these studies for the overall DASS have ranged from 0.84-0.897 (Crawford & Henry, 2003; Lovibond & Lovibond, 1995). Cronbach alpha for the DASS anxiety subscale likewise indicates good reliability, ranging from 0.897- 0.92 (Antony, 1998; Brown, Chorpita, Korotitsch, & Barlow, 1997; Crawford & Henry, 2003; Cunningham, Brown, Brooks, & Page, 2013; Nieuwenhuijsen, de Boer, Verbeek, Blonk, & van Dijk, 2003). Validity of the DASS anxiety subscale has been assessed using several methods. In a sample of over 700 psychology students, concurrent validity was measured against the Beck Anxiety Inventory. The two scales were highly correlated ($r = 0.81$) (Lovibond & Lovibond, 1995). Convergent validity between the anxiety subscale of the DASS and the anxiety subscale of the Hospital Anxiety and Depression Scale and the Personal Disturbance Scale, Beck Anxiety Inventory and the State Trait Anxiety Inventory were significantly correlated across studies with correlations ranging from $r = 0.67 - 0.84$. These findings indicate that the DASS anxiety subscale conceptually measures anxiety similarly to other established measures (Antony, 1998; Crawford & Henry, 2003; Nieuwenhuijsen et al., 2003). Confirmatory factor analysis of the three subscales of the overall DASS has been replicated with both community and clinical samples. No previous use of the DASS anxiety subscale in women recalled for false-positive mammograms was found.

2.3.3 Ryff Scale of Psychological Well-Being.

Psychological well-being was assessed using the Ryff Scale of Psychological Well-Being (SPWB). Six dimensions of psychological well-being are measured with separate subscales and include: autonomy, purpose in life, positive relations with others, personal growth, environmental mastery, and self-acceptance. The total scale includes 84 items. Each subscale consists of 14 items to which participants are asked to rate responses on a six-point Likert scale ranging from (1) strongly disagree to (6) strongly agree. Higher scores indicate higher well-being. Internal consistency coefficients for the subscales have tested between .86 and .93. Test retest of all subscales are in the range of .81 - .88 (C. D. Ryff & Keyes, 1995; C.D. Ryff, 1989). The Ryff SPWB was used for validity hypothesis testing in this analysis.

2.4. Methods for Testing Psychometric Properties of the DASS Anxiety Subscale

All data analysis was performed using IBM® SPSS® Statistics (version 21). The level of significance was set at a p value of .05 or less. Descriptive statistics including means, standard deviations and frequency percentages were used to characterize the sample demographics.

2.4.1 Reliability.

Cronbach coefficient alpha, a measure of internal consistency among anxiety subscale items, was used to determine reliability. A Cronbach coefficient alpha greater than .70 was considered acceptable. Inter-item correlations and item-total correlations were used to test the characteristics of the anxiety subscale items and to test their relationship to each other. Inter-item correlations between .20 and .80 were considered acceptable. Reliability was also tested using the split-half technique, which yields a

Spearman-Brown coefficient greater than .70. A coefficient greater than 0.70 was considered acceptable.

2.4.2 Construct and Factorial Validity.

Construct and factorial validity were assessed using hypothesis testing and factor analysis. The hypothesis tested was that of a negative correlation between psychological well-being and anxiety. To measure the strength of the hypothesized relationship between anxiety and SPWB, scores were analyzed using the Pearson product-moment correlation.

Confirmatory factor analysis of the DASS anxiety subscale was conducted. Suitability for factor analysis was confirmed by evaluating the basic requirements of a minimum number of at least three response options, minimum sample size (at least 100), and ten cases per item. Bartlett's test of sphericity was used to evaluate the correlation matrix. Matrix sample adequacy was evaluated using the Keiser-Meyer-Olkin (KMO) test. KMO criterion values greater than .60 were considered adequate. Principal component analysis extraction with varimax rotation was performed; eigenvalues of greater than one were retained and a scree test was used to plot the eigenvalues of the factors. Loadings greater than .40 were used to identify items associated with a factor. Crossloaded factors were defined as those loading similarly on more than one factor with a difference of less than .20.

2.5. Results

2.5.1 Sample Characteristics.

Table 2.1 shows the characteristics of the women recalled for a false positive mammogram (n = 2672). All demographic variables were self-reported and in some

cases, were self-defined. For example the question asking about main wage earner status asked “are you the main wage earner in your household?” and participants answered “yes” or “no”. The sample was predominately Caucasian (92%), married/partnered (71%), had completed college or graduate school (70%), was employed full- or part-time (66%) and the majority reported an income level greater than $40,000 per year (72%). Most participants did not identify themselves as the primary wage earner (62%). Over 90% identified themselves as having a religious affiliation and 69% had a family history of cancer (< 1% were adopted or did not know). The mean age of women in this sample was 50 (± 11).

The mean anxiety score was 4.3 (± 6, range 0-42) which is consistent with mean normative DASS anxiety scores for women (Lovibond & Lovibond, 1995; Nieuwenhuijsen et al., 2003). The median anxiety score was two. Anxiety scores ranged from zero to forty-two. Six hundred fifteen women had an anxiety score of zero accounting for 23% of the sample. Two women had a score of 42 (Table 2.2).

2.5.2 Reliability.

Cronbach alpha for the DASS anxiety subscale was .895, indicating good internal consistency among the items. The overall mean for the anxiety subscale item correlations in this sample was .396, indicating good interrelatedness among the items. Table 2.3 displays inter-item correlations, item-total correlations, means and standard deviations. Inter-item correlations ranged from .217 - .633 indicating good correlations of each item with the total score. Item specific means ranged from a low of .146 ± .447 to a high of .634 ± .894. The standard deviation is higher than the mean for all items which is indicative of the low overall anxiety scores in this sample.

Deletion of any one item from the anxiety subscale would maintain the Cronbach alpha between .88 - .90, therefore no indication of poor items in this subscale was found (Table 2.4). The Spearman-Brown Coefficient for split-half reliability testing was acceptable at .891

2.5.3 Construct Validity.

2.5.3.1 Hypothesis Testing.

To test the hypothesis of a negative correlation between DASS anxiety subscale scores and SPWB scores, the Pearson product-moment correlation was calculated. A significant negative correlation was found between anxiety and psychological well-being ($r = -.496$, $p < .01$), resulting in a rejection of the null hypothesis.

2.5.3.2 Principal Component Analysis.

The 14 item DASS anxiety subscale was assessed with principal component analysis (PCA). Before analysis, the suitability of the DASS anxiety subscale for PCA was assessed. The subscale met the requirements for number of response criteria. Requirements for sample size and number of cases per item were also met. Bartlett's test of sphericity was significant ($p < .01$) therefore the null hypothesis that the correlation matrix is an identity matrix is rejected. The matrix sample adequacy is considered adequate (KMO = .946) and the determination of the correlation matrix was adequate (.004).

The minimum number of factors represented in the subscale was evaluated. Two factors were retained and rotated using varimax rotation (Table 2.5) based on eigenvalues greater than one, scree plot and explanation of total variance. The two factors split between emotional/psychological manifestations of anxiety and physical manifestations

of anxiety. Those items in the emotional/psychological dimension included words such as panic, terror, feeling scared, fear and anxiety. Those items in the physical dimension included DASS items referring to breathing difficulty, dry mouth, faintness, shakiness, difficulty swallowing, heart rate or rhythm and perspiration. DASS item 41 "I found it difficult to work up the initiative to do things" met criteria for retention and crossloading (.509 for the first factor and .560 for the second factor). The item was retained to the factor with the highest loading. A cutpoint of .40 was used to define factor loading.

2.6. Discussion

Reliability and validity of the DASS anxiety subscale in women undergoing false positive recalls is supported by this analysis. Measures of internal consistency and correlation of items within the subscale confirmed reliability in this sample. Construct validity was supported with hypothesis testing. Factor analysis provided support for two factors. The first factor includes six items which measure emotional/psychological dimensions of anxiety such as panic, terror and fear. The second factor includes eight items that measure action and physical symptoms of anxiety such as sweating, rapid or irregular heart rate and dry mouth. One item met crossloading criteria (i.e. loading similarly on more than one factor with a difference of less than .20) but fell more closely within the second factor items in the physical dimension and was retained to that factor.

Although anxiety has been previously reported to be a negative effect of false positive mammograms, the mean anxiety score of 4.3 for this sample falls within the normal range. In this study, however, 23% of women had an anxiety score of zero. Five percent reported anxiety levels over 15. Levels over 15 are considered high levels of anxiety as measured by the DASS (Lovibond & Lovibond, 1995). This finding is

consistent with previous reports in which a subset of women exhibit heightened anxiety in this setting (Gotzsche & Jorgensen, 2013). It is possible that this subset of women exhibited baseline heightened anxiety or trait anxiety. In this secondary analysis, however, examination is limited to the data collected and examination of those considerations is not possible. It is also possible that this sample is not representative of the population. It was a convenience sample and subjects volunteered to be part of the study. It is possible that the sample is biased toward women with lower anxiety who volunteered to participate and absent those with heightened anxiety who refused to participate.

In the original study, completion of the entire packet of questionnaires took less than 20 minutes. The complete DASS was just one part of that packet. From a feasibility perspective, use of the DASS anxiety subscale to assess anxiety would be possible in a clinical setting. It would not take much time to complete and as demonstrated by the original study, is easy to distribute as women wait for their diagnostic mammograms. The subscale is concise, consisting of only 14 items. Currently, no consistent method or practice standard for measurement of anxiety in this population of women exists but implementation of an assessment tool could improve anxiety diagnosis, intervention and overall quality of care in this setting.

2.7. Limitations

Secondary data analyses are limited to analyzing data on the variables that were examined. For example, another measure of anxiety, even breast screening –specific anxiety, may have provided meaningful information Variables were self-reported and may be subject to bias. The sample was homogenous in terms of income, education and

marital status. A sample drawn from a more heterogeneous population might have produced different results. This positive skew may be reflective of the lack of volunteers among women with heightened anxiety in this setting.

2.8. Conclusions

The DASS anxiety subscale showed good reliability in women recalled for false positive mammograms and validity was supported by both hypothesis testing and factor analysis. A 14-item subscale is concise and feasible for use in a clinical setting. The potential benefits of breast cancer screening with mammography are evident in the increased survival and shift toward early stage diagnosis. Potential harms, including anxiety, still need to be addressed. Informed consent should ideally include accurate information about potential benefits and harms of screening but until anxiety is consistently measured and until the subsets of women with heightened anxiety are more fully described, full disclosure of this potential harm is not possible. Consistent use of the DASS anxiety subscale in this setting is encouraged as is the replication of reliability and validity testing with its use in women recalled for false positive mammograms.

2.9. Acknowledgements

The original study from which the data were obtained for this secondary analysis was funded by a University of Kentucky College of Nursing Faculty Research Support Grant in 2009.

Table 2.1

Characteristics of Women Recalled for False-Positive Mammograms

Demographic	Total Sample (n = 2672)
Age (years), mean (± SD)	50 ± 11
Race/Ethnicity	
Caucasian	2459 (92)
Non-Caucasian	213 (8)
Marital Status	
Married/Partnered	1891 (71)
Divorced/Separated/Single/ Widowed	781 (29)
Education	
Elementary/High School	800 (30)
College/Graduate School	1872 (70)
Employment	
Full- or Part-Time	1763 (66)
Other	909 (34)
Income	
<20,000	252 (9)
20,001 to 40,000	473 (18)
40,001 to 80, 000	893 (33)
>80,000	1054 (39)
Primary Wage Earner	
Yes	1011 (38)
No	1661 (62)
Religious Affiliation	
None	251 (9)
Catholic/Protestant/Jewish/Muslim/Other	2421 (91)
Family History of Cancer	
Yes	1833 (69)
No	820 (30)
Adopted	19 (1)

Table 2.2

DASS Anxiety Subscale Scores

	Total Sample (n = 2672)
Mean (± SD)	4.3 ± 6
Median	2
Range	0 – 42

Table 2.3

DASS Anxiety Subscale Inter-item Correlations, Item-Total Correlations, Means and Standard Deviations

	Item Correlations																
	DASS 2	**DASS 4**	**DASS 7**	**DASS 9**	**DASS 15**	**DASS 19**	**DASS 20**	**DASS 23**	**DASS 25**	**DASS 28**	**DASS 30**	**DASS 36**	**DASS 40**	**DASS 41**	**Item-Total Correlation**	**Mean**	**SD**
DASS 2	1.000														.399	.634	.894
DASS 4	.306	1.000													.574	.315	.680
DASS 7	.298	.457	1.000												.650	.270	.626
DASS 9	.303	.379	.449	1.000											.629	.594	.827
DASS 15	.276	.395	.501	.362	1.000										.566	.146	.447
DASS 19	.259	.312	.384	.347	.327	1.000									.501	.298	.685
DASS 20	.217	.346	.433	.424	.376	.367	1.000								.625	.256	.592
DASS 23	.302	.393	.387	.332	.371	.265	.338	1.000							.508	.148	.462
DASS 25	.265	.464	.413	.384	.390	.336	.400	.326	1.000						.572	.384	.708
DASS 28	.286	.464	.504	.571	.456	.395	.591	.379	.478	1.000					.752	.273	.656
DASS 30	.217	.323	.322	.457	.306	.289	.451	.306	.336	.483	1.000				.556	.279	.623
DASS 36	.220	.349	.442	.424	.370	.334	.568	.319	.366	.633	.426	1.000			.633	.202	.572
DASS 40	.267	.359	.440	.530	.341	.386	.493	.338	.386	.613	.536	.543	1.000		.671	.282	.637
DASS 41	.313	.440	.610	.452	.468	.378	.439	.383	.433	.575	.385	.509	.520	1.000	.685	.224	.599

DASS Subscale Items: DASS 2 "I was aware of dryness of my mouth," **DASS 4** "I experienced breathing difficulty (eg. excessively rapid breathing, breathlessness in the absence of physical exertion," **DASS 7** "I had a feeling of shakiness (eg, legs going to give way," **DASS 9** "I found myself in situations that made me so anxious I was almost relieved when they ended," **DASS 15** "I had a feeling of faintness," **DASS 19** "I perspired noticeably (eg hands sweaty) in the absence of high temperatures or physical exertion," **DASS 2**0 "I felt scared without any good reason," **DASS 23** "I had difficulty swallowing," **DASS 25** "I was aware of the action of my heart in the absence of physical exertion (eg sense of heart rate increase, heart missing a beat)," **DASS 28** I felt I was close to panic," **DASS 30** "I feared that I would be 'thrown' by some trivial but unfamiliar task," **DASS 36:** "I fell terrified," **DASS40** "I was worried about situations in which I might panic and make a fool of myself," **DASS 41**" I found it difficult to work up the initiative to do things"

Table 2.4

DASS Anxiety Subscale: Cronbach Alpha by Deleted Items

DASS Anxiety Subscale Item	**Cronbach alpha if Item Deleted**
DASS2 I was aware of dryness of my mouth	.900
DASS4 I experienced breathing difficulty (eg excessively rapid breathing, breathlessness in the absence of physical exertion)	.888
DASS7 I had a feeling of shakiness (eg legs going to give way)	.885
DASS9 I found myself in situations that made me so anxious I was almost relieved when they ended	.886
DASS15 I had a feeling of faintness	.890
DASS19 I perspired noticeably (eg hands sweaty) in the absence of high temperatures or physical exertion	.891
DASS20 I felt scared without any good reason	.886
DASS23 I had difficulty swallowing	.891
DASS25 I was aware of the action of my heart in the absence of physical exertion (eg sense of heart rate increase, heart missing a beat)	.888
DASS28 I felt I was close to panic	.880
DASS30 I feared that I would be “thrown” by some trivial but unfamiliar task	.889
DASS36 I feel terrified	.886
DASS40 I was worried about situations in which I might panic and make a fool of myself	.884
DASS41 I found it difficult to work up the initiative to do things	.884

Table 2.5

Factor Analysis with Varimax Rotation of the DASS Anxiety Subscale (n = 2672)

Item	Factors	
DASS 40 I was worried about situations in which I might panic and make a fool of myself	.766	.247
DASS 36 I feel terrified	.751	.227
DASS 28 I felt I was close to panic	.747	.385
DASS 20 I felt scared without any good reason	.720	.245
DASS 30 I feared that I would be “thrown” by some trivial but unfamiliar task	.706	.151
DASS 9 I found myself in situations that made me so anxious I was almost relieved when they ended	.608	.362
DASS 4 I experienced breathing difficulty (eg excessively rapid breathing, breathlessness in the absence of physical exertion)	.255	.675
DASS 2 I was aware of dryness of my mouth		.644
DASS 15 I had a feeling of faintness	.282	.639
DASS 7 I had a feeling of shakiness (eg legs going to give way)	.395	.639
DASS 23 I had difficulty swallowing	.215	.618
DASS 41 I found it difficult to work up the initiative to do things	.509	.560
DASS 25 I was aware of the action of my heart in the absence of physical exertion (eg sense of heart rate increase, heart missing a beat)	.364	.555
DASS 19 I perspired noticeably (eg hands sweaty) in the absence of high temperatures or physical exertion	.380	.427

CHAPTER THREE:

Critical Review of Decisional Conflict Scales for Use during Breast Cancer Surgical Decision Making

3.1. Introduction

Decisional conflict is defined as a perceived state of uncertainty about a course of action (Legare et al., 2010; Annette M. O'Connor, 1995). It is more likely to occur when making choices that are serious, affect potential gains and losses, involve risk, require value trade-offs in the decision, and when regret, from either the choice taken or the choice rejected, and is a possibility (Koedoot et al., 2001; A.M. O'Connor, 1993). The surgery decision making process among women with early-stage breast cancer has the potential for decisional conflict.

Decisional conflict is an indication of level of comfort with a decision (Annette M. O'Connor, 1995). Among women with early-stage breast cancer, surgical decisions are complex in and of themselves, but other factors may contribute to the complexity. The time from diagnosis to surgical consultation is short, often spanning only a few days resulting in a situation in which decisions are made quickly, possibly without sufficient consideration. Consultation time with providers can be limited. In addition, health literacy among women making these decisions may vary widely. Choices among decisions may carry significant risk and hidden meaning. In this setting, measurement of decisional conflict may facilitate communication between patients and healthcare providers about the level of comfort with the surgical decision (Kokufu, 2012). Opportunities for improvements in the decision making process may become apparent if decisional conflict is known (Legare et al., 2003).

Measurement of decisional conflict may also provide a method for evaluation of interventions in this setting. For example, research on the effect of decision aids, education or counseling sessions have included decisional conflict scales to evaluate the effect of the intervention (Kryworuchko, Stacey, Bennett, & Graham, 2008; Obeidat, Finnell, & Lally, 2011). The purpose of this critical review and analysis is to examine decisional conflict measurement in order to evaluate utilization of those scales during the time of surgical decision making among women with early-stage breast cancer from both a research and clinical perspective.

3.2. Breast Cancer and Surgical Decisions

Breast cancer is the most commonly diagnosed cancer and the second leading cause of cancer-related mortality among women in the United States. Over 252,710 new cases of breast cancer and 40,610 deaths due to breast cancer are expected to occur in 2017 (Siegel et al., 2017). At time of presentation, the majority of breast cancers are unilateral and localized. They are described as early-stage disease including Stage I, Stage II and the non-invasive Stage 0 tumors (Siegel et al., 2017). For women with unilateral, early-stage breast cancer, surgical treatment options for the affected breast include either breast-conserving surgery (BCS) or mastectomy. Some women choose mastectomy with contralateral prophylactic mastectomy. Surgical choice in early-stage breast cancer is described as a preference-based decision that is not well understood (Mamtani & Morrow, 2017).

Choosing among surgical options is a shared decision making process involving recommendations from health care providers from both a disease and cosmetic perspective. Opinions of family and significant others as well as personal choice

regarding the procedure are involved. Option-specific considerations of time, travel, comfort and desired outcome may also be included. The potential for decisional conflict is evident in this situation involving high-stakes choices which may impact risk of recurrence and chance of survival. Potential loss or significant physical alterations of one or both breasts, trade-offs in terms of quality of life and functioning due to treatment and future surveillance, and potential future regret for any of the choices which are made are also involved.

3.3. Decisional Conflict and Measurement

The identification of conflict as a component of decision making was described in the 1970's in the conflict-theory model of decision making (Janis & Mann, 1976). In this model, stress is recognized as a component of decision making, an influence on the coping pattern exhibited throughout the decision making process and ultimately as an alterant of the perceived quality of the decision. Stress from conflict may contribute to failure in achieving high-quality decisions (Mann, Burnett, Radford, & Ford, 1997). High quality decisions are thought to increase adherence and limit post decisional regret (Balneaves & Long, 1999). More recent research into decision making reported decisions as a review of a "personal balance account… [which] comprises the physical and emotional gains patients hope to get minus the risks and other negative aspects."(Noone, 2002) It is the choice between options that underlie conflict and stress. In the early 1990's, O'Connor developed the Decisional Conflict Scale (DCS) to measure personal perceptions of uncertainty in the decision, factors that add to perceptions of uncertainty which are potentially modified (such as feeling unsupported in the decision) and the effectiveness of the decision (A.M. O'Connor, 1993).

Psychometric properties of the DCS were published in 1995 (Annette M. O'Connor, 1995). Subsequently, an adapted and shorter decisional conflict scale known as the Sure of myself, Understand information, Risk-benefit ratio, Encouragement (SURE) screening test was derived from the DCS (Legare et al., 2010). The DCS and SURE were chosen for review and analysis. Characteristics of the scales are outlined in Table 3.1.

3.4. Analysis of Decisional Conflict Measures

3.4.1 Decisional Conflict Scale.

The original DCS consists of 16 total items in statement format. Responses are made using a five point Likert scale ranging from 0 (strongly agree) to 4 (strongly disagree). Total scores are summed, divided by 16 and then multiplied by 25, resulting in a decisional conflict score ranging from 0 to 100. Low scores represent low decisional conflict and high scores represent high decisional conflict. Scores above 37.5 are associated with feeling unsure about the decision and with decisional delay (Annette M. O'Connor, 1995). The DCS is formatted at an 8^{th} grade reading level and takes 10 – 20 minutes to complete (Legare et al., 2010; A.M. O'Connor, 1993; Annette M. O'Connor, 1995).

The 16-item DCS is made up of the following five subscales: uncertainty, informed, values clarity, support, and effective decision. Three items constitute each subscale except for the effective decision subscale which includes four items. The effective decision subscale is intended for use only after a decision has been made. Other subscales may be used in the process of decision making and/or after a decision has been made. High subscale scores represent high decisional conflict in that specific area. No specific

score is identified as indicative of high verses low decisional conflict within a subscale (A.M. O'Connor, 1993).

A summary of DCS and subscale reliability and validity is provided in Table 3.2. Various formats, translations and modifications of formats have been tested and reported. Coefficient alpha for the total DCS has been acceptable ($\alpha > 0.70$ in all reports) (Katapodi, Munro, Pierce, & Williams, 2011; Linder et al., 2011; Mancini, Santin, Chabal, & Julian-Reynier, 2006; A.M. O'Connor, 1993; Annette M. O'Connor, 1995). Psychometric testing of DCS English and French versions, when the scale was post-exploratory, reported coefficient alphas > 0.90 which may suggest item redundancy. In both reports, factor analysis resulted in an alternate factor model (Katapodi et al., 2011; Mancini et al., 2006). Lam, et al. (2012), tested a Chinese version of the DCS and found two cross-loading items, one from the uncertainty subscale "Are you clear about the best choice for you?" and one from the effective decision subscale, 'Do you feel you have made an informed choice?" Both were removed. The coefficient alpha tested on the 14-item scale = 0.81.

Subscale reliability testing is difficult to summarize owing to the modifications made to subscales across reports (see Table 3.2). The original three subscales are reported by O'Connor (1995) and Koedoot (2001). Modified subscales are reported by Katapodi (2011) and Lam (2012). The current five subscales for the 16-item DCS are reported by Mancini (2006). Linder (2011) tested the 10-item DCS and reported the standard four subscales of informed, values clarity, support and uncertainty (Linder et al., 2011). The support subscale resulted in coefficient alpha <0.70 in three reports, two of which tested

the standard DCS subscales (Linder et al., 2011; Mancini et al., 2006) and one which tested a modified support subscale (Lam et al., 2012).

Tests of validity have included the known-groups approach in which groups within samples were compared based on whether a decision had been made or not. Hypotheses testing was also reported (Table 3.2). In each test of validity, the DCS performed well. Factor analysis has been conducted without confirmation of the current scale's five-factor model. Mancini (2006) and Koedoot (2001) report a four-factor model, Katapodi (2011) and Lam (2012) report a three-factor model. Regarding the low-literacy, 10-item version of the DCS, a four-factor model was confirmed (Linder et al., 2011).

The groups chosen for reliability and validity testing were dissimilar as was the gravity of the decision being made. The samples included healthy populations of students and healthcare workers considering influenza vaccination and healthy women considering breast cancer screening as well as women newly diagnosed with breast cancer considering treatment and those with metastatic cancer considering palliative chemotherapy. Context of decision-making may warrant consideration in evaluating DCS and subscales psychometrics as noted by Mancini (2006) with low level of conflict making it more difficult to distinguish between factors when tested (Mancini et al., 2006). English, French, Dutch and Chinese versions of the DCS were tested with the French, Dutch and Chinese versions translated for testing. It is possible for translations to account for some differences in psychometric testing. The "wording" of items is specifically noted as a potential for differences in factorial validity in the Dutch translation (Koedoot et al., 2001).

3.4.2 SURE Screening Test.

The Sure of myself, Understand information, Risk-benefit ratio, Encouragement (SURE) screening test was developed to be a shorter, less time intensive decisional conflict measure as compared to the DCS. In developing a more concise measure, the investigators hoped to provide a measure that would be clinically useful in health care settings, especially as an efficient screening tool for decisional conflict (Legare et al., 2010). The scale is based on the DCS and the core concepts of the Ottawa Decision Support Framework including: feeling uncertain, feeling informed, feeling clear about values and feeling supported in decision making (Legare et al., 2010; Legare, O'Connor, Graham, Wells, & Tremblay, 2006). SURE scales were developed concurrently in both French and English and were framed in such a way as to form the acronym SURE in both languages. The SURE scale is a 4-item test in which all statements are positively worded. Respondents answers “yes,” or “no” to each item. A score of 1 is assigned to “yes” answers and a score of 0 is assigned to “no” answers. Scores are summed and range from 0 (high decisional conflict) to 4 (no decisional conflict). A score of ≤ 3 is indicative of decisional conflict (Ferron Parayre, Labrecque, Rousseau, Turcotte, & Légaré, 2014; A.M. O'Connor, 1993).

Results of reliability and validity testing for the SURE test were first published in 2010. The measure was tested in two groups of patients actively involved in making a healthcare decision. The first group was made up of 123 French speaking, pregnant women who were in the process of making decisions about participation in prenatal Downs Syndrome screening. The second group was made up of 1474 English speaking patients facing various health care decisions for chronic conditions and cancers. Fifteen

percent of the French speaking, and 33% of the English speaking sample, had scores indicative of decisional conflict (i.e. ≤ 3) (Legare et al., 2010).

Reliability of the SURE test may be described as moderate with Cronbach alpha of 0.54 in the French-speaking pregnant women and 0.65 in the English-speaking patients. Removing the Encouragement item (Do you have enough support and advice to make the choice?), resulted in an increased Cronbach alpha to 0.61 in the French-speaking pregnant women group. Item-to-total Pearson correlation coefficients ranged from 0.32 to 0.59 with the exception of the Encouragement item which showed a very minimal positive correlation of 0.07. Item-to-item correlations were positive, ranging from 0.46 to 0.71 with the exception of the Encouragement item which was negatively correlated with both the Knowledge and Value items (Legare et al., 2010).

Several tests of SURE validity were completed. Before testing began, content validity of the SURE test was "field-tested" by what Legare et al (2010) describe as experts and graduate students taking courses in decisional support. Unfortunately, no discussion of how the experts were recruited or exclusion/inclusion criteria was provided. Convergent validity was assessed in the group of 123 women who completed both the DCS and SURE. SURE scores were negatively correlated with the DCS score (Pearson $r = -0.46$, $p < 0.0001$). The hypothesis that the SURE test scores would discriminate between patients who had made a decision and those who had not was tested. Patients who had not made decisions about treatment had significantly lower scores than those who had made a decision ($p < .0001$). A factor analysis in the scores from the group of pregnant women was conducted, finding two factors accounting for 72% of the variance. All items except

the Encouragement item loaded under one factor (Legare et al., 2010). Overall, the SURE test was acceptably valid and moderately reliable in the initial validation work.

A secondary data analysis of psychometric properties of the SURE test was published in 2013. Six hundred fifty four primary care patients who participated in a randomized trial assessing an intervention on shared decision making completed both the DCS and SURE test. DCS and SURE scores were significantly correlated (Spearman's $p = -0.45$, $p < 0.0001$) (Ferron Parayre et al., 2014).

3.5. Strengths and Limitations

A particular strength of decisional conflict scales can be found in the theoretical and empirical background of the construct. The construct of decisional conflict is well developed and researched and has been an accepted nursing diagnosis for over two decades. The behavioural and minor manifestations of decisional conflict are identified as consequences and interventions (A.M. O'Connor, 1993). According to O'Connor (1995), the conceptual framework for the construct of decisional conflict served as the basis for DCS development (Annette M. O'Connor, 1995). The SURE test was based on the DCS and developed from the Ottawa Decision Support Framework of which decisional conflict is a part (Legare et al., 2010).

The DCS scales are reported as feasible and understandable. The scale with the greatest numbers of items is the DCS (16 items) and may take 10 – 20 minutes to complete. The SURE test has only 4 items and is a clinical-use version of the DCS.

Testing of the scales indicates moderate to acceptable reliability with some exceptions for subscale items. Overall, subscale and total DCS reliability testing showed acceptable internal consistency. Moderate reliability was found with the SURE test

(Cronbach alpha of 0.54 - 0.65 in two groups). Reliability was increased with the removal of one item. In the current SURE test, all four items continue to be included (A.M. O'Connor, 1993). More testing with larger samples in various populations has been encouraged by the investigators (Legare et al., 2010). Factor analysis should be addressed in future studies (Legare et al., 2010).

A limitation consistent to decisional conflict scales is the lack of discussion regarding scale development; O'Connor (1995) describes item and subscale development to be based on the construct of decisional support. Unfortunately, very little information is provided about the development, testing and revision of items, subscales and total scale (Annette M. O'Connor, 1995). The actual development of the particular items is not described in detail. Cut-off scores or scores of significance are also not well described in the literature. A score of 37.5 is reported to have meaning for the DCS scale yet an associated reference is not provided (A.M. O'Connor, 1993).

3.6. Recommendations for New Directions in Measurement of Decisional Conflict

In regard to the psychometric properties of the decisional conflict scales reviewed and analyzed in this manuscript, some questions remain. For the 16-item DCS, a three-, four-, and five-dimension structure has been reported in different populations and with different translations of the instrument. The support subscale in particular, shows variation in reliability and factor analyses. Perhaps the targeted population for testing is an important factor. For example, decisional conflict may be present in higher levels or may be related to different aspects of the construct and therefore exhibit different dimensions, depending on the nature of the population, decision being made, or the wording used for the instrument. It seems probable that decisional conflict exhibited by someone making a

decision about immunization could be different from decisional conflict exhibited by someone facing a life-threatening illness and surgery. Future research should be focused on the nature of decisional conflict in different populations and the meaning and usefulness of all subscales across all populations.

In the population of women with early-stage breast cancer making surgical decisions, decisional conflict should be a focus of further study. Several retrospective reviews have investigated patient and practitioner predictors of surgical decision making. To date, very few prospective studies of the decision-making process have been completed. Most research in this setting which includes measurement of decisional conflict is focused on the use of decision aids or interventions. The differences in decisional conflict scores are assessed pre- and post-intervention but baseline information about decisional conflict in this setting is not well-described.

3.7. Conclusion

Women with early stage breast cancer may move quickly from being part of the "healthy" population completing cancer screening or follow-up to becoming a person diagnosed with cancer. Surgical decisions occur rapidly and decisional conflict may affect the decisions which are made and may affect the quality of those decisions. Decisional conflict measurement may also be useful for interventional research in this setting and may promote the opportunity for high-quality surgical decision making among women with early stage breast cancer.

Table 3.1

Characteristics of Decisional Conflict Scales

	Decisional Conflict Scale			**SURE**
Format	Statement	Question	Question Low Literacy Version	Question
Total Number of Items	16	16	10	4
Responses	Strongly Agree = 0 Agree = 1 Neither Agree nor Disagree = 2 Disagree = 3 Strongly Disagree = 4	Yes = 0 Probably Yes = 1 Unsure = 2 Probably No = 3 No = 4	Yes = 0 Unsure = 2 No = 1	Yes = 1 No = 0
Scoring	Scores are summed, divided by 16 and multiplied by 25. Range from 0 to 100	Scores are summed, divided by 16 and multiplied by 25. Range from 0 to 100	Scores are summed, divided by 10 and multiplied by 25. Range from 0 to 100	Can only be calculated if all are answered Scores are summed Range from 0 to 4
Score Interpretation	Scores >37.5 indicate high Decisional Conflict			Scores ≤ 3 indicate high Decisional Conflict
Sample Items	“I feel sure about what to choose”	“Do you feel sure about what to choose?”	“Do you feel sure about what to choose?”	“Do you feel SURE about the best choice for you?”

Based on information from: (Legare et al., 2010; A.M. O'Connor, 1993; Annette M. O'Connor, 1995)

Table 3.2

Summary of Reliability and Validity of the Decisional Conflict Scale (DCS)

First Author (Year)	DCS Format	Sample	Reliability	Validity and Factor Analysis
O'Connor (1995)(Annette M. O'Connor, 1995)	Statement Format 16-Items 3 Subscales	Health science students considering influenza vaccinations (n=45) Healthcare employees considering influenza vaccinations (n=115) Patients with cardiac and respiratory problems considering influenza vaccinations (n=283) Women ages 50-69 considering breast cancer screening (n=360)	Total Scale: • Test-Retest correlation coefficient (tested in health science students) = 0.81 • Cronbach alpha ranged from 0.78—0.92 (tested in all groups) Subscale Cronbach alpha: • Uncertainty = 0.73-0.92 (tested in all groups) • Effective decision making = 0.77-0.86 (tested in all groups) • Factors contributing = 0.58 (cardiac/respiratory patients) and 0.70 (women considering breast screening)	Known groups approach tested in group of health science students showed statistically significant difference ($p < 0.001$) Hypothesis testing conducted in the breast cancer screening group, DCS scores were inversely correlated to knowledge tests about breast cancer (Pearson $r = -0.16$, $p<0.05$)
Koedoot (2006) (Koedoot et al., 2001)	Statement Format 16-Items 3 Subscales	Women with metastatic cancer considering palliative chemotherapy (n=29) Women with early-stage breast cancer choosing between mastectomy or lumpectomy (n =	Total Scale not reported Subscale Cronbach alpha (both groups): • Uncertainty = 0.61 (metastatic cancer group) and 0.75 (early-stage breast cancer group) • Effective decision making = 0.83 (metastatic cancer	Known groups approach showed statistically significant difference in the metastatic cancer group for all three subscales and showed significant differences for the uncertainty ($p <0.001$) and factors contributing ($p <0.001$) subscale among women with early-stage breast cancer

Table 3.2 (Continued)

		141)	group) and 0.81 (early-stage breast cancer group) • Factors contributing = 0.77 (metastatic cancer group) and 0.83 (early-stage breast cancer group)	Factor analysis resulted in a 4-factor model explaining 67.5% of the variance
Katapodi (2011)	Statement Format 16-Items 3 Subscales	Women with cancer participating in hereditary breast and ovarian genetic testing (n = 200)	Total Scale: • Cronbach alpha = 0.96 Subscale Cronbach alpha reported for modifications of the DCS subscales post Factor Analysis: • Knowledge about the decision = 0.97 • Lack of autonomy in decision making = 0.94 • Lack of confidence in decision making = 0.87	Factor Analysis resulted in 3-factor model explaining 82% of the variance.
O'Connor (1993)(A.M. O'Connor, 1993) Updated 2010	Question Format 16-Items 5 Subscales	Breast Cancer Back Surgery Hip and Knee Surgery PSA Testing	Reported as "currently being tested"	Reported as "currently being tested"
Lam (2012)(Lam et al., 2012)	Question Format 16-Items 5 Subscales	Newly diagnosed breast cancer patients, prior to consultation with a surgeon (n = 471)	Total Scale reported on a modified, 14-item version of a 3-factor scale: • Cronbach alpha = 0.81 Subscale Cronbach alpha reported on modifications of DCS subscales post Factor Analysis: • Uncertainty and Effective Decisions = 0.71 • Informed and Values Clarity = 0.87	Known groups approach (tested on modified 14-item DCS with 3 subscales) showed statistically significant differences for the total scale and all subscales • Total Scale $p < 0.001$ • Subscale: Uncertainty and Effective Decisions $p < 0.001$ • Informed and Values Clarity Subscale, $p = 0.025$

Table 3.2 (Continued)

			• Support = 0.51	• Support Subscale, p<0.001 Hypothesis Testing: The 14-item DCS and the modified 3-factor subscales showed positive correlations with anxiety and depression as measured with the Hospital Anxiety and Depression Scale (r ranging from 0.20 – 0.42 for anxiety and 0.20 – 0.41 for depression, p<0.05). The 14-item DCS and the modified 3-factor subscales showed negative correlation with patient satisfaction with medical consultation as measured by the Treatment Decision Making Difficulties Scale (r ranging from -0.37 to -0.52, p <.05) Factor Analysis of the 14-item DCS resulted in 3-factor model explaining 53% of the variance.
Mancini (2006)(Mancini et al., 2006)	Format not identified 16-Items 5 Subscales	Women with cancer considering genetic testing (n = 553), control group divided into two samples (n = 134 and n = 125), experimental group (n = 294)	Total Scale: • Cronbach alpha = 0.905-0.916 Subscale Cronbach alpha: • Uncertainty = 0.764-0.823 • Informed = 0.842-0.883 • Values Clarity = 0.67-0.703 • Support = 0.441-0.593 • Effective Decision = 0.838-0.892	Factor Analysis resulted in 4-factor model with support dimension part of informed dimension

Table 3.2 (Continued)

O'Connor (1993)(A.M. O'Connor, 1993) Updated 2010	Low- Literacy Question Format 10-items 4 Subscales	Women with breast cancer (n = 63)	Total Scale: Cronbach alpha = 0.86	Not reported
Linder (2011)(Linder et al., 2011)	Low- Literacy Question Format 10-items 4 Subscales	Men eligible for prostate cancer screening (n = 149) tested at two time intervals.	Cronbach alpha > 0.80 for total DCS and for interclass (subscale) correlation coefficients and for all subscales except the Supported subscale (Cronbach alpha = <0.60)	Known groups approach showed statistically significant difference ($p < 0.001$) Factor analysis resulted in four-factor model with one Support Subscale item not loading on any factor and another item showed cross-loading.

Based on information from: (Koedoot et al., 2001; Lam et al., 2012; Linder et al., 2011; Mancini et al., 2006; A.M. O'Connor, 1993; Annette M. O'Connor, 1995)

CHAPTER FOUR:

Factors Influencing Preference for Surgical Choice among Women with Early Stage Breast Cancer

4.1. Introduction

A consensus conference statement was released by The National Institute of Health in the 1990's to address treatment of early-stage breast cancer. Multiple prospective randomized trials comparing breast conserving surgery (lumpectomy) and mastectomy had demonstrated no statistical difference in survival (McGuire et al., 2009). In the statement, breast conserving surgery (BCS) was recognized as an appropriate treatment for the majority of women with early stage disease and was deemed "preferable" to mastectomy (National Institutes of Health, 1991, p. 394). Significant and widespread practice adoption of BCS was expected once surgeons could allow women to choose a breast conserving approach (Balch & Jacobs, 2009). Mastectomies continued to be performed in substantial numbers however, ranging from 30% to over 50% of cases in reported series (Chagpar et al., 2006; Collins et al., 2009; Nattinger, Gottlieb, Veum, Yahnke, & Goodwin, 1992).

After the consensus statement was released, several states enacted legislation mandating provision of information and unbiased discussion of surgical treatment alternatives in breast cancer. Those policy initiatives were advocacy efforts undertaken to promote informed consent with the anticipated result of increased BCS utilization. It was assumed that if women were given the choice, they would choose BCS in greater numbers (Lantz, Zemencuk, & Katz, 2002). Within the medical community, BCS rates are viewed as indicators of quality (Katz & Hawley, 2007). In addition, national

accreditation standards monitor rates of BCS, recommending that at least 50% of surgery for all eligible, early stage breast cancer patients should be BCS (National Accreditation Program for Breast Centers, 2017).

In recent years, increasing rates of mastectomy with contralateral prophylactic mastectomy (CPM) have been reported among women with unilateral, early stage breast cancer (Dragun et al., 2013; Jones et al., 2009; King et al., 2011; Tuttle et al., 2007; Tuttle et al., 2009). The prophylactic surgery, i.e. removal of the contralateral breast, decreases the risk of contralateral breast cancer yet confers no survival advantage (Lostumbo, Carbine, & Wallace, 2010). If eligible for a choice between surgical options, a woman's decision becomes one of preference in a decision making process that is poorly understood.

From multiple retrospective reviews of national and single-institution databases, several predictors of the surgical choice for mastectomy with CPM have been identified. These predictors have fallen into the categories of demographic and clinical factors. Younger age, higher level of education, positive family history of breast cancer, white/Caucasian/nonHispanic ethnicity, positive BRCA1 or 2 status and having a personal history of breast cancer have been associated with the choice of bilateral mastectomy. Tumor characteristics such as size, invasion, histology, receptor and lymph node status have been identified as predictors (Arrington, Jarosek, Virnig, Habermann, & Tuttle, 2009; Damle et al., 2011; Guth et al., 2012; Jones et al., 2009; King et al., 2011; Stucky, Gray, Wasif, Dueck, & Pockaj, 2010; Tuttle et al., 2007; Tuttle et al., 2009; Yi et al., 2009). In addition, the use of preoperative breast magnetic resonance imaging (MRI)

and genetic counselling have been associated with the choice of mastectomy with CPM (King et al., 2011; Sorbero, Dick, Beckjord, & Ahrendt, 2009; Stucky et al., 2010).

In retrospective reviews using surveys and interviews with women after surgical treatments have been completed, factors of a more personal nature have been identified. Fear or worry about recurrence and second breast cancer, distress and anxiety have been described as important, and in some studies, as associated with the choice of bilateral mastectomy (Beesley, Holcombe, Brown, & Salmon, 2013; Han et al., 2011; Hawley et al., 2014; Jagsi et al., 2017; Pedersen et al., 2010; Rosenberg et al., 2015; Rosenberg et al., 2013; Soran et al., 2015; Spittler, Pallikathayil, & Bott, 2012). Quality of life issues such as body image and concerns about cosmetic surgical outcomes have also been described as part of this preference-sensitive treatment decision (Baptiste et al., 2017; Beesley et al., 2013; Buchanan et al., 2016; Fisher et al., 2012; Spittler et al., 2012). In addition, women have identified desire to avoid radiation therapy and more frequent medical visits as part of their reasons for choosing mastectomy with CPM (Baptiste et al., 2017; Fisher et al., 2012; Han et al., 2011). Factors as yet unknown may contribute to surgical decision-making. Studies using prospective designs may provide needed information. The purpose of this exploratory study is to prospectively identify demographic, clinical, cognitive and affective factors influencing a woman's decision to choose either breast conserving surgery (BCS) or mastectomy with CPM and to identify self-reported sources of information in the surgical decision-making process.

4.2. Research Questions

The following research question will be addressed: What factors influence a woman's choice between two surgical options, BCS and mastectomy with CPM following a diagnosis of early stage breast cancer and prior to surgical treatment?

Specific research aims are: 1) to examine differences between women choosing two surgical options (breast conserving surgery and mastectomy with CPM) related to the following factors: demographics, diagnostic processes, tumor characteristics, depression, anxiety, stress, distress, breast cancer specific distress and decisional conflict, 2) to examine differences in breast surgery beliefs and expectations between women choosing between the two surgical options and, 3) to identify information sources important to women in the decision-making process.

4.3. Conceptual Framework

The Ottawa Decision Support Framework, a conceptual model for shared decision making, served as an organizing framework for this study. In the model, the desired outcome of shared decision making is a quality decision, described as one based on both the best scientific evidence and on patient values. Positive outcomes such as minimized decisional delays and post-decisional regret are purported to result from quality decisions. Within the framework, participants in the decision making process have decisional needs which may include conflict, expectations, and specific personal and clinical characteristics (Ottawa Hospital Research Institute, 2015). Decisional needs are modifiable with decision support interventions that provide information, clarify needs and values, and facilitate progress (Légaré, O'Connor, Graham, Wells, & Tremblay, 2006).

4.4. Study Design

This prospective, exploratory, cross-sectional, mixed-methods study was designed to gather information during the time period in which surgical decision-making occurred. Both participant self-report and medical record information were collected. The study was approved by the Baptist Health Lexington Institutional Review Board and oversight agreement was given by the University of Kentucky Office of Research Integrity.

Immediately prior to enrollment, women were examined by a breast surgeon and completed a surgery decision-making consultation visit with the surgeon and breast cancer nurse navigator. Enrollment in this manner allowed confirmation of early stage disease. In addition, eligibility for choice among the surgical options was confirmed by the surgeon. Other inclusion criteria included unilateral breast carcinoma, older than 18 years of age, able to read and understand English and with no personal history of cancer with the exception of non-melanoma skin cancer.

4.4.1 Sample and setting.

An a priori power analysis was conducted. Based on a moderate effect size of 0.5, alpha of 0.05 and power of 80%, a sample size of 128 was planned, 64 in the group choosing BCS and 64 in the group choosing mastectomy with CPM. Enrollment began in August 2016 and continued to August 2017 (n = 112). Sixteen participants (14%) did not return completed questionnaires. Eight chose unilateral mastectomy and were excluded from this analysis. Ten (9%) were ineligible after enrollment: two participants had a prior history of cancer and were inadvertently enrolled, one completed the survey after surgery was completed, and eight were subsequently found on further workup to have either bilateral breast cancer, locally advanced Stage III disease or multifocal disease

making them ineligible. For analysis, n = 78 including 47 in the BCS group and 31 in the bilateral mastectomy (BM) group. All other parameters remaining the same, a repeated power analysis of these unequal groups reveals a post-hoc power of 57%. Less than 5% of those invited declined to participate.

The setting for the study was a 391-bed community hospital and an affiliated, seven-surgeon group office practice. Patients were eligible for enrollment consecutively, on the day of consultation with the breast surgeon and immediately after the surgical decision-making conference occurred with the breast surgeon and breast nurse navigator. A study investigator approached potential participants in a private area of the physician office to explain the study and obtain informed consent to participate. If a surgical decision had been made, enrolled patients were offered the option to complete the study packet at that time and were given a $10.00 gift card. If a surgical decision had not been made at that point or as the patient requested, participants were provided with the packet and a stamped, postage-paid return mailing envelope. Verbal and written instructions were provided including a reminder to complete the study packet after a surgical decision was made but prior to the surgery. The principal investigator tracked enrolled participants who had not returned packets and completed a minimum of one reminder telephone call to participants as needed. Instruction to complete the packet after a decision had been made and prior to surgery was included in reminder phone calls. Participants completing and returning packets were provided with a $10.00 gift card mailed to the participant in a self-addressed envelope.

4.4.2 Variables and measures.

Participants were given a packet that contained: demographic questionnaire, items pertaining to Gail risk calculation, Depression Anxiety Stress Scale, Impact of Event Scale, Decisional Conflict Scale, Breast Surgery Beliefs and Expectations Scale, list of Information Sources, open-ended prompt and question about intention (Appendix). This packet could be completed in approximately 15 – 20 minutes. Medical record information was abstracted from the electronic medical record by the principal investigator.

4.4.2.1 Personal, demographic and clinical information.

The following demographic information was retrieved from participants: age, race, marital status, level of education, employment status, income level, insurance status, personal and family history. Clinical information was collected from the medical record and included: breast imaging information including MRI and post-MRI biopsies, genetic counselling consultation, genetic testing results and pathologic features of surgical specimens including tumor prognostic indicators such as receptor status, histology and grade.

4.4.2.2 Depression, Anxiety and Stress Scale.

The Depression Anxiety Stress Scale (DASS) consists of a total of 42 items to which respondents are asked to signify an answer on a four-point scale ranging from 0 (did not apply to me at all) to 3 (applied to me very much or most of the time). Participants are asked to include experiences from the preceding week when responding. Fourteen items of the DASS pertain to depression, 14 to anxiety and 14 to stress and items for each of these three subscales are interspersed among the other subscale items.

Reported mean scores in a normative, non-clinical sample include: total score M= 18.38 (SD = 18.82), depression subscale M = 5.55 (SD = 7.48), anxiety subscale M = 3.56 (SD = 5.39) and stress subscale M= 9.27 (SD = 8.04). Higher scores represent higher depression, anxiety and stress on the representative subscale and overall distress for the total score. Levels of symptom severity have been established with severe levels defined as: depression score > 20, anxiety score > 14 and stress score > 26 (Crawford & Henry, 2003).

The DASS has been found to have high reliability in prior studies. Cronbach alpha for the overall DASS have been reported in the range of 0.84-0.97 for the total DASS and for the three subscales (Crawford & Henry, 2003; Lovibond & Lovibond, 1995). In this study reliability was high, with coefficient alpha ranging from 0.86-0.96 for the overall and three DASS subscales.

4.4.2.3 Impact of Event Scale.

The Impact of Event Scale (IES) is a self-report measure of distress associated with a serious life event. With identification of a specific event within the instructions for completing the IES, the scale was linked with the personal experience of breast cancer for each participant. Fifteen questions are divided among two subscales, intrusion and avoidance. The intrusion subscale contains seven items and the avoidance subscale contains eight items. Each item asks the respondent to consider how frequently the item was true in the past seven days. Items are rated on a four-point Likert scale ranging from "not at all," "rarely,", "sometimes," to "often." Items are scored as 0, 1, 3, and 5 respectively. The resulting range of scores for each scale is 0 to 35 for the intrusion

subscale and 0 to 40 for the avoidance subscale (Epping-Jordan et al., 1999). Higher scores represent higher breast-cancer specific distress.

Acceptable reliability has been reported with the IES. In the breast cancer population specifically, coefficient alpha levels of 0.90 for the total scale, 0.70-0.71 for the intrusion scale and 0.83-0.85 for the avoidance subscale have been reported (Epping-Jordan et al., 1999; Miller, Schnur, Weinberger-Litman, & Montgomery, 2014). In this study, acceptable coefficient alpha was 0.93 for the IES total, 0.89 for the intrusion subscale and 0.87 for the avoidance subscale.

4.4.2.4 Decisional Conflict Scale.

The Decisional Conflict Scale (DCS) consists of 16 total items in statement format. Responses are made using a five point Likert scale ranging from 0 (strongly agree) to 4 (strongly disagree). Responses are summed, divided by 16 and then multiplied by 25, resulting in a decisional conflict score ranging from 0 to 100. Low scores represent low decisional conflict and high scores represent high decisional conflict. Scores above 37.5 are associated with feeling unsure about the decision and with decisional delay (O'Connor, 1995). Coefficient alpha for the scale in previous studies ranges from 0.78—0.92, demonstrating acceptable internal consistency (O'Connor, 1993). The five subscales of the DCS include: informed, values clarity, support, uncertainty and effective decision. Three items make up each subscale except for the effective decision subscale which is comprised of four items. High subscale scores represent high decisional conflict in that specific area.

4.4.2.5 Breast Surgery Beliefs and Expectations Scale.

In order to assess the way in which women think about breast surgery options, a measure of the beliefs and expectations was developed. Items for the scale were drawn from the primary investigator's clinical experience and from previous published assessments of disease-specific knowledge (Collins et al., 2009; Fagerlin et al., 2006; Sepucha, Ozanne, Silvia, Partridge, & Mulley, 2007). The Breast Surgery Beliefs and Expectations Scale (BS-BES) included nine items to which participants were asked to assign a level of importance using a Likert scale ranging from 1 (not at all important) to 4 (very important). Higher scores on each item represented higher importance of that item in the surgical decision.

The BS-BES was reviewed by three oncology nurses prior to use. A breast cancer nurse navigator, oncology clinical nurse specialist and oncology nurse read the items to evaluate clarity, measurement format and with consideration of the scale's intent. Revisions were made for clarity and concision.

4.4.2.6. Information sources.

Participants were asked to identify sources of information in their surgery decision-making process. A list of information sources was developed from the investigator's clinical experience and from published reports (Covelli, Baxter, Fitch, McCready, & Wright, 2014; Dickerson, Alqaissi, Underhill, & Lally, 2011; Lally, 2009; Spittler et al., 2012). Women were provided an opportunity to add sources not found on the list and asked to delineate the most influential source among their list.

4.4.2.7 Intention.

Intention to choose either BCS or mastectomy with CPM was assessed using a single question. Participants were asked to respond "yes" or "no" to the question, "Did your initial intent regarding surgery match your final decision?"

4.4.3 Open-ended prompt.

Given the lack of prospective studies, the opportunity to explore personal, self-generated information was important. An open-ended prompt asking for comments about the reason for the surgical choice was provided.

4.5. Data Analysis

Data analysis was performed using IBM SPSS® Statistics (version 24). Frequency distributions were used to examine all variables including outliers and distributions. Descriptive statistics including means, standard deviations and frequency percentages were used to characterize the total sample and both subgroups as appropriate.

Categorical and continuous level data for demographic, clinical and diagnostic characteristics as well as information sources and intention were analyzed using independent sample t-tests and chi-square tests as appropriate to the level of data. Odds-ratios were calculated. For those categorical variables in which cell counts were less than five, Fisher's exact test was used to compare groups.

Total scores and subscales scores of the DASS, IES and DCS for each group were compared. Independent t-tests were used to compare total scale and subscale data. Given the exploratory nature of this study a Bonferroni correction was not calculated.

Factor analysis was performed on the investigator-designed BS-BES to evaluate the shared variance of the nine items. The factor analysis provided the basis for

identifying three subscales within the instrument. Suitability assumptions for factor analysis were met in number of response options of at least three and ten cases per item. The sample size was 77 for this scale, which is below the minimum recommended for factor analysis. Bartlett's test of sphericity was used to test the correlation matrix and Kaiser-Meyer-Olkin (KMO) was used to evaluate matrix sample adequacy. A KMO value greater than 0.5 was considered minimally acceptable. Principal component analysis extraction with varimax rotation was performed. Items were identified to a factor with loadings greater than 0.40. Cross-loaded factors were defined as those loading on more than one factor.

4.6. Results

4.6.1 Research Aim 1: To examine differences between women choosing two surgical options (breast conserving surgery and mastectomy with contralateral prophylactic mastectomy) related to the following factors: demographics, diagnostic processes, tumor characteristics, depression, anxiety, stress, distress, breast cancer specific distress and decisional conflict.

4.6.1.1 Demographic, diagnostic and clinical factors.

Demographic characteristics of the sample and subgroups are summarized in Table 4.1. The participants were 57 (SD 12) years of age on average, almost exclusively Caucasian (94%), and the majority were married/partnered (66%). The majority of participants had an education level greater than a high school education with 49% completing some college or university study and 20% completing some graduate level education. Sixty percent of participants were employed full- or part-time and 77% reported an income level greater than or equal to, $40,000 per year. Only four women in

the study reported having Medicaid and all of those women elected to have BCS. A statistical comparison of groups was not able to be completed for insurance status due to distribution of this variable.

A significant difference was found for age ($t(77) = 5.098$, $p < .001$, $r = .59$) and employment ($\chi 2\ (1) = 3.78$, $p < .05$) between women choosing BCS and women choosing mastectomy with CPM. Women choosing mastectomy with CPM were 12 years younger on average (M 50, SE = 1.9) as compared to those choosing BCS (M 62, SE = 1.5). Those who worked either full or part-time were 2.6 times more likely to choose bilateral mastectomy. There were no differences in race, marital status, education level and income.

Diagnostic factors are shown in Table 4.2. The total sample was evenly divided between those who did and did not complete preoperative breast MRI. In comparing the groups however, different distributions are seen with 60% of women in the BCS group and 35.5% of women in the bilateral mastectomy group completing preoperative imaging with breast MRI. The majority of participants (58%) did not complete genetic counseling but distribution differences in the subgroups are again noted. In the BCS group, 28% completed genetic counseling and in the mastectomy with CPM group, 64.5% completed genetic counseling. The majority of the total sample and each subgroup did not require a post-MRI biopsy, did not have genetic testing, did not have a family history in first degree relatives and were not defined as high-risk prior to diagnosis as calculated by the Gail risk model.

Statistically significant differences were found between the groups for preoperative breast MRI and genetic counseling. Among those who did have

preoperative breast MRI, women were 2.68 times more likely to choose BCS, $\chi 2$ (1) = 4.336, $p < .05$ and among those who had preoperative genetic counseling, women were 4.8 times more likely to choose bilateral mastectomy as compared to BCS χ 2 (1) = 10.396, $p < .01$ (Table 4.2).

Clinical characteristics are shown in Table 4.3. The mean tumor size was 1.5 cms (SD 1.2) in largest dimension. Those choosing bilateral mastectomy had tumors averaging 2.2 cms in largest dimension as opposed to an average size of 1.1 cm in the BCS group, $t(76) = -4.343$, $p < .001$, $r = .4$. Tumor size was the only variable with a significant difference between the groups in terms of clinical characteristics. Most tumors were invasive or in situ ductal carcinomas (91%), lymph node negative (74%), ER/PR positive (95/96%) and HER2-neu negative (72%).

4.6.1.2 DASS, IES, and DCS Scores and Subscale Scores.

The properties of DASS, IES and DCS scales and subscales are outlined in Table 4.4. Cronbach coefficient alpha > 0.70 was considered acceptable. All scales and subscales met criteria for acceptable reliability with the exception of the uncertainty DCS subscale ($\alpha = 0.67$).

Overall, mean DASS total scores and subscores were within the normal range criteria (Table 4.4). Only six (8%) and nine (12%) participants reported greater than moderate levels of depression and anxiety, respectively. No participants reported stress above moderate levels (Table 4.5).

Breast cancer specific distress measured by the IES, resulted in the following mean scores for the sample as a whole (Table 4.4): IES-total (M = 28.20; SD 18.54), IES-Intrusion (M = 13.52; SD 9.49) and IES-Avoidance (M = 14.59; SD 10.17). Scores

greater than 26 indicate a stress impact in the moderate to severe range (Horowitz, 1994). The two items with the highest proportion of "sometimes" and "often" scores were items four, "I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came into my mind" and five, "I had waves of strong feelings about it." Twenty-two and 19 women reported sometimes and often experiencing items four and five respectively. Among all participants, 39 (50%) demonstrated a moderate to severe impact from the breast cancer diagnosis (IES score > 26). A greater percentage of women reported an IES score 26 or above in the mastectomy with CPM subgroup (58%) as opposed to the BCS group (45%).

The total DCS score (M = 9.10; SD 12.62) was low; well below the 37.5 score indicative of decisional delay or insecurity with the decision. DCS subscales scores were all low with the highest score noted on the Uncertainty Subscale (M = 14.85; SD 17.29) (Table 4.4).

DASS, IES and DCS total scores and subscale scores for the subgroups, women choosing BCS and women choosing mastectomy with CPM were compared (Table 4.6). DASS and IES scores were higher on average for women in the bilateral mastectomy group as compared to those in the BCS group. DCS total and subscale scores, with the exception of the uncertainty subscale, were the opposite. Women in the BCS group had higher total decisional conflict and had higher DCS subscale scores with the exception of the uncertainty subscale for which women in the bilateral mastectomy group had higher mean scores.

Statistically significant differences with small to medium effect size were found in DASS Anxiety Subscale and in the intrusive impact of the diagnosis as measured by

the IES-Intrusion subscale. Women in the mastectomy with CPM group were more anxious on average (M = 7, SE = 0.7) than women choosing BCS (M = 4, SE = 0.7), $t(75) = -2.298$, $p < .010$, $r = .25$. Breast cancer specific distress as measured by the IES-Intrusion Subscale, was higher in the group choosing mastectomy with CPM (M 17, SE 1.7) as compared to those choosing BCS (M 11, SE 1.2), $t(75) = -2.852$, $p < .01$, $r = .31$.

Decisional conflict was higher among women choosing BCS. Statistically significant differences between the two subgroups were found for the DCS scale as a whole and for the values clarity, support and effective decision subscales. Effect sizes were small. Mean decisional conflict scores for women choosing BCS were 10 (SE = 2.2) as compared to mean scores of 8 (SE = 1.4) for those choosing mastectomy with CPM, $t(76) = 0.9$, $p < .05$, $r = .10$. Women choosing BCS were more unclear about personal values in the decision making (M 7, SE = 2.6) as compared to those choosing mastectomy with CPM (M 4, SE = 2.1), $t(76) = 1.613$, $p \leq .05$, $r = .18$. They also felt more unsupported in their decision making (M 7, SE = 2.1) as compared to those choosing mastectomy with CPM (M 4, SE = 1.4), $t(76) = 1.230$, $p \leq .05$, $r = .14$. Women choosing BCS reported higher scores for ineffective decisions (M 10, SE = 2.3) as compared to those choosing bilateral mastectomy (M 6, SE = 1.6), $t(76) = 1.340$, $p \leq .05$, $r = .15$.

4.6.2 Research Aim 2: To examine the differences in breast surgery beliefs and expectations between women choosing two surgical options (breast conserving surgery and mastectomy with contralateral prophylactic mastectomy).

The BS-BES was an investigator-designed scale, used for the first time in this study. A summary of all responses to the nine-item scale is provided in Table 4.7. Over

80% of participants rated the items “minimize the chance of breast cancer coming back” and “minimize the chance of dying from breast cancer,” as very important. Forty-nine and 47% of participants rated the item “avoid the need for future mammograms/breast screening” and “have the option to improve my breasts through reconstruction” as not at all important.

A factor analysis was conducted for the nine-item scale, which met requirements for number of response criteria and number of cases per item. Bartlett’s test of sphericity was significant ($p < .001$). The null hypothesis that the correlation matrix is an identity matrix is rejected. Minimal matrix sample adequacy was met (KMO = .636) and the determination of the correlation matrix was adequate (.077).

Factor Analysis with Varimax Rotation was performed. A cut point of .40 was used to define factor loading and cross-loaded factors were defined as those which loaded similarly on more than one factor. Three factors are represented in the subscale (Table 4.8), a Mastectomy Factor (Factor 1), a Recurrence/Survival Factor (Factor 2) and a BCS Factor (Factor 3). The Mastectomy Factor is made up of four items: “remove breast for peace of mind,” “avoid radiation,” “avoid the need for future mammograms/breast screening,” and “have the option to improve my breasts through reconstruction.” The Recurrence/Survival Factor is made up of two items, one about minimizing the chance of recurrence and one about minimizing the chance of dying from breast cancer. The BCS Factor consists of two items related to the choice of BCS, “do as little surgery as possible” and “keep my breast.” One factor of the nine, “minimize the length of treatment,” crossloaded on both the Mastectomy Factor and the BCS Factor and was removed from analysis.

Higher scores represent higher importance for each item on this scale. Higher factor scores, therefore represent higher importance for that factor. Scores for each factor were compared across subgroups. Significant differences were found in all three comparisons. Mastectomy factor scores were greater for women choosing bilateral mastectomy (M 12, SE .5) than those choosing BCS (M 7, SE .5), $t(75) = -6.240$, $p < .001$, $r = .58$. Recurrence/Survival Factor scores were also higher among women choosing bilateral mastectomy (M 7.96, SD 0.2) than those choosing BCS (M 7.29, SD 1.2), $t(75) = p < .001$, $r = .24$. In contrast, BCS Factor scores were higher among women choosing BCS (M 5, SE .25) than among women choosing bilateral mastectomy (M 4, SE .26), $t(75)$, $p < .01$, $r = .29$.

4.6.3 Research Aim 3: To identify information sources important to women in the decision-making process.

Sources of information identified by participants are shown in Figure 4.1 (percentage of all participants) and Figure 4.2 (percentage of each subgroup participants). One hundred percent of the participants in this study identified their surgeon as an information source in the decision-making process. The top five information sources (by %) were similar between the two groups. For the BCS group, the top five were: 1) surgeon, 2) family, 3) nurse navigator, 4) friends and 5) spouse/partner. For the bilateral mastectomy group, the top five were: 1) surgeon, 2) nurse navigator, 3) family, 4) spouse/partner and 5) friends. Nine women choosing BCS wrote in an additional information source. The breast MRI was added as an information source by three women. Genetic counselling, medical oncologist, “God/Jesus/Prayers,” and “other breast

cancer survivors," and "myself" were each added by one participant. No additional information sources were provided by women choosing mastectomy with CPM.

Participants were asked to identify the most influential information source among those identified. Spouse/partner and family categories were collapsed into one category for analysis. There were significant differences between the groups identifying the most influential information source (Table 4.9). The odds of a woman with early stage, unilateral breast cancer choosing BCS were 6.4 times more likely if she identified the surgeon as the most influential, X^2 (1) = 10.397, $p < .05$. The odds of a woman with the same diagnosis choosing mastectomy with CPM were 4.1 times more likely if she identified spouse and family as the most influential, X^2 (1) = 5.964, $p < .05$.

4.6.4 Intention

On the questionnaire, a yes/no question was asked regarding intention, "did your initial intent regarding surgery match your final decision?" Sixty-one (78%) of the participants answered "yes" to that question. There was no statistically significant difference between the groups as analyzed by chi-square.

4.6.5 Comments

Participant comments were invited with the prompt, "In your own words, please describe the reason for your surgical choice." All participants provided at least one handwritten response. Comments were extracted verbatim and compiled into lists sorted by breast surgery. Three reviewers, two of whom have extensive clinical experience with breast cancer patients and one of whom has an oncology research background with expertise in both qualitative and quantitative methods read all comments. Initially, comments were examined independently by the reviewers as main ideas were identified

and comments were sorted accordingly. Reviewers then met and discussed common and discrepant groupings until agreement was reached.

Among the 31 women in this study who chose mastectomy with contralateral prophylactic mastectomy, the most common reason cited for surgical choice was worry about recurrence and the "peace of mind" gained by the choice. Twenty-three women described their decision in those ways including comments such as: "I wanted to not worry the rest of my life," "I'm only 40, and already worried that it would come back, "I want peace of mind to know I'm doing everything I can to ensure that I beat it." Eight women wrote of their concern for family as a reason for their choice with comments including, "I have two small children and want to be here to watch them grow up. I know having me here is more important to myself, my spouse, and my children than having breasts" and "anything I can do to minimize having to put my family and me through this again is worth it." Eight women identified avoidance of future surveillance as a rationale, writing "I do not want my life to revolve around worry and mammograms in the future," "no fear of a bad mammogram," and "I don't want to have to be watched closely with mammograms." A family history was reported as a reason for the decision by five women.

Less than five comments were reported in the following categories: maximizing survival, getting rid of the cancer, making the decision to achieve a better cosmetic outcome and as a means of avoiding radiation treatment. Three women wrote of the relative importance of their breast with such comments as: "no real attachment to breasts," "breasts don't define who I am or enhance/diminish my self-worth," and a woman who was a below the knee amputee commented "I'm OK losing another body

part." Two women reported previous issues with pain and discomfort in both breasts as a reason for the decision to choose bilateral mastectomies.

Among participants choosing breast conserving surgery, the overwhelming majority of comments included very clinical information. Included in this group of 23 comments were references to the histology and stage of the individual's cancer such as "cancer is in situ and not invasive." There were also comments about survival and recurrence statistics such as "the ten year prognosis between lumpectomy and mastectomy was no different" or "the survival rate is the exact same for each." Breast MRI and genetic testing results were also included in that category. Fourteen comments made reference to the advice of, or consultation with, physicians including: "The surgeon explained the pros and cons of all procedures and it was best for my situation," "primary care physician and surgeon both gave same advice," "it just makes sense to take medical advice from physicians I trust," and "the surgeon convinced me that lumpectomy would be as effective with only a small chance of the cancer returning." Breast conserving surgery was described as a means to maintain normalcy or return to normal more quickly and as the least invasive approach by 14 study participants. Eight women specifically wrote about the desire to preserve their breast. Five women wrote about choosing breast conserving surgery now with the idea that a mastectomy could be done later, for example, "if this cancer comes back and we have to do more radical surgery," and "my surgeon let me now that I could change my mind about having a mastectomy at a later date if the cancer comes back." Two women in this group referred to mastectomies as scary and one woman used the term "creepy."

There were differences in comments between the groups. While both groups commented about their decision as pertaining to issues with recurrence of disease, the focus was different. Those choosing mastectomy with contralateral prophylactic mastectomy wrote about recurrence in connection with emotional terms like worry and seeking peace of mind. The breast conserving surgery group wrote about recurrence risk in a very cognitive way, citing percentages and specific clinical information and medical rationale. As it pertained to lifestyle and family, rationale for the surgical choice was also dissimilar with women in the bilateral mastectomy group focused on avoiding future issues for their family and the breast conserving group writing about a short recovery time and quick return to normal life now. Avoiding radiation or avoiding future mammograms were reported as rationale in the bilateral mastectomy group and the breast conserving surgery group conversely chose a surgery committing to both. In the breast conserving surgery group, comments about a physician's advice or counsel were common and physicians were rarely mentioned by women in the other group. An unexpected rationale for bilateral mastectomies was breast pain and very few women choosing mastectomies spoke about cosmetic rationale such as symmetry or reconstruction.

4.7. Discussion

This study demonstrated differences between women choosing among two surgical options as treatment for early stage breast cancer. Age was significantly different between the two groups with younger women more likely to choose mastectomy with CPM. This is consistent with findings from previous studies (King et al., 2011; Tuttle et al., 2007; Tuttle et al., 2009). A reason may be the way in which women of different ages view recurrence risk and the requisite surveillance activities post-surgery.

Women choosing BCS, for example, have elected to preserve breast tissue and therefore have a local recurrence risk greater than women who have elected to have mastectomy. Women choosing BCS will be scheduled to participate in breast cancer surveillance activities (i.e. mammograms). Choosing bilateral mastectomy decreases the risk of local recurrence significantly and relieves the woman of future surveillance by breast imaging. Mammograms from younger women with greater breast density are more difficult to evaluate. Recall for diagnostic films and false positive findings are more common for that reason. Younger women may be familiar with that issue already and may choose mastectomy in response. Age differences may be important in light of family and work concerns. Women who have young children in the home or who are establishing themselves in the workforce may view the surgical options and recovery periods differently than women with older or adult children who are more established in their careers.

The majority of women in both subgroups were employed either part- or full-time. A meaningful finding in this study was a difference between the subgroups in terms of employment. This finding is new in this area, perhaps because employment status is not included in cancer registry data and could therefore not be tested in retrospective studies drawn from cancer databases.

Participation in genetic counseling and preoperative breast MRI were both significantly different between the groups. Participation in genetic counseling has been identified in previous studies as predictive of choosing mastectomy with CPM (Soran, Kamali Polat, Johnson, & McGuire, 2014; Stucky et al., 2010) which is consistent with findings in this study. Higher rates of CPM have been associated with preoperative

breast MRI in previous studies (Sorbero et al., 2009; Stucky et al., 2010). In this study, however, women who had preoperative breast MRI were more likely to choose BCS. This may be a result of changing practice patterns in the use of breast MRI. In the setting in which this study was conducted, breast MRI is often recommended for women prior to BCS to assess for multifocal and bilateral disease before undertaking a conservative surgical approach. Women choosing mastectomy with CPM do not need to undergo breast MRI because concerns about re-excision for positive margins or diffuse multifocal disease are not relevant.

The prospective design of this study allowed for observation of something not previously reported regarding breast MRI. In this study, eight of the 112 participants were excluded from the study after positive findings on breast MRI. Those eight women who had been diagnosed with early stage cancers no longer met immediate eligibility criteria for a choice among surgical options. Retrospective studies are unable to gather this level of data and previous studies finding associations between breast MRI and bilateral mastectomy may include patients who are truly not eligible for a breast conserving approach after breast MRI.

Overall levels of distress, depression, anxiety and stress were within normal levels for the participants. This may be related to the baseline characteristics of an educated, insured, higher socioeconomic group of women who have support from spouses/partners. There was some variability in these measures within the sample, however with some women exhibiting high levels of distress, depression and anxiety and breast cancer-specific distress in both subgroups. Significant differences between the two groups were seen for generalized measures of anxiety and for the intrusive impact of the breast cancer

diagnosis; those choosing mastectomy with CPM exhibited higher levels of both as compared to women choosing BCS. The lack of previous, prospective studies in this population provides very little comparison. Higher perceived risk for contralateral breast cancer has been associated with higher levels of anxiety in one study (Portschy et al., 2015). In a prospective study of women with early and locally advanced, newly diagnosed breast cancer, total IES scores were not significantly associated with CPM. Subscale IES scores were not reported in that study (Parker et al., 2016). Exploration of those affective factors are possible in a study of this design and the differences between the groups are new findings.

Overall, the participants exhibited low decisional conflict. In the breast conserving surgery group, mean DCS scores were higher and standard deviations were wider suggesting higher and more varied decisional conflict as compared to women in the mastectomy with CPM group. Significantly higher decisional conflict was seen in the BCS group as compared to women choosing bilateral mastectomy. In addition, women choosing BCS expressed greater lack of values clarity and support in their decision making and expressed higher levels of conflict in terms of effective decision-making. Among women electing mastectomy with CPM, previous reports have described high satisfaction, low decisional conflict and low decisional regret with the decision (Buchanan et al., 2016; Lally, 2009; Mamtani & Morrow, 2017; Moffat & Yakoub, 2016; Soran et al., 2014)

A scale was developed for this study to assess women's beliefs and expectations about surgery options for breast cancer. This is the first use of the scale; validity and reliability testing is warranted. Factor analysis identified three dimensions in the scale

which were used to test differences between the groups. The groups differed significantly for all three factors. Woman choosing mastectomy with CPM reported higher importance on the mastectomy factor, women choosing BCS reported higher importance on the BCS factor, and women choosing mastectomy with CPM reported higher importance on the recurrence/survival factor. One item on the BS-BES scale crossloaded on both mastectomy and BCS factors. This was unexpected. The item, "minimize the length of treatment" appears to have been interpreted differently among the participants. It was intended to be a measure predictive of bilateral mastectomy choice in that mastectomy would alleviate the need for a post-surgical course of radiation therapy and future breast surveillance. Participants interpreted the item differently which is perhaps explained by comments from women in the BCS group who reported quicker recovery time and return to normal as rationale for their choice of BCS. Multiple reconstruction procedures may have been considered "treatment" by participants.

In both groups, the majority of women reported choosing the surgery they had originally intended to choose. This might be related to the fact that no unexpected findings occurred with their workup, therefore recommendations and options remained stable and as expected. It could also reflect a commitment to a choice made prior to consultation with the surgeon as was found in a qualitative study of women in the surgical decision-making process. In that study, some women were found to have preferences about surgery choice that were made prior to the surgical consultation (Lally, 2009).

All of the participants in the study, no matter the subgroup, identified the surgeon as an information source. Information sources were similar between the two groups with

the same top five sources identified by both groups. An unexpected finding was the identification of the 6th choice for both subgroups, a professional from the breast imaging area. The mastectomy with CPM group identified a breast imaging nurse and the BCS group identified a breast imaging radiologist as an information source. This has not been reported previously and brings a new perspective to the surgical decision making process. The role of breast imaging professionals in this process should be further explored and defined. Breast imaging may be an area in which decisional support counselling and resources could be focused.

In regard to the designation of the most influential information source, subgroups differed. The surgeon was chosen as most influential in the BCS group and spouse/family were chosen as most influential in the bilateral mastectomy group. This finding could be relevant in research studies and implementation of decisional support interventions. The identification of family as the most influential information source points to the importance of decisional support that would include the family.

When asked to provide comments about the reason for their surgical choice, all of the participants in the study responded. Some participants replied with more than one page of comments. Categories of comments provided a contrast between the groups. Recurrence was mentioned by both groups as important in their decision making but the way in which it was expressed was different. Women in the bilateral mastectomy group wrote about recurrence in more emotional terms, associated with words like worry, fear and "peace of mind." They also expressed their surgical decision as one that was more future-oriented in reducing the risk of breast cancer coming back. Women in the BCS group wrote about recurrence in association with medical information about their disease

specifically and about chance or odds. They were more oriented to the present time, writing of a quicker return to normal or aversion to more extensive surgeries or even multiple reconstructive surgeries.

Comments provided new information in the rationale for mastectomy related to a history of breast pain and very few women commented on a cosmetic rationale for choosing bilateral mastectomy. A new insight into the choice of BCS was highlighted in comments about going through BCS first with the option of mastectomy later. It could be presumed that the larger tumor size in the group of women choosing bilateral mastectomy might have led more women to choose the procedure because of cosmetic outcomes which may have been less positive with larger resections. As evaluated by the lack of comments about cosmetic rationale, this does not appear to be the case.

Comments also provided information which was used in data analysis and interpretation. Women in the BCS group overwhelmingly wrote about the influence of the surgeon in their surgical choice while very few women in the mastectomy with CPM group commented about the surgeon. The difference informed the comparison of groups by the information source they chose as most influential.

4.8. Limitations

This study was conducted in one community hospital. The sample lacked diversity in terms of race/ethnicity, socioeconomic and insurance status. Generalizations to other populations are a limitation. Similarly, the healthcare setting in which this study was carried out may have specific procedures, standards of care or staff which may be unlike breast cancer care in other settings which would also limit generalization of findings.

4.9. Implications for Nursing

Knowledge regarding predictors of decision making among women with early stage breast cancer is limited. Research thus far has been largely retrospective and descriptive in nature. Given the personal nature of this decision, with resulting effects on a woman's body, lifestyle and emotions, the way in which women think and feel about the decision warrants exploration. Prospective research, studies that are qualitative in nature and particularly those that allow the opportunity to explore questions more fully may provide much needed information about why women choose mastectomy with CPM or BCS.

Patient decision making is optimized when knowledge is increased and participation is satisfactory to the patient (Katz & Hawley, 2007). A better understanding of decision needs could impact clinical practice, perhaps optimizing decisional support and decision quality. This study contributes to the body of knowledge in this area. Overall, women choosing either surgery were not experiencing severe levels of distress, depression, anxiety or stress although there were individual variations. Women choosing mastectomy with contralateral prophylactic mastectomy were more anxious and had more frequent intrusive thoughts about the diagnosis. They also had less decisional conflict as compared to women choosing breast conserving surgery. The influence of the surgeon was very important for women choosing breast conserving surgery. In contrast, family were the most influential among women choosing mastectomy with contralateral prophylactic mastectomy. In both groups, intention for surgical choice was matched by the final decision. There are many factors influencing surgical choice among women with early stage breast cancer. Previous work has focused on clinical, demographic and

diagnostic processes influencing the decision. With this study, evidence regarding the influence of cognitive and affective factors is described.

Table 4.1

Demographic Characteristics of the Sample (n = 78)

Demographic	Total Sample (n = 78)	Breast Conserving Surgery (n = 47)	Mastectomy with Contralateral Prophylactic Mastectomy (n = 31)	p
Age (years), mean (± SD)	57 ± 12	62 ± 10	50 ± 11	.000*
Race/Ethnicity				
Caucasian	73 (94)	44 (94)	29 (93.5)	
Non-Caucasian	5 (6)	3 (6)	2 (6.5)	0.99
Marital Status				
Married/Partnered	52 (66)	30 (64)	22 (71)	
Divorced/Separated/Single/Widow	25 (33)	16 (34)	9 (29)	
Missing Data	1 (1)	1 (2)	0	0.60
Education				
Elementary/High School	23 (30)	15 (32)	8 (26)	
College/University	38 (49)	24 (51)	14 (45)	
Graduate School	16 (20)	7 (15)	9 (29)	
Missing	1 (1)	1 (2)	0	0.34
Employment				
Full- or Part-Time	47 (60)	24 (51)	23 (74)	
Other	30 (39)	22 (47)	8 (26)	
Missing	1 (1)	1 (2)	0	.05*
Income				
< 40,000	16 (21)	10 (21)	6 (19)	
40,001 to 80, 000	23 (30)	14 (30)	9 (29)	
>80,000	37 (47)	21 (45)	16 (52)	
Missing	2 (3)	2 (4)	0	.91
Insurance				
Medicaid	4 (5)	4 (9)	0	
Any Commercial Insurance	51 (65)	25 (53)	26 (84)	a
Medicare /Medicare + Supplement	22 (28)	17 (36)	5 (16)	
Missing	1 (1)	1 (2)	0	

Data presented as mean ± SD or frequency (%)

Age compared by independent t-test, Race/Ethnicity compared with Fisher's Exact test, all other variables compared with Chi-square tests

*significant $p \leq .05$

[a] statistical comparison of groups not completed

Table 4.2

Comparison of Diagnostic Factors between Breast Conserving Surgery and Mastectomy with Contralateral Prophylactic Mastectomy (n = 78)

Diagnostic Factors	Total Sample (n = 78)	Breast Conserving Surgery (n = 47)	Mastectomy with Contralateral Prophylactic Mastectomy (n = 31)	p
Breast Magnetic Resonance Imaging (MRI) prior to surgery				
Yes	39 (50)	28 (60)	11 (35.5)	
No	39 (50)	19 (40)	21 (65.5)	.037*
Post MRI Biopsy				
Yes	17 (22)	13 (28)	4 (13)	
No	61 (78)	34 (72)	27(87)	.122
Genetic Counseling				
Yes	33(42)	13 (28)	20 (64.5)	
No	45 (58)	34 (72)	11 (35.5)	.002*
Genetic Testing Results				
Positive	3 (4)	0	3 (10)	
Negative	30 (39)	13 (28)	17 (55)	
None	45 (58)	34 (72)	11 (35)	.261
Family History in First Degree Relative				
Yes	20 (26)	10 (21)	10 (32)	
No	58 (74)	37 (79)	21 (68)	.277
High-Risk (Gail risk ≥ 20%)				
Yes	8 (10)	3 (6)	5 (16)	
No	70 (90)	44 (94)	26 (84)	.254

Data presented as frequency (%)
Breast MRI prior to surgery, post MRI biopsy, genetic counseling, family history in first degree relative compared with Chi-square tests
Genetic testing results and high-risk status compared with Fisher's Exact test
*significant $p \leq .05$

Table 4.3

Clinical Characteristics of the Sample (n = 78)

Clinical Characteristics	Total Sample (n = 78)	Breast Conserving Surgery (n = 47)	Mastectomy with Contralateral Prophylactic Mastectomy (n = 31)	p
Tumor Size (cms.), mean (± SD)	1.5 ± 1.24	1.1 ± 0.67	2.2 ± 1.5	.000*
Tumor Histology				
Ductal (In Situ or Invasive)	71 (91)	41 (87)	30 (97)	
Lobular (In Situ or Invasive)	7 (9)	6 (13)	1 (3)	.233
Lymph Node Status				
Positive	8 (10)	2 (4)	6 (19)	
Negative	58 (74)	33 (70)	25 (81)	
Not Applicable	12 (15)	12 (26)	0	.134
Estrogen Receptor				
Positive	74 (95)	45 (96)	29 (94)	
Negative	4 (5)	2 (4)	2 (7)	1.0
Progesterone Receptor				
Positive	75 (96)	45 (96)	29 (94)	
Negative	4 (5)	2 (4)	1 (3)	1.0
HER2-neu Receptor				
Positive	6 (8)	3 (6)	3 (10)	
Negative	56 (72)	32 (68)	24 (77)	
Not Applicable	16 (21)	12 (26)	26 (81)	1.0

Data presented as frequency (%)
Tumor size compared by independent t-test
Histology, lymph node status, estrogen receptor status, progesterone receptor status and HER2-neu compared with Fisher's Exact test
*significant $p \leq .05$

Table 4.4

Properties of Study Scales and Subscales: Depression Anxiety Stress Scale (DASS), Impact of Events Scale (IES), Decisional Conflict Scale (DCS)

Scale/Subscale	n	M	SD	α	Range	
					Potential	Actual
DASS	75	20.10	18.09	.96	0 - 126	0 - 75
DASS Depression Subscale	76	6.38	8.24	.95	0 - 42	0 - 40
DASS Anxiety Subscale	78	5.44	6.26	.86	0 - 42	0 - 27
DASS Stress Subscale	77	9.39	7.32	.91	0 - 42	0 - 25
IES	77	28.20	18.54	.93	0-75	0 - 67
IES Intrusion Subscale	77	13.52	9.49	.89	0-35	0-35
IES Avoidance Subscale	78	14.59	10.17	.87	0-40	0-36
DCS	78	9.10	12.62	.95	0-100	0-73.44
DCS Informed Subscale	78	7.16	12.72	.89	0-100	0-66.67
DCS Values Clarity Subscale	78	10.04	16.14	.93	0-100	0-75
DCS Support Subscale	78	5.56	12.06	.92	0-100	0-75
DCS Uncertainty Subscale	78	14.85	17.29	.67	0-100	0-75
DCS Effective Decision Subscale	78	8.17	13.60	.92	0-100	0-75

Table 4.5

Distribution of Depression, Anxiety, and Stress Scores by Level of Symptom Severity (n = 78)

	Depression		Anxiety		Stress	
Level*	Range	Frequency (Percent)	Range	Frequency (Percent)	Range	Frequency (Percent)
Normal	0 – 9	62 (80)	0 – 7	56 (72)	0 – 14	58 (74)
Mild	10 – 13	2 (3)	8 – 9	6 (8)	15 – 18	6 (8)
Moderate	14 – 20	6 (8)	10 – 14	7 (9)	19 – 25	13 (17)
Severe	21 – 27	4 (5)	15 – 19	6 (8)	26 – 33	0
Extremely Severe	28 – 42	2 (3)	20 – 42	3 (4)	34 – 42	0

* Lovibond and Lovibond (1995)

Table 4.6

Comparison of Scores: Depression Anxiety Stress Scale (DASS) and Subscales, Impact of Events Scale (IES) and Subscales and Decisional Conflict Scale (DCS) and Subscales among Women Choosing Breast Conserving Surgery (BCS) or Mastectomy with Contralateral Prophylactic Mastectomy (CPM)

Measure (range of potential scores)	BCS (n = 47)	Mastectomy with CPM (n = 31)	p
DASS Total (0-126)	18 (SD 17)	24 (SD 19)	.587
DASS Depression Subscale (0-42)	6 (SD 9)	7 (SD 9)	.592
DASS Anxiety Subscale (0-42)	4 (SD 5)	7 (SD 8)	.004*
DASS Stress Subscale (0-42)	8 (SD 7)	11 (SD 8)	.345
IES Total (0-75)	25 (SD 18)	33 (SD 9)	.503
IES Intrusion Subscale (0-35)	11 (SD 9)	17 (SD 10)	.006*
IES Avoidance Subscale (0-40)	14 (SD 10)	16 (SD 11)	.395
DCS Total (0-100)	10 (SD 15)	8 (SD 8)	.021*
DCS Informed Subscale (0-100)	8 (SD 14)	5 (SD 8)	.183
DCS Values Clarity Subscale (0-100)	7 (SD 12)	4 (SD 8)	.021*
DCS Support (0-100)	7 (SD 14)	4 (SD 8)	.053*
DCS Uncertainty (0-100)	13 (SD 19)	17 (SD 14)	.199
DCS Effective Decision (0-100)	10 (SD 16)	6 (SD 9)	.013*

Mean (Standard Deviation)
Independent sample t-test
*significant $p \leq .05$

Table 4.7

Breast Surgery Beliefs and Expectation Scale (n = 77)

	Not At All Important	Somewhat Important	Important	Very Important
Keep my breast	14 (18)	37 (48)	17 (22)	9 (12)
Minimize the chance of breast cancer coming back	0	2 (3)	12 (16)	63 (82)
Avoid Radiation	24 (31)	19 (25)	18 (23)	16 (21)
Minimize the length of treatment*	11 (14)	22 (29)	14 (18)	29 (38)
Remove breast for peace of mind	25 (33)	14 (18)	12 (16)	26 (34)
Avoid the need for future mammograms/breast screening	38 (49)	9 (12)	13 (17)	17 (22)
Do as little surgery as possible	17 (22)	28 (36)	13 (17)	19 (25)
Minimize the chance of dying of breast cancer	2 (3)	5 (7)	2 (3)	68 (88)
Have the option to improve my breasts through reconstruction	36 (47)	12 (16)	8 (10)	21 (27)
Values given as frequency (%) *missing data = 1				

Table 4.8

Breast Surgery Belief and Expectation Scale Factor Analysis with Varimax Rotation (n = 77)

Item	Factors		
	1	2	3
BSBE5 Remove breast for peace of mind	.803	.354	-.194
BSBE3 Avoid Radiation	.797		.266
BSBE6 Avoid the need for future mammograms/breast screening	.706		
BSBE9 Have the option to improve my breasts through reconstruction	.511	.275	
BSBE2 Minimize the chance of breast cancer coming back	.157	.871	
BSBE8 Minimize the chance of dying of breast cancer	.125	.848	.105
BSBE7 Do as little surgery as possible	.192		.806
BSBE1 Keep my breast	-.182	.101	.747
BSBE4 Minimize the length of treatment	.480		.537

Table 4.9

Most Influential Information Source of Women Choosing BCS or Mastectomy with CPM

Most Influential Information Source	Total Sample (n = 78)	BCS (n = 47)	Mastectomy with CPM (n = 31)	p
Physician				
Yes	30 (39)	25 (53)	5 (16)	
No	32 (41)	14 (30)	18 (58)	
Missing	16 (21)	8 (17)	8 (26)	.001*
Spouse/Family				
Yes	16 (21)	6 (13)	10 (32)	
No	46 (59)	33 (70)	13 (42)	
Missing	16 (21)	8 (17)	8 (74)	.015*
Data presented as frequency (%) Comparison by chi-square *significant $p \leq .05$				

Figure 4.1

Sources of Information Identified by Women with Early Stage Breast Cancer Making Surgical Decisions (reported in %, n = 78)

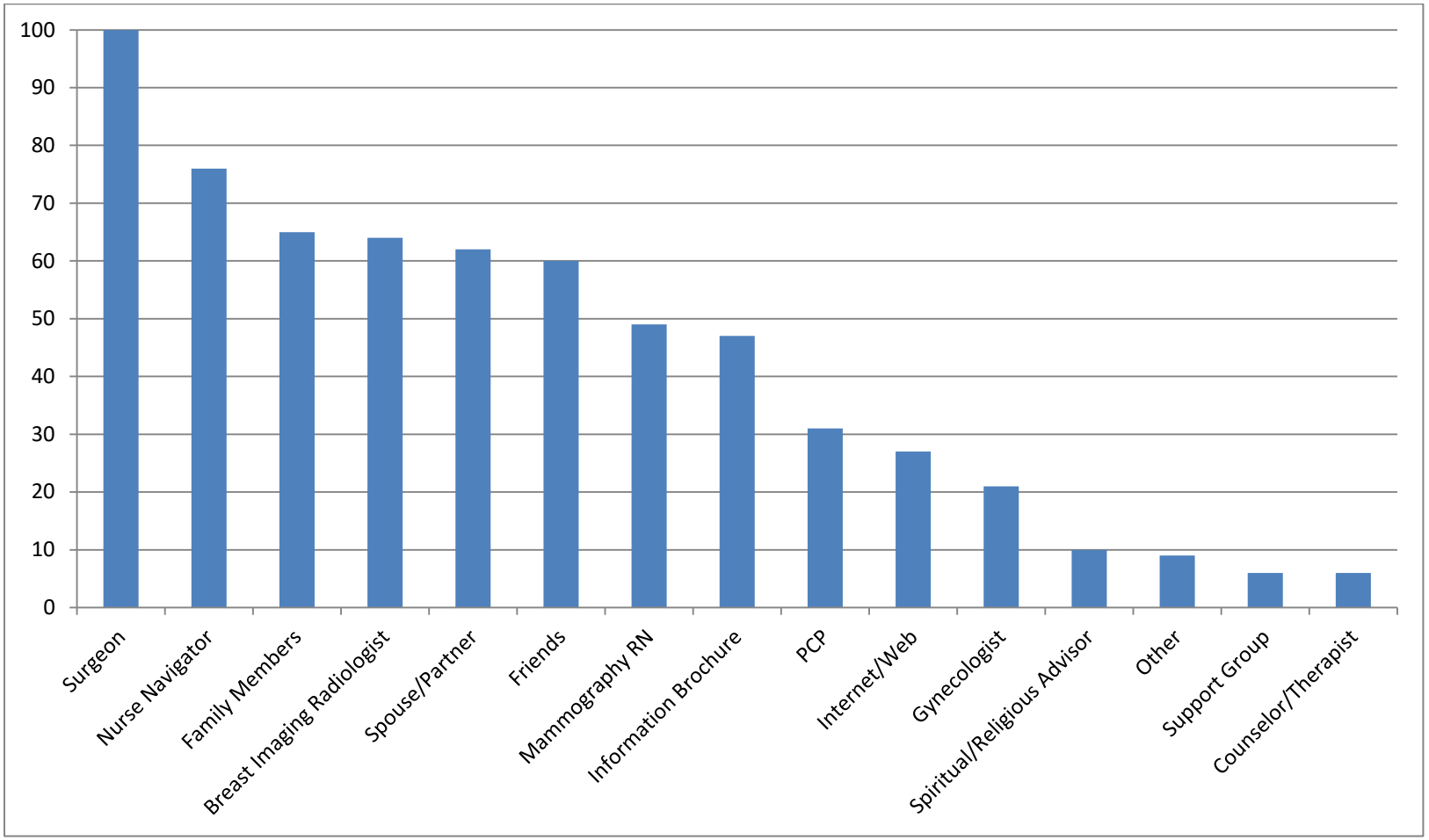
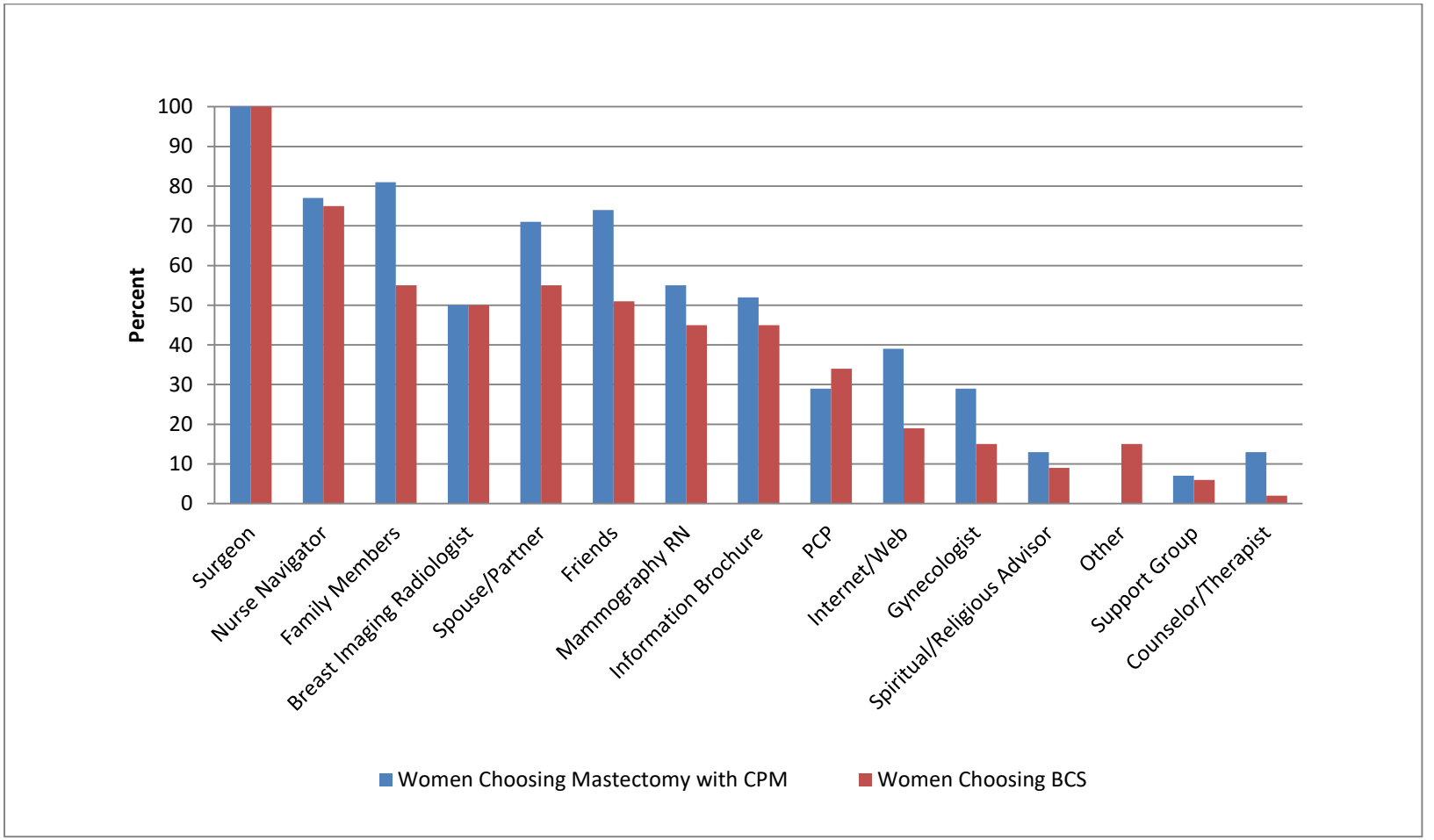


Figure 4.2

Sources of Information Identified by Women Choosing Mastectomy with Contralateral Prophylactic Mastectomy (CPM) and Breast Conserving Surgery (BCS) (reported in %, n = 78)



CHAPTER FIVE:

Conclusion

The essential basis of shared decision-making is a choice among options. The options are neither right nor wrong, they are different. Such is the case in clinical practice with early stage, unilateral breast cancer patients who are making choices among surgery options. The choices are quite different and are optimally discussed in a shared decision-making process between patient and healthcare provider. The goal is a quality decision, based on personal values and on the best evidence (Ottawa Hospital Research Institute, 2015). In an effort to study the decision making process among women with early stage breast cancer, this dissertation was undertaken.

Chapter Two of this dissertation is a psychometric evaluation of an anxiety measure. The Depression Anxiety Stress Scale (DASS), a valid and reliable measure in various settings, had not been tested with women recalled for false-positive mammograms. Women in the original study completed questionnaires including the DASS. In this secondary data analysis, the DASS Anxiety subscale was evaluated in a subset of 2672 women from the original study. Analysis supported the reliability and validity of the DASS anxiety subscale with women recalled for false-positive mammograms.

Anxiety has been reported in women recalled for false-positive mammograms and in women who are diagnosed with breast cancer (Nelson et al., 2016; Pedersen et al., 2010). In the breast cancer setting, levels of anxiety have been found to both be correlated and to not be correlated with surgery type (i.e. breast conserving surgery or mastectomy) when measured post-operatively (Lim, Devi, & Ang, 2011). There is some

evidence of coincident anxiety during the decision-making process and elevated levels of anxiety in the preoperative time period have been consistently described in studies of women diagnosed with breast cancer (Epping-Jordan et al., 1999; Goel et al., 2001; Pedersen et al., 2010; Rakovitch et al., 2003).

Chapter Three is a critical review of decisional conflict scales. This review was undertaken to evaluate decisional conflict scales for use during breast cancer surgical decision making. The background of scale development and psychometric properties of decision conflict scales were reported in this chapter. The Decisional Conflict Scale (DCS) has demonstrated reliability and validity overall but some variation in factor structure has been reported. The DCS is widely used in research about medical decision-making. The analysis from this chapter provided important information for the study described in Chapter Four.

Chapter Four completes the dissertation with the report of a prospective, exploratory, cross-sectional, mixed-methods study. The study was designed to generate new knowledge about factors influencing preference for surgical choice among women with early stage breast cancer. There has been a lack of prospective research on this topic. Most of the research conducted to date has been retrospective reviews of large cancer database information. Some retrospective surveys and interviews with patients have also been conducted. Prospective studies are needed to describe beliefs, expectations and emotions which may influence decisions as decision-making takes place.

In the study described in Chapter Four, factors were compared between subgroups of women choosing breast conserving surgery (n = 47) and mastectomy with contralateral

prophylactic mastectomy (n = 31). There was significant difference between the groups regarding: age, employment, tumor size, completion of preoperative breast magnetic resonance imaging and genetic counseling. Women choosing mastectomy with CPM were younger, had larger tumors, and completed genetic counseling prior to surgery which is consistent with previous reports. Results from this study contradict previous work in which preoperative MRI has been predictive of bilateral mastectomy. In this study, women who completed preoperative breast MRI were more likely to choose breast conserving surgery. Women who worked part- or full-time were more likely to choose bilateral mastectomy which is a new finding.

Anxiety and breast-cancer specific distress were significantly higher among women choosing mastectomy with contralateral mastectomy. Decisional conflict was higher among women choosing breast conserving surgery. The significant differences between the groups for both anxiety and decisional conflict are new findings. A new scale, the Breast Surgery Beliefs and Expectations Scale was developed for use in this study to examine differences between the two groups. Factor analysis was completed and the resulting three factors were analyzed by subgroup. Significant differences between the two groups for all three factors were found. Information sources were similar between the groups but the surgeon was the most influential information source to women choosing breast conserving surgery and family was the most influential source for those choosing bilateral mastectomy. This study provides evidence regarding the influence of factors such as anxiety, intrusive impact, surgery beliefs and expectations, and information sources in the decision-making process.

Appendix

Study Packet

#_____

Factors Influencing Preference for Surgical Choice among Women with Early Stage Breast Cancer

Demographic Questionnaire

How old are you? _____ years

Instructions: To each item, please circle the response that best describes you

1.Race 1. Caucasian (White) 2. African-American 3. Hispanic 4. Asian 5. American-Indian 6. Alaskan-Indian 7. Other _____	**4. Marital Status** 1. Married/Partnered 2. Divorced/Separated/Single/Widowed
2.Education: Circle the highest level of education completed 1. Elementary 2. High school 3. College/University 4. Graduate School	**5.Employment** 1. Employed Full or Part Time 2. Other
3.Household Income 1. Less than $20,000 2. $20,001 - $40,000 3. $40,001 - $80,000 4. More than $80,001	**6.Insurance** 1. No Insurance/Self Pay 2. Medicaid 3. Any commercial insurance (Anthem, Blue Grass Family Health, United, etc) 4. Medicare with or without a supplement

Instructions: To each item, please fill in the blanks or circle the response that best describes you

Do you have a personal history of a genetic mutation that increases the risk of breast cancer (i.e. BRCA1 or BRCA2)

1) Yes
2) No
3) I don't know

Has anyone ever told you that your lifetime risk of contracting Breast Cancer was higher than an average woman of your age?

1) Yes
2) No
3) I don't know

If yes, please write in your percentage of lifetime risk for developing Breast Cancer if you know it _____%

At what age did you experience menarche (first period)?_____

At what age was your first live birth?_____

Prior to any biopsies for *this* breast cancer diagnosis, how many breast biopsies have you had?

1) 0
2) 1
3) >1

Have any of those biopsies prior to this diagnosis shown any of the following?
Please circle any and all of previous biopsy findings

1) ADH (Atypical Ductal Hyperplasia)
2) ALH (Atypical Lobular Hyperplasia)
3) LCIS (Lobular Carcinoma in Situ)
4) DCIS (Ductal Carcinoma in Situ)
5) Not Applicable/No biopsies prior to this diagnosis

Family History of Breast Cancer in First Degree Relatives

Please circle "Yes" or "No" indicating any of your relatives who have been diagnosed with Breast Cancer

Relative	**Diagnosed with Breast Cancer**
Parent (either mother or father)	Yes No
Any one sister	Yes No
More than one sister	Yes No
Any one daughter	Yes No
More than one daughter	Yes No

DASS

Please read each statement and circle a number 0, 1, 2 or 3 which indicates 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:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1	I found myself getting upset by quite trivial things	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I just couldn't seem to get going	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I had a feeling of shakiness (eg, legs going to give way)	0	1	2	3
8	I found it difficult to relax	0	1	2	3
9	I found myself in situations that made me so anxious I was most relieved when they ended	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting upset rather easily	0	1	2	3
12	I felt that I was using a lot of nervous energy	0	1	2	3
13	I felt sad and depressed	0	1	2	3
14	I found myself getting impatient when I was delayed in any way (eg, elevators, traffic lights, being kept waiting)	0	1	2	3
15	I had a feeling of faintness	0	1	2	3
16	I felt that I had lost interest in just about everything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I perspired noticeably (eg, hands sweaty) in the absence of high temperatures or physical exertion	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life wasn't worthwhile	0	1	2	3

Reminder of the rating scale:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

22	I found it hard to wind down	0	1	2	3
23	I had difficulty in swallowing	0	1	2	3
24	I couldn't seem to get any enjoyment out of the things I did	0	1	2	3
25	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
26	I felt down-hearted and blue	0	1	2	3
27	I found that I was very irritable	0	1	2	3
28	I felt I was close to panic	0	1	2	3
29	I found it hard to calm down after something upset me	0	1	2	3
30	I feared that I would be "thrown" by some trivial but unfamiliar task	0	1	2	3
31	I was unable to become enthusiastic about anything	0	1	2	3
32	I found it difficult to tolerate interruptions to what I was doing	0	1	2	3
33	I was in a state of nervous tension	0	1	2	3
34	I felt I was pretty worthless	0	1	2	3
35	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
36	I felt terrified	0	1	2	3
37	I could see nothing in the future to be hopeful about	0	1	2	3
38	I felt that life was meaningless	0	1	2	3
39	I found myself getting agitated	0	1	2	3
40	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
41	I experienced trembling (eg, in the hands)	0	1	2	3
42	I found it difficult to work up the initiative to do things	0	1	2	3

Impact of Event Scale

Instructions: Please read each item, and then indicate how frequently those comments were true for you during the past 7 days with respect to your experience with breast cancer
0 = Not at all, 1 = Rarely, 3 = Sometimes, 5 = Often

	Not at all	Rarely	Sometimes	Often
1. I thought about it when I didn't mean to	0	1	3	5
2. I avoided letting myself get upset when I thought about it or was reminded of it	0	1	3	5
3. I tried to remove it from my memory	0	1	3	5
4. I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came into my mind	0	1	3	5
5. I had waves of strong feelings about it	0	1	3	5
6. I had dreams about it	0	1	3	5
7. I stayed away from reminders of it	0	1	3	5
8. I felt as if it hadn't happened or wasn't real	0	1	3	5
9. I tried not to talk about it	0	1	3	5
10. Pictures about it popped into my mind	0	1	3	5
11. Other things kept making me think about it	0	1	3	5
12. I was aware I still had a lot of feelings about it but I didn't deal with them	0	1	3	5
13. I tried not to think about it	0	1	3	5
14. Any reminder brought back feelings about it	0	1	3	5
15. My feelings about it were kind of numb	0	1	3	5

Decisional Conflict

A. Which breast surgery option have you chosen? *Please check √ one.*

☐ Lumpectomy (Breast conserving surgery)

☐ Mastectomy (Removal of one breast only)

☐ Bilateral Mastectomy (Removal of both breasts)

B. Considering the option you prefer, please answer the following questions:

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
1. I know which options are available to me.	☐	☐	☐	☐	☐
2. I know the benefits of each option.	☐	☐	☐	☐	☐
3. I know the risks and side effects of each option.	☐	☐	☐	☐	☐
4. I am clear about which benefits matter most to me.	☐	☐	☐	☐	☐
5. I am clear about which risks and side effects matter most to me.	☐	☐	☐	☐	☐
6. I am clear about which is more important to me (the benefits or the risks and side effects).	☐	☐	☐	☐	☐
7. I have enough support from others to make a choice.	☐	☐	☐	☐	☐
8. I am choosing without pressure from others.	☐	☐	☐	☐	☐
9. I have enough advice to make a choice.	☐	☐	☐	☐	☐
10. I am clear about the best choice for me.	☐	☐	☐	☐	☐
11. I feel sure about what to choose.	☐	☐	☐	☐	☐
12. This decision is easy for me to make.	☐	☐	☐	☐	☐
13. I feel I have made an informed choice.	☐	☐	☐	☐	☐
14. My decision shows what is important to me.	☐	☐	☐	☐	☐
15. I expect to stick with my decision.	☐	☐	☐	☐	☐
16. I am satisfied with my decision.	☐	☐	☐	☐	☐

Breast Surgery Beliefs and Expectations

Instructions: Circle the number that best indicates the importance of each item as you were making your decision about surgery.				
The rating scale is as follows: 1 = Not at all Important or Not Applicable, 2 = Somewhat Important, 3 = Important, 4 = Very Important				
	Not at all Important	Somewhat Important	Important	Very Important
Keep my breast	1	2	3	4
Minimize the chance of breast cancer coming back	1	2	3	4
Avoid Radiation	1	2	3	4
Minimize the length of treatment	1	2	3	4
Remove breast for peace of mind	1	2	3	4
Avoid the need for future mammograms/breast screening	1	2	3	4
Do as little surgery as possible	1	2	3	4
Minimize the chance of dying of breast cancer	1	2	3	4
Have the option to improve my breasts through reconstruction	1	2	3	4

Breast Surgery Beliefs and Expectations

Please rank the following 9 factors in order of importance to you as you were making your surgical choice. 1 = Most Important, 9 = Least Important

_____ Keep my breast

_____ Minimize the chance of breast cancer coming back

_____ Avoid Radiation

_____ Minimize the length of treatment

_____ Remove breast for peace of mind

_____ Avoid the need for future mammograms/breast screening

_____ Do as little surgery as possible

_____ Minimize the chance of dying of breast cancer

_____ Have the option to improve my breasts through reconstruction

Sources of Information

Please check all of the following which/who served as a source of information to you as you considered your breast cancer surgical decision

_____Surgeon

_____Gynecologist

_____Primary Care Provider

_____Mammography/Breast Imaging Physician

_____Nurse Navigator

_____Mammography/Breast Imaging Nurse

_____Spouse/Partner

_____Family Member(s)

_____Friend(s)

_____Support Group Members

_____Counselor/Therapist

_____Spiritual/Religious Advisor

_____Internet/Web

_____Informational Brochure/Written Materials

_____Other (please specify)_____

****Of the choices you marked above, please indicate which/who was <u>the most influential</u> in your decision. Please circle that response.*

Comment

In your own words, please describe the reason for your surgical choice:

Did your initial intent regarding surgery match your final decision?
Please check yes or no:

☐ Yes

☐ No

Thank you!

References

American Cancer Society. (2013). *Breast Cancer Facts & Figures, 2013-2014*. Retrieved from Atlanta, GA:

Antony, M. M. (1998). Psychometric Properties of the 42-Item and the 21-Item Versions of the Depression Anxiety Stress Scales in Clinical Groups and a Community Sample. *Psychological Assessment, 10*(2), 176-181.

Arrington, A. K., Jarosek, S. L., Virnig, B. A., Habermann, E. B., & Tuttle, T. M. (2009). Patient and surgeon characteristics associated with increased use of contralateral prophylactic mastectomy in patients with breast cancer. *Annals of Surgical Oncology, 16*(10), 2697-2704. doi:10.1245/s10434-009-0641-z

Balch, C. M., & Jacobs, L. K. (2009). Mastectomies on the rise for breast cancer: "the tide is changing". *Annals of Surgical Oncology, 16*(10), 2669-2672. doi:10.1245/s10434-009-0634-y

Balneaves, L. G., & Long, B. (1999). An embedded decisional model of stress and coping: implications for exploring treatment decision making by women with breast cancer. *Journal of Advanced Nursing, 30*(6), 1321-1331.

Baptiste, Dadrie F., MacGeorge, Erina L., Venetis, Maria K., Mouton, Ashton, Friley, L. Brooke, Pastor, Rebekah, . . . Bowling, Monet W. (2017). Motivations for contralateral prophylactic mastectomy as a function of socioeconomic status. *BMC Women's Health, 17*, 1-9. doi:10.1186/s12905-017-0366-2

Beesley, H., Holcombe, C., Brown, S. L., & Salmon, P. (2013). Risk, worry and cosmesis in decision-making for contralateral risk-reducing mastectomy: analysis of 60 consecutive cases in a specialist breast unit. *Breast, 22*(2), 179-184. doi:10.1016/j.breast.2012.06.005

Bolejko, A., Hagell, P., Wann-Hansson, C., & Zackrisson, S. (2015). Prevalence, Long-term Development, and Predictors of Psychosocial Consequences of False-Positive Mammography among Women Attending Population-Based Screening. *Cancer Epidemiology, Biomarkers and Prevention, 24*(9), 1388-1397. doi:10.1158/1055-9965.epi-15-0060

Boughey, J. C., Attai, D. J., Chen, S. L., Cody, H. S., Dietz, J. R., Feldman, S. M., . . . Margenthaler, J. A. (2016). Contralateral Prophylactic Mastectomy (CPM) Consensus Statement from the American Society of Breast Surgeons: Data on CPM Outcomes and Risks. *Annals of Surgical Oncology, 23*(10), 3100-3105. doi:10.1245/s10434-016-5443-5

Breast Cancer Surveillance Consortium. *BCSC Mammography Data*. Retrieved from http://breastscreening.cancer.gov/data/mammography_data.html

Brett, J., & Austoker, J. (2001). Women who are recalled for further investigation for breast screening: psychological consequences 3 years after recall and factors affecting re-attendance. *Journal of Public Health Medicine, 23*(4), 292-300.

Brett, J., Bankhead, C., Henderson, B., Watson, E., & Austoker, J. (2005). The psychological impact of mammographic screening. A systematic review. *Psycho-Oncology, 14*(11), 917-938. doi:10.1002/pon.904

Brewer, N. T., Salz, T., & Lillie, S. E. (2007). Systematic review: the long-term effects of false-positive mammograms. *Annals of Internal Medicine, 146*(7), 502-510.

Brodersen, J., & Siersma, V. D. (2013). Long-term psychosocial consequences of false-positive screening mammography. *Annals of Family Medicine, 11*(2), 106-115. doi:10.1370/afm.1466

Brown, T. A., Chorpita, B. F., Korotitsch, W., & Barlow, D. H. (1997). Psychometric properties of the Depression Anxiety Stress Scales (DASS) in clinical samples. *Behaviour Research and Therapy, 35*(1), 79-89.

Buchanan, P. J., Abdulghani, M., Waljee, J. F., Kozlow, J. H., Sabel, M. S., Newman, L. A., . . . Momoh, A. O. (2016). An Analysis of the Decisions Made for Contralateral Prophylactic Mastectomy and Breast Reconstruction. *Plastic and Reconstructive Surgery, 138*(1), 29-40. doi:10.1097/prs.0000000000002263

Burke, E. E., Portschy, P. R., & Tuttle, T. M. (2015). Prophylactic mastectomy: who needs it, when and why. *Journal of Surgical Oncology, 111*(1), 91-95. doi:10.1002/jso.23695

Chagpar, A. B., Studts, J. L., Scoggins, C. R., Martin, R. C., 2nd, Carlson, D. J., Laidley, A. L., . . . McMasters, K. M. (2006). Factors associated with surgical options for breast carcinoma. *Cancer, 106*(7), 1462-1466. doi:10.1002/cncr.21728

Collins, E. D., Moore, C. P., Clay, K. F., Kearing, S. A., O'Connor, A. M., Llewellyn-Thomas, H. A., . . . Sepucha, K. R. (2009). Can women with early-stage breast cancer make an informed decision for mastectomy? *Journal of Clinical Oncology, 27*(4), 519-525. doi:10.1200/JCO.2008.16.6215

Covelli, A. M., Baxter, N. N., Fitch, M. I., McCready, D. R., & Wright, F. C. (2014). 'Taking Control of Cancer': Understanding Women's Choice for Mastectomy. *Annals of Surgical Oncology*. doi:10.1245/s10434-014-4033-7

Crawford, J. R., & Henry, J. D. (2003). The Depression Anxiety Stress Scales (DASS): normative data and latent structure in a large non-clinical sample. *British Journal of Clinical Psychology, 42*(Pt 2), 111-131. doi:10.1348/014466503321903544

Cunningham, N. K., Brown, P. M., Brooks, J., & Page, A. C. (2013). The structure of emotional symptoms in the postpartum period: is it unique? *J Affect Disord, 151*(2), 686-694. doi:10.1016/j.jad.2013.08.002

Damle, S., Teal, C. B., Lenert, J. J., Marshall, E. C., Pan, Q., & McSwain, A. P. (2011). Mastectomy and contralateral prophylactic mastectomy rates: an institutional review. *Annals of Surgical Oncology, 18*(5), 1356-1363. doi:10.1245/s10434-010-1434-0

DeSantis, C., Ma, J., Bryan, L., & Jemal, A. (2014). Breast cancer statistics, 2013. *CA: A Cancer Journal for Clinicians, 64*(1), 52-62. doi:10.3322/caac.21203

Dickerson, Suzanne S., Alqaissi, Nesreen, Underhill, Meghan, & Lally, Robin M. (2011). Surviving the wait: defining support while awaiting breast cancer surgery. *Journal of Advanced Nursing, 67*(7), 1468-1479. doi:10.1111/j.1365-2648.2011.05612.x

Dragun, A. E., Pan, J., Riley, E. C., Kruse, B., Wilson, M. R., Rai, S., & Jain, D. (2013). Increasing use of elective mastectomy and contralateral prophylactic surgery among breast conservation candidates: a 14-year report from a comprehensive cancer center. *American Journal of Clinical Oncology, 36*(4), 375-380. doi:10.1097/COC.0b013e318248da47

Durand, M. A., Stiel, M., Boivin, J., & Elwyn, G. (2008). Where is the theory? Evaluating the theoretical frameworks described in decision support technologies. *Patient Education and Counseling, 71*(1), 125-135. doi:10.1016/j.pec.2007.12.004

Early Breast Cancer Trialists' Group. (2011). Effect of radiotherapy after breast-conserving surgery on 10-year recurrence and 15-year breast cancer death: meta-analysis of individual patient data for 10,801 women in 17 randomised trials. *Lancet, 378*(9804), 1707-1716. doi:10.1016/s0140-6736(11)61629-2

Ekeberg, O., Skjauff, H., & Karesen, R. (2001). Screening for breast cancer is associated with a low degree of psychological distress. *Breast, 10*(1), 20-24. doi:10.1054/brst.2000.0177

Elwyn, G., Stiel, M., Durand, M. A., & Boivin, J. (2011). The design of patient decision support interventions: addressing the theory-practice gap. *Journal of Evaluation in Clinical Practice, 17*(4), 565-574. doi:10.1111/j.1365-2753.2010.01517.x

Epping-Jordan, J. E., Compas, B. E., Osowiecki, D. M., Oppedisano, G., Gerhardt, C., Primo, K., & Krag, D. N. (1999). Psychological adjustment in breast cancer: processes of emotional distress. *Health Psychology, 18*(4), 315-326.

Fagerlin, A., Lakhani, I., Lantz, P. M., Janz, N. K., Morrow, M., Schwartz, K., . . . Katz, S. J. (2006). An informed decision? Breast cancer patients and their knowledge about treatment. *Patient Education and Counseling, 64*(1-3), 303-312. doi:10.1016/j.pec.2006.03.010

Ferron Parayre, A., Labrecque, M., Rousseau, M., Turcotte, S., & Légaré, F. (2014). Validation of SURE, a Four-Item Clinical Checklist for Detecting Decisional Conflict in Patients. *Medical Decision Making, 34*(1), 54-62. doi:10.1177/0272989x13491463

Fisher, C. S., Martin-Dunlap, T., Ruppel, M. B., Gao, F., Atkins, J., & Margenthaler, J. A. (2012). Fear of recurrence and perceived survival benefit are primary motivators for choosing mastectomy over breast-conservation therapy regardless of age. *Annals of Surgical Oncology, 19*(10), 3246-3250. doi:10.1245/s10434-012-2525-x

Gao, X., Fisher, S. G., & Emami, B. (2003). Risk of second primary cancer in the contralateral breast in women treated for early-stage breast cancer: a population-based study. *International Journal of Radiation Oncology, Biology, Physics, 56*(4), 1038-1045.

Goel, V., Sawka, C. A., Thiel, E. C., Gort, E. H., & O'Connor, A. M. (2001). Randomized trial of a patient decision aid for choice of surgical treatment for breast cancer. *Medical Decision Making, 21*(1), 1-6.

Gotzsche, P. C., & Jorgensen, K. J. (2013). Screening for breast cancer with mammography. *Cochrane Database Syst Rev, 6*, Cd001877. doi:10.1002/14651858.CD001877.pub5

Graves, K. D., Peshkin, B. N., Halbert, C. H., DeMarco, T. A., Isaacs, C., & Schwartz, M. D. (2007). Predictors and outcomes of contralateral prophylactic mastectomy among breast cancer survivors. *Breast Cancer Research and Treatment, 104*(3), 321-329. doi:10.1007/s10549-006-9423-5

Guth, U., Myrick, M. E., Viehl, C. T., Weber, W. P., Lardi, A. M., & Schmid, S. M. (2012). Increasing rates of contralateral prophylactic mastectomy - a trend made in USA? *European Journal of Surgical Oncology, 38*(4), 296-301. doi:10.1016/j.ejso.2011.12.014

Hafslund, B., Espehaug, B., & Nortvedt, M. W. (2012). Effects of false-positive results in a breast screening program on anxiety, depression and health-related quality of life. *Cancer Nursing, 35*(5), E26-34. doi:10.1097/NCC.0b013e3182341ddb

Han, E., Johnson, N., Glissmeyer, M., Wagie, T., Carey, B., DelaMelena, T., & Nelson, J. (2011). Increasing incidence of bilateral mastectomies: the patient perspective. *American Journal of Surgery, 201*(5), 615-618. doi:10.1016/j.amjsurg.2011.01.018

Hawley, S. T., Jagsi, R., Morrow, M., Janz, N. K., Hamilton, A., Graff, J. J., & Katz, S. J. (2014). Social and Clinical Determinants of Contralateral Prophylactic Mastectomy. *JAMA Surg*. doi:10.1001/jamasurg.2013.5689

Horowitz, M.J. (1994). Measures for Clinical Practice: A Sourcebook (2nd ed., Vol. 2, pp. 275-277). New York: The Free Press.

Jagsi, R., Hawley, S. T., Griffith, K. A., Janz, N. K., Kurian, A. W., Ward, K. C., . . . Katz, S. J. (2017). Contralateral Prophylactic Mastectomy Decisions in a Population-Based Sample of Patients With Early-Stage Breast Cancer. *JAMA Surg, 152*(3), 274-282. doi:10.1001/jamasurg.2016.4749

Janis, I. L., & Mann, L. (1976). Coping with Decisional Conflict: An analysis of how stress affects decision-making suggests interventions to improve the process. *American Scientist, 64*(6), 657-667.

Jones, N. B., Wilson, J., Kotur, L., Stephens, J., Farrar, W. B., & Agnese, D. M. (2009). Contralateral prophylactic mastectomy for unilateral breast cancer: an increasing trend at a single institution. *Annals of Surgical Oncology, 16*(10), 2691-2696. doi:10.1245/s10434-009-0547-9

Katapodi, M. C., Munro, M. L., Pierce, P. F., & Williams, R. A. (2011). Psychometric Testing of the Decisional Conflict Scale:Genetic Testing Hereditary Breast and Ovarian Cancer. *Nursing Research, 60*(6), 368-377. doi:10.1097/NNR.0b013e3182337dad

Katz, S. J., & Hawley, S. T. (2007). From policy to patients and back: surgical treatment decision making for patients with breast cancer. *Health Affairs, 26*(3), 761-769. doi:10.1377/hlthaff.26.3.761

King, T. A., Sakr, R., Patil, S., Gurevich, I., Stempel, M., Sampson, M., & Morrow, M. (2011). Clinical management factors contribute to the decision for contralateral prophylactic mastectomy. *Journal of Clinical Oncology, 29*(16), 2158-2164. doi:10.1200/JCO.2010.29.4041

Koedoot, N., Molenaar, S., Oosterveld, P., Bakker, P., de Graeff, A., Nooy, M., . . . de Haes, H. (2001). The decisional conflict scale: further validation in two samples of Dutch oncology patients. *Patient Education and Counseling, 45*(3), 187-193.

Kokufu, H. (2012). Conflict accompanying the choice of initial treatment in breast cancer patients. *Japan Journal of Nursing Science, 9*(2), 177-184. doi:10.1111/j.1742-7924.2011.00200.x

Kryworuchko, J., Stacey, D., Bennett, C., & Graham, I. D. (2008). Appraisal of primary outcome measures used in trials of patient decision support. *Patient Education and Counseling, 73*(3), 497-503. doi:10.1016/j.pec.2008.07.011

Lally, R. M. (2009). In the moment: women speak about surgical treatment decision making days after a breast cancer diagnosis. *Oncology Nursing Forum, 36*(5), E257-265. doi:10.1188/09.ONF.E257-E265

Lam, W. W., Kwok, M., Liao, Q., Chan, M., Or, A., Kwong, A., . . . Fielding, R. (2012). Psychometric assessment of the Chinese version of the decisional conflict scale in Chinese women making decision for breast cancer surgery. *Health Expect*. doi:10.1111/hex.12021

Lantz, P. V., Zemencuk, J. K., & Katz, S. J. (2002). Is mastectomy overused? A call for an expanded research agenda. *Health Services Research, 37*(2), 417-431.

Legare, F., Kearing, S., Clay, K., Gagnon, S., D'Amours, D., Rousseau, M., & O'Connor, A. (2010). Are you SURE?: Assessing patient decisional conflict with a 4-item screening test. *Canadian Family Physician, 56*(8), e308-314.

Legare, F., O'Connor, A. M., Graham, I. D., Wells, G. A., & Tremblay, S. (2006). Impact of the Ottawa Decision Support Framework on the agreement and the difference between patients' and physicians' decisional conflict. *Med Decis Making, 26*(4), 373-390. doi:10.1177/0272989X06290492

Legare, F., Tremblay, S., O'Connor, A. M., Graham, I. D., Wells, G. A., & Jacobsen, M. J. (2003). Factors associated with the difference in score between women's and doctors' decisional conflict about hormone therapy: a multilevel regression analysis. *Health Expect, 6*(3), 208-221.

Légaré, France, O'Connor, Annette M., Graham, Ian D., Wells, Georges A., & Tremblay, Stéphane. (2006). Impact of the Ottawa Decision Support Framework on the Agreement and the Difference between Patients' and Physicians' Decisional Conflict. *Medical Decision Making, 26*(4), 373-390. doi:10.1177/0272989x06290492

Lim, C. C., Devi, M. K., & Ang, E. (2011). Anxiety in women with breast cancer undergoing treatment: a systematic review. *Int J Evid Based Healthc, 9*(3), 215-235. doi:10.1111/j.1744-1609.2011.00221.x

Linder, S. K., Swank, P. R., Vernon, S. W., Mullen, P. D., Morgan, R. O., & Volk, R. J. (2011). Validity of a low literacy version of the Decisional Conflict Scale. *Patient Education and Counseling, 85*(3), 521-524. doi:10.1016/j.pec.2010.12.012

Lostumbo, Liz, Carbine, Nora E., & Wallace, Judi. (2010). Prophylactic mastectomy for the prevention of breast cancer. *Cochrane Database of Systematic Reviews*(11). doi:10.1002/14651858.CD002748.pub3

Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy, 33*(3), 335-343.

Mamtani, A., & Morrow, M. (2017). Why Are There So Many Mastectomies in the United States? *Annual Review of Medicine, 68*, 229-241. doi:10.1146/annurev-med-043015-075227

Mancini, J., Santin, G., Chabal, F., & Julian-Reynier, C. (2006). Cross-cultural validation of the Decisional Conflict Scale in a sample of French patients. *Quality of Life Research, 15*(6), 1063-1068. doi:10.1007/s11136-005-6003-9

Mann, L., Burnett, P., Radford, M., & Ford, S. (1997). The Melbourne Decision Making Questionnaire: An Instrument for Measuring Patterns for Coping with Decisional Conflict. *Journal of Behavioral Decision Making, 10*(1), 1-19.

McGuire, K. P., Santillan, A. A., Kaur, P., Meade, T., Parbhoo, J., Mathias, M., . . . Cox, C. E. (2009). Are mastectomies on the rise? A 13-year trend analysis of the selection of mastectomy versus breast conservation therapy in 5865 patients. *Annals of Surgical Oncology, 16*(10), 2682-2690. doi:10.1245/s10434-009-0635-x

Miller, Sarah J., Schnur, Julie B., Weinberger-Litman, Sarah L., & Montgomery, Guy H. (2014). The relationship between body image, age, and distress in women facing breast cancer surgery. *Palliative & Supportive Care, 12*(5), 363-367. doi:10.1017/S1478951513000321

Moffat, F. L., Jr., & Yakoub, D. (2016). Bilateral mastectomy and the retreat from breast-conserving surgery. *Breast Cancer Research and Treatment, 159*(1), 15-30. doi:10.1007/s10549-016-3909-6

Montgomery, M., & McCrone, S. H. (2010). Psychological distress associated with the diagnostic phase for suspected breast cancer: systematic review. *Journal of Advanced Nursing, 66*(11), 2372-2390. doi:10.1111/j.1365-2648.2010.05439.x

National Accreditation Program for Breast Centers. (2017, October 24, 2017). 2018 National Accreditation Program for Breast Centers Standards Manual. Retrieved from https://www.facs.org/quality-programs/napbc/standards

National Institutes of Health. (1991). NIH consensus conference. Treatment of early-stage breast cancer. *JAMA, 265*(3), 391-395.

Nattinger, A. B., Gottlieb, M. S., Veum, J., Yahnke, D., & Goodwin, J. S. (1992). Geographic variation in the use of breast-conserving treatment for breast cancer. *New England Journal of Medicine, 326*(17), 1102-1107. doi:10.1056/nejm199204233261702

Nelson, H. D., Pappas, M., Cantor, A., Griffin, J., Daeges, M., & Humphrey, L. (2016). Harms of Breast Cancer Screening: Systematic Review to Update the 2009 U.S. Preventive Services Task Force Recommendation. *Annals of Internal Medicine, 164*(4), 256-267. doi:10.7326/m15-0970

Nieuwenhuijsen, K., de Boer, A. G., Verbeek, J. H., Blonk, R. W., & van Dijk, F. J. (2003). The Depression Anxiety Stress Scales (DASS): detecting anxiety disorder and depression in employees absent from work because of mental health problems. *Occupational and Environmental Medicine, 60 Suppl 1*, i77-82.

Noone, J. (2002). Concept analysis of decision making. *Nursing Forum, 37*(3), 21-32.

Obeidat, R., Finnell, D. S., & Lally, R. M. (2011). Decision aids for surgical treatment of early stage breast cancer: A narrative review of the literature. *Patient Education and Counseling, 85*(3), e311-321.

O'Connor, A. M. (1993, 2010). User Manual - Decisional Conflict Scale. Retrieved from http://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf

O'Connor, A. M. (1995). Validation of a Decisional Conflict Scale. *Medical Decision Making, 15*(1), 25-30. doi:10.1177/0272989x9501500105

Ottawa Hospital Research Institute (Producer). (2015, 6/22/15). Ottawa Decision Support Framework Retrieved from https://decisionaid.ohri.ca/odsf.html

Parker, P. A., Peterson, S. K., Bedrosian, I., Crosby, M. A., Shen, Y., Black, D. M., . . . Brewster, A. M. (2016). Prospective Study of Surgical Decision-making Processes for Contralateral Prophylactic Mastectomy in Women With Breast Cancer. *Annals of Surgery, 263*(1), 178-183. doi:10.1097/sla.0000000000001216

Pedersen, A. E., Sawatzky, J. A., & Hack, T. F. (2010). The sequelae of anxiety in breast cancer: a human response to illness model. *Oncology Nursing Forum, 37*(4), 469-475. doi:10.1188/10.onf.469-475

Pesce, C. E., Liederbach, E., Czechura, T., Winchester, D. J., & Yao, K. (2014). Changing surgical trends in young patients with early stage breast cancer, 2003 to 2010: a report from the National Cancer Data Base. *Journal of the American College of Surgeons, 219*(1), 19-28. doi:10.1016/j.jamcollsurg.2014.03.043

Pierce, P. F. (1993). Deciding on breast cancer treatment: a description of decision behavior. *Nursing Research, 42*(1), 22-28.

Portschy, P. R., Abbott, A. M., Burke, E. E., Nzara, R., Marmor, S., Kuntz, K. M., & Tuttle, T. M. (2015). Perceptions of Contralateral Breast Cancer Risk: A Prospective, Longitudinal Study. *Annals of Surgical Oncology*. doi:10.1245/s10434-015-4442-2

Quan, G., Pommier, S. J., & Pommier, R. F. (2008). Incidence and outcomes of contralateral breast cancers. *American Journal of Surgery, 195*(5), 645-650; discussion 650. doi:10.1016/j.amjsurg.2008.01.007

Rakovitch, E., Franssen, E., Kim, J., Ackerman, I., Pignol, J. P., Paszat, L., . . . Redelmeier, D. A. (2003). A comparison of risk perception and psychological morbidity in women with ductal carcinoma in situ and early invasive breast cancer. *Breast Cancer Research and Treatment, 77*(3), 285-293.

Reyna, V. F. (2008). Theories of medical decision making and health: an evidence-based approach. *Medical Decision Making, 28*(6), 829-833. doi:10.1177/0272989x08327069

Rosenberg, S. M., Sepucha, K., Ruddy, K. J., Tamimi, R. M., Gelber, S., Meyer, M. E., . . . Partridge, A. H. (2015). Local Therapy Decision-Making and Contralateral Prophylactic Mastectomy in Young Women with Early-Stage Breast Cancer. *Annals of Surgical Oncology, 22*(12), 3809-3815. doi:10.1245/s10434-015-4572-6

Rosenberg, S. M., Tracy, M. S., Meyer, M. E., Sepucha, K., Gelber, S., Hirshfield-Bartek, J., . . . Partridge, A. H. (2013). Perceptions, knowledge, and satisfaction with contralateral prophylactic mastectomy among young women with breast cancer: a cross-sectional survey. *Annals of Internal Medicine, 159*(6), 373-381. doi:10.7326/0003-4819-159-6-201309170-00003

Ryff, C. D. (1989). Happiness Is Everything or Is It? Explorations on the Meaning of Psychological Well-Being. *Journal of Personality and Social Psychology, 57*(6), 1069-1081.

Ryff, C. D., & Keyes, C. L. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology, 69*(4), 719-727.

Schou Bredal, I., Karesen, R., Skaane, P., Engelstad, K. S., & Ekeberg, O. (2013). Recall mammography and psychological distress. *European Journal of Cancer, 49*(4), 805-811. doi:10.1016/j.ejca.2012.09.001

Sepucha, K., Ozanne, E., Silvia, K., Partridge, A., & Mulley, A. G., Jr. (2007). An approach to measuring the quality of breast cancer decisions. *Patient Education and Counseling, 65*(2), 261-269. doi:10.1016/j.pec.2006.08.007

Siegel, Miller, K. D., & Jemal, A. (2017). Cancer Statistics, 2017. *CA: A Cancer Journal for Clinicians, 67*(1), 7-30. doi:10.3322/caac.21387

Smith, R. A., Duffy, S. W., & Tabar, L. (2012). Breast cancer screening: the evolving evidence. *Oncology (Williston Park, N.Y.), 26*(5), 471-475, 479-481, 485-476.

Soran, A., Ibrahim, A., Kanbour, M., McGuire, K., Balci, F. L., Polat, A. K., . . . Johnson, R. (2015). Decision making and factors influencing long-term satisfaction with prophylactic mastectomy in women with breast cancer. *American Journal of Clinical Oncology, 38*(2), 179-183. doi:10.1097/COC.0b013e318292f8a7

Soran, A., Kamali Polat, A., Johnson, R., & McGuire, K. P. (2014). Increasing trend of contralateral prophylactic mastectomy: what are the factors behind this phenomenon? *Surgeon, 12*(6), 316-322. doi:10.1016/j.surge.2014.02.005

Sorbero, M. E., Dick, A. W., Beckjord, E. B., & Ahrendt, G. (2009). Diagnostic breast magnetic resonance imaging and contralateral prophylactic mastectomy. *Annals of Surgical Oncology, 16*(6), 1597-1605. doi:10.1245/s10434-009-0362-3

Spittler, C. A., Pallikathayil, L., & Bott, M. (2012). Exploration of how women make treatment decisions after a breast cancer diagnosis. *Oncology Nursing Forum, 39*(5), E425-433. doi:10.1188/12.ONF.E425-E433

Stucky, C. C., Gray, R. J., Wasif, N., Dueck, A. C., & Pockaj, B. A. (2010). Increase in contralateral prophylactic mastectomy: echoes of a bygone era? Surgical trends for unilateral breast cancer. *Annals of Surgical Oncology, 17 Suppl 3*, 330-337. doi:10.1245/s10434-010-1259-x

Tuttle, T. M., Habermann, E. B., Grund, E. H., Morris, T. J., & Virnig, B. A. (2007). Increasing use of contralateral prophylactic mastectomy for breast cancer patients: a trend toward more aggressive surgical treatment. *Journal of Clinical Oncology, 25*(33), 5203-5209. doi:10.1200/JCO.2007.12.3141

Tuttle, T. M., Jarosek, S., Habermann, E. B., Arrington, A., Abraham, A., Morris, T. J., & Virnig, B. A. (2009). Increasing rates of contralateral prophylactic mastectomy among patients with ductal carcinoma in situ. *Journal of Clinical Oncology, 27*(9), 1362-1367. doi:10.1200/JCO.2008.20.1681

Watson, E. K., Henderson, B. J., Brett, J., Bankhead, C., & Austoker, J. (2005). The psychological impact of mammographic screening on women with a family history of breast cancer--a systematic review. *Psycho-Oncology, 14*(11), 939-948. doi:10.1002/pon.903

Winefield, H. R., Gill, T. K., Taylor, A. W., & Pikington, R. M. (2012). Psychological Well-Being and Psychological Distress: Is It Necessary to Measure Both? *Psychology of Well-Being: Theory, Research and Practice, 2*(3), 1-14.

Wong, S. M., Freedman, R. A., Sagara, Y., Aydogan, F., Barry, W. T., & Golshan, M. (2017). Growing Use of Contralateral Prophylactic Mastectomy Despite no Improvement in Long-term Survival for Invasive Breast Cancer. *Annals of Surgery, 265*(3), 581-589. doi:10.1097/sla.0000000000001698

Yi, M., Meric-Bernstam, F., Middleton, L. P., Arun, B. K., Bedrosian, I., Babiera, G. V., . . . Hunt, K. K. (2009). Predictors of contralateral breast cancer in patients with unilateral breast cancer undergoing contralateral prophylactic mastectomy. *Cancer, 115*(5), 962-971. doi:10.1002/cncr.24129

Vita

Susan G Yackzan

Place of Birth: Maysville, KY

Education

Institution	Degree or Diploma	Date	Field(s) of Study
St. Louis University St. Louis, MO	MSN (Research Option)	1991	Oncology
Vanderbilt University Nashville, TN	BSN	1986	Nursing

Professional Experience:

Dates	Institution and Location	Position
1/16 – Present	Baptist Health Lexington Lexington, KY	Research Consultant/Oncology Clinical Nurse Specialist
1/12-1/16	Baptist Health Lexington Lexington, KY	Director of Clinical Oncology
9/11-1/12	Baptist Health Lexington Lexington, KY	Interim Director of Outpatient Infusion
4/01- 1/12	Baptist Health Lexington Lexington, KY	Oncology Clinical Nurse Specialist
2007 – Present	University of Kentucky College of Nursing Lexington, KY	Appointed Voluntary Clinical Faculty
2007 – Present	University of Louisville School of Nursing Louisville, KY	Appointed Clinical Faculty
3/00-4/01	University of Kentucky, Markey Cancer Center Lexington, KY	Staff Nurse
10/99-Present		Independent Consultant & Educator
8/91-10/99	St. Louis University Hospital St. Louis, MO	Oncology Clinical Nurse Specialist
1/99-10/99	St. Louis University – Department of Hematology/Oncology St. Louis, MO	PRN Staff Nurse, Outpatient Clinic

Dates	Institution and Location	Position
9/90-8/91	St. Louis University Hospital St. Louis, MO	PRN Staff Nurse, Oncology
7/88-9/90	St. Louis University Hospital St. Louis, MO	Assistant Head Nurse, Oncology
7/87-7/88	St. Louis University Hospital St. Louis, MO	Staff Nurse, Intensive Care
6/86-7/87	St. Thomas Hospital Nashville, TN	Staff Nurse, Oncology

Honors and Awards

2016	Recipient, Celebration of Care Award, Baptist Health Lexington Foundation
2008	Advanced Oncology Certified Nurse of the Year, Awarded by the National Oncology Nursing Certification Corporation
1998	St. Louis Oncology Nurse of the Year, Awarded by St. Louis Chapter, Oncology Nursing Society
1992	Oncology Nursing Society/Schering Excellence in Cancer Nursing Research Award Nominee
1991	Finalist, Sigma Theta Tau, Delta Lambda Chapter Award
1990-91	National American Cancer Society Master's Degree Scholarship Recipient
1986	Cum Laude Graduate – Vanderbilt University
1985	Sigma Theta Tau Induction

Publications:

Bugasjski, A., Lengerich, A., Marchese, M., Hall, B., Yackzan, S., Davies, C., Brockopp, D.,(2017). The Importance of Factors Related to Nurse Retention: Using the Baptist Health Nurse Retention Questionnaire®, Part 2. *Journal of Nursing Administration, 47(6),* 308-312.

Lengerich, A., Bugajski, A., Marchese, M., Hall B., Yackzan, S. Davies, C., Brockopp, D (2017). The Baptist Health Nurse Retention Questionnaire: A Methodological Study, Part 1 *Journal of Nursing Administration, 47*(5), 289-293.

Weyl ,H., Yackzan, S., Ross, K., Henson, A., Moe, K., & Lewis, C.P. (2015). Understanding colorectal screening behaviors and factors associated with screening in a community hospital setting. *Clinical Journal of Oncology Nursing, 19*(1), 89-93.

Harrison, B.R., Ketts, J.R., Schultz, M.Z., Yackzan, S. (2000). Docetaxel-induced extravasation injury: A report of three cases. *J Oncol Pharm Practice*, 6, 122-125.

Yackzan, S.G. (1994). Chemotherapy administration. *Topics in Hospital Pharmacy Management*, 14(2), 34-58.

Mahon, S.M., Casperson, D.S., Yackzan, S., Goodner, S., Hasse, B., Hawkins, J., Parham, J., Rimkus, C., Schlomer, M., & Wichter, V. (1994). Safe handling practices of cytotoxic drugs: The results if a chapter survey. *Oncology Nursing Forum*, 21(7), 1157-1165.

Book Chapters;

Yackzan, S (2011). Pathophysiology and Staging of Breast Cancer. In S.M. Mahon (Ed.), *Site-Specific Cancer Series: Breast Cancer* (2nd ed.) Pittsburgh: Oncology Nursing Society.

Yackzan, S & Hatch, J. (2011). Surgical Management of Breast Cancer. In S.M. Mahon (Ed.), *Site-Specific Cancer Series: Breast Cancer* (2nd ed.) Pittsburgh: Oncology Nursing Society.

Mahon, S. & Yackzan, S. (2010). Skin Cancer. In C.H. Yarbro, D. Wujcik, & B.H. Gobel (Eds.), *Cancer Nursing Principles and Practice* (7th ed.) (pp. 1650-1683). Boston: Jones and Bartlett Publishers.

Yackzan, S. (2009). In B. Peters (Ed.), (5th ed.). *Pocket Guide to Injectable Chemotherapeutic Agents.*

Yackzan, S (2007). Pathophysiology and Staging of Breast Cancer. In S.M. Mahon (Ed.), *Site-Specific Cancer Series: Breast Cancer* (pp. 51-62). Pittsburgh: Oncology Nursing Society.

Yackzan, S (2007). Systemic Treatment. In S.M. Mahon (Ed.), *Site-Specific Cancer Series: Breast Cancer* (pp.91-103). Pittsburgh: Oncology Nursing Society.

Mahon, S. & Yackzan, S. (2005). Skin Cancers. In C.H. Yarbro, et al. (Eds.), *Cancer Nursing Principles and Practice (6th ed.)* (pp. 1581-1616). Boston: Jones and Bartlett Publishers.

Yackzan, S. (2004). In B. Peters (Ed.), (4th ed.). *Pocket Guide to Injectable Chemotherapeutic Agents.*

Yackzan, S. (2001). In B. Peters (Ed.), (3rd ed.). *Pocket Guide to Injectable Chemotherapeutic Agents.*

Mahon, S. & Yackzan, S. (2000). Skin Cancers. In C.H. Yarbro, et al. (Eds.), *Cancer Nursing Principles and Practice* (5th ed.) (pp. 1452-1482). Boston: Jones and Bartlett Publishers.

Yackzan, S. (1998). In B. Peters (Ed.), (2nd ed.). *Pocket Guide to Injectable Chemotherapeutic Agents.*

Yackzan, S. (1997). In B. Peters (Ed.). *Pocket Guide to Injectable Chemotherapeutic Agents*.

Published Abstracts:

International

Moe, K., Brockopp, D., Abner, J., Hatch, J., Schreiber, J., Yackzan, S., Hick, M.…Varghese, A. (July 11 – 16, 2010). Predictors of Psychological Well-Being: 1150 Women. The 27th International Congress of Applied Psychology. Melbourne, Australia.

Brockopp, D., Abner, J., Hatch, J., Hick, M., Moe, K., Schreiber, J., Varghese, A., & Yackzan, S. (2010, April). The influence of a belief system on psychological well-being among women undergoing a diagnostic mammogram. The 2010 International Nursing Conference. Phuket, Thailand.

National

Yackzan, S., Barker, S., Glass, A., Stanifer, S., Weyl, H., Wheeler, P. (2017 May). *The*

Effect of Oncology Nurse Navigators on Patient Satisfaction. Abstract Poster Presentation, Oncology Nursing Society National Congress, Denver, CO.

Brockopp, DA., Hatch, J., Moe, K., Schreiber, J., Yackzan, S., Abner, J. et al (2010 May). *The Influence of a Belief System on Psychological Well-Being Among Women Undergoing a Diagnostic Mammogram.* Abstract Podium Presentation, Oncology Nursing Society National Congress, San Diego, CA

Yackzan, S., Casey, R., Eckert, S., Malone, MA (2010 May), *Chemotherapy Competence for Nurses in Non-Traditional Settings*, Abstract Poster Presentation, Oncology Nursing Society National Congress, San Diego, CA.

Yackzan, S., Ross, K., Hatch, J. et al. (2009 May) *Breast Cancer Tumor Site Strategy Team Enhances Patient Services and Quality*. Abstract Poster Presentation at Oncology Nursing Society National Congress, San Antonio, TX

Yackzan, S (1992 May) *Amphotericin B-Induced Shivering.* Abstract Presentation at Oncology Nursing Society National Congress, San Diego CA

Yackzan, S. (1992 January) *Amphotericin B-Induced Shivering*. Poster Presentation at American Cancer Society Research Conference, Baltimore, MD