

Factors That Affect the Surgical Decision-Making Process Among Women With Breast Cancer

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Abstract

There are multiple factors that influence surgical treatment decision making at the time of diagnosis for women with breast cancer. The purpose of this study is to identify these factors that may be related to the surgical choice made in the treatment of breast cancer by women. Gaps in the existing research literature revealed a lack of prospective (pre-surgical) studies. The proposed study addresses this gap by focusing on pre-surgical decision making regarding the various factors that impact why women choose mastectomy when the stage of and type of their cancer allows breast conserving surgery as an option. This prospective, mixed mode design was conducted in a mid-Michigan oncology private practice setting. The purposive sample included a total of 10 participants, 3 scheduled for modified radical mastectomy (MRM) surgery and the other 7 scheduled for breast conserving surgery (BCS). A Factor List developed by Ward and colleagues (1989) was adapted to use in content analysis of narrative data from an open-ended question for participants' thoughts and feelings about their surgical treatment decisions. Results revealed most participants were ≤ 60 years of age, Caucasian, married, employed, and had full coverage health insurance. The following content analysis findings were consistent with previous post-op findings. Among the 10 participants, 90% stated that their physician's opinion was an impact in surgical treatment choice. Fear of side effects from chemo and radiation, length of recovery, and fear of recurrence were also discovered as influences regarding type of surgical treatment chosen. In addition, 10 new factors/themes emerged including fear (nonspecified) (60%), involved support system (60%), information given (40%), personal decision (30%) and strong faith/spirituality beliefs (30%). Other factors/themes (10-20%) were previous experience with someone with breast cancer, guidance from the nurse navigator, trust (nonspecified), age,

and fear of subsequent surgeries. Fisher's Exact test revealed no significant relationship between type of surgery (MRM, BCS) and actual breast satisfaction ratings by participants. There was no significant relationship between demographic variables and breast satisfaction. Findings are beneficial to nurse practitioners and other health care providers who can enhance their understanding about the experience women go through during this difficult time, and may ultimately facilitate the surgical treatment decision making process for patients with breast cancer.

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Chapter I

Introduction

Breast cancer is a disease that affects thousands of women every year. According to the National Cancer Institute (2007), there have already been an estimated 178,480 new cases and 40,460 deaths in women from breast cancer in 2007. The American Cancer Society has documented 6,880 new cases of breast cancer in Michigan alone for 2007. When diagnosed with breast cancer, women are not only facing a life altering disease, but also a physical and emotional surgical decision. Healthcare providers need to be aware that the diagnosis of breast cancer immediately changes a woman's life (Boehmke & Dickerson, 2006). Surgical intervention continues to be the primary treatment for these women. The surgical options available to women are modified radical mastectomy (MRM) with or without immediate reconstruction, breast conserving surgery (BCS) or lumpectomy, and prophylactic mastectomy.

BCS, also known as a lumpectomy, is the surgical removal of the breast lump or tumor, not the entire breast. MRM is the removal of the entire breast and nipple, some skin, and some underarm lymph nodes. Following BCS surgery, women will need additional treatment with radiation therapy. After MRM, radiation treatment is not common (Yarbro, Frogge, Goodman, & Groenwald, 2000). Women diagnosed with breast cancer have several decisions to make and an abundance of information to absorb regarding treatment possibilities. In the State of Michigan, it is required by law that all women receive a booklet entitled, "Breast Cancer: What You Need to Know Before Treatment" (Michigan Department of Community Health, 2003). The purpose of this booklet is to inform women about treatment options for breast cancer.

Clinical trials have demonstrated that the survival rates between women receiving modified radical mastectomy or breast conserving surgery combined with radiation therapy have

no significant difference in disease outcome (Reaby, 1998). Eight-year studies conducted by Fisher et al. (1989) illustrate the equivalence of the survival rates of mastectomy and breast conserving surgery with radiation among women with early stage breast cancer. Despite this well-known research, many women continue to choose modified radical mastectomy as opposed to breast conserving surgery. Numerous factors may impact the woman during this decision making process. Possible factors that may influence the surgical treatment decision for women with breast cancer include: previous knowledge of cancer, reaction to diagnosis, perceived urgency of treatment, support people, information provided, demographics, and body image (Halkett, Arbon, Scutter, & Borg, 2005). Other plausible factors that may influence a women's treatment decision include family history, presence of BRCA 1 and BRCA 2 genes, fear, breast satisfaction, and demographic components.

Throughout the review of literature, the majority of the studies conducted were retrospective. Ward et al. (1989) makes note that retrospective report bias is a concern with these types of studies because the researchers cannot be certain that the patients would have responded in the same way if they were interviewed prior to surgery. Ananian et al. (2004) similarly state that there have been no prospective studies conducted to assess the importance of women's body image when patients have to make their choice of surgical treatment. Harcourt and Rumsey (2001) suggest that gaps in the existing research literature such as the majority of retrospective studies need to be addressed. Harcourt and Rumsey state that research must be prospective and multi-centered to fill these gaps. These implications for future research have justified the need and development of this research question, "What factors influence the surgical treatment decision-making at the time of diagnosis for women with breast cancer?"

Chapter II

Literature Review

Theoretical Framework

Polit and Beck (2004) describe the first step of developing a theory as the process of formulating relevant concepts and creating a conceptual analysis. According to Higgins and Moore (2000), “the terms theory, theoretical (or conceptual model), theoretical framework, and theoretical system...can be used interchangeably” (p. 179). However, the level of theoretical thinking must be defined. This study is theory-generating. It is a prospective study which means data are collected before surgical intervention. This prospective design will allow a greater understanding about the decision making for women soon after their diagnosis with breast cancer by formulating relevant concepts.

Ward, Heidrich, & Wolberg (1989) conducted a retrospective study of 22 women using the “Factor List” (Appendix A). This list was composed of 16 fixed response questions using a Likert scale. Eleven of these women chose breast conserving surgery, and the eleven other women chose modified radical mastectomy. These researchers found that women chose breast conserving surgery because they desired to maintain their body integrity. They also found a trend in those choosing breast conserving surgery to be more concerned about their partner’s feelings regarding breast removal. Other findings revealed that involvement in decision-making was important to the participants.

An Australian research team also used the Factor List (Ward, Heidrich & Wolberg, 1989) in their study, “Factors influencing women’s decisions for choice of surgery for Stage I and Stage II breast cancer in Western Australia” (Mastaglia & Kristjanson, 2001). This study

followed a retrospective design. The researchers found fear of recurring cancer, fear of dying, and avoiding future surgeries were all factors that influenced treatment decision making among women who chose MRM. Women who chose BCS identified physician preference, fear of recurrence and dying as influential factors in their treatment decision. Both research teams contributed knowledge post surgery that was useful to the investigators in designing their prospective study especially related to guiding the literature review.

Throughout the review of literature, recurrent factors were identified by women who had surgical treatment for breast cancer. Body image and self concept, demographic factors, family history and genetic composition, fear, and preferred role in the decision making process were among the most frequent occurring themes in past retrospective studies.

Body Image and Self-Concept

Cancer of the breast is unique. Not only does this disease cause pain, suffering, and the possibility of death, but it also imposes a potential threat to a woman's perceptions of herself through an attack on her body that is endowed with the symbolic significance of femininity and womanliness (cited in Reaby, 1998, p. 252).

The term body image can overlap with other aspects such as self-esteem, self-concept, confidence level, and sexuality. Hopwood (1993) acknowledges that this can make the assessment of body image very complicated. There is not a universal instrument that measures body image. Therefore, researchers often develop their own assessment tools which can cause difficulties when comparing studies (Harcourt & Rumsey, 2001). Several studies suggest there is a strong correlation between body image and the breast cancer surgical intervention (Mock,

1993; Al-Ghazal, Sully, Fallowfield, & Blamey, 2000; Ward et al., 1989; Halkett et al., 2005; Margolis, Goodman, & Rubin, 1990). Body image also impacts the choice of breast reconstructive surgery following mastectomy (Ananian et al., 2004; Harcourt & Rumsey).

Several retrospective study designs revealed interesting results. Al-Ghazal and colleagues (2000) performed a retrospective study using a body image scale specifically designed for women who had surgery for breast cancer. Results of this European study showed women who had immediate reconstruction had higher body image scores than women who delayed their reconstructive surgeries. Al-Ghazal made no comparison with women who had mastectomy alone without reconstruction. In another study, Lasry et al. (1987) studied body image satisfaction three years postmastectomy and breast conserving surgery in a randomized clinical trial. Body image was measured using a tool designed by the researchers entitled, the “Body Image Index.” Results showed women with mastectomy had lower levels of body image satisfaction than women with breast conserving surgery ($p < .001$). In an interesting study conducted by Ward, Heidrich, & Wolberg (1989) with 22 women, eleven of these women chose breast conserving surgery, and the eleven other women chose modified radical mastectomy. Ward found that women chose breast conserving surgery because they desired to maintain their body integrity. Ward also found a trend in those choosing breast conserving surgery to be more concerned about their partner’s feelings about breast removal. A limitation of this study was the small sample size and the homogenous sample purposely obtained from one clinical setting. A retrospective postal survey using a larger sample size of 257 women (Mock, 1993) found women who underwent breast conserving surgery had higher body image scores as compared to the mastectomy group ($p < .001$). The mastectomy group was made up of some women who had reconstruction and others who did not. This study also found that these women were still

adapting to their body image one year following surgery, which led the author to recognize the need for longitudinal prospective research in this area (Mock).

A prospective, cross-sectional French study (Ananian et al., 2004) determined factors that affect women's choice to undergo reconstruction with mastectomy. Self-administered questionnaires were given to the women prior to surgery. Those who opted for breast reconstruction frequently realized that their body image was important to them ($p < .01$).

A qualitative study (Margolis et al., 1990) focused on the psychological aspects of breast conserving surgery. Researchers found women choosing breast conserving surgery did so based on concerns of negative impact to their body image and sexuality. A limitation of this study was the sample containing women choosing breast conserving surgery only. Women choosing mastectomy were not included.

Kraus' 1999 study illustrated results that are in contrast to the findings of the literature reviewed by the investigators for their study. Kraus examined body image, decision-making, and breast cancer treatment using a prospective design to compare 31 women with breast cancer undergoing surgical intervention to 30 women without breast cancer. The women with breast cancer experienced a decrease in body image scores postoperatively. However, contrary to previous research, "there was a trend in the data for the mastectomy group to be more satisfied with their body image than the breast conserving surgery group before and after treatment" (p. 425). One explanation Kraus gave for these findings suggested that for women faced with a life threatening illness such as breast cancer, physical importance is second to survival. This explanation is supported by a cited work in Beaver et al stating, "...decision-making ability is limited as a result of the life-threatening nature of the condition" (Parry, G. as cited in Kraus,

1999, p. 17). A second possibility for these findings may be some women used denial as a defense mechanism against negative body image. A longitudinal study with a larger sample size is necessary to refute the previous research and support Kraus's results.

Demographic Factors

Previous research, although not solely focusing on one demographic variable, has identified links between numerous factors and breast cancer surgical treatment choice. These variables include age, socioeconomic status, education, and marital status. Women choosing reconstruction, for example, were found to be younger, highly educated, of higher socioeconomic status, and more likely to be in a relationship (Ananian et al., 2004; Harcourt & Rumsey, 2001). Age was also recurrent factor that correlated with the type of surgical intervention women chose. Younger women tended to choose breast-conserving surgery, whereas older women choose modified radical mastectomy (Ananian et al.). An epidemiological surveillance showed that women greater than 85 years old and younger than 55 years had higher rates for breast conserving surgery (Samet, Hunt, & Farrow, 1994). A retrospective study by Ward, Heidrich, and Wolberg (1989) found the mean age for women who chose breast-conserving surgery was 50. This was significantly younger than the mean age of the women choosing modified radical mastectomy, at 59.5 years (SD = 8.9 years). When making a decision for breast cancer surgery, older women may consider their life expectancy, the efficacy of treatment, toxicity, and possible effects on their quality of life in differently than younger women (Kutner, Vu, Prindville, & Byers, 2000).

Family History/Genetic Composition

A breast cancer (BRCA) gene test is a blood test to check for specific mutations in genes that help control normal cell growth. Breast cancer susceptibility has been linked to mutations within these genes. BRCA 1, located on chromosome 17q, is believed to account for 30-45% of breast cancer cases in families with a high incidence of early onset of both breast and ovarian cancers. BRCA2, located on chromosome 13q, is also believed to account for approximately 35% of families with early breast cancer. Researchers are continuing to explore further genes that may also be responsible for increasing one's susceptibility to breast cancer. Since approximately less than 1% of the population has this mutation the implications and testing remains complicated. Any changes in the BRCA1 and BRCA2 genes assist providers to determine a woman's chance of developing breast and ovarian cancer (Yarbro, Frogge, Goodman, & Groenwald, 2000).

There are other risk factors for breast cancer. These include age > 50, postmenopausal obesity, early menarche with late menopause, first pregnancy after age 30, use of oral contraceptives before age 20 and lasting greater than 6 years, benign breast disease, diet, alcohol, and hormone replacement therapy (Yarbro et al., 2000). If women have any of these risk factors for breast cancer, they may also opt to have genetic testing for the BRCA genes. If a woman is known to carry the mutation, she can use this information to assist with decision making. It is often these women who are considered high risk and are positive for BRCA gene mutations who choose prophylactic mastectomy. A study done by Hartmann, Schaid, & Woods et al., (1999) found a greater than 90% reduction in risk of breast cancer in women who had a family history of breast cancer and were high risk who underwent prophylactic mastectomy.

In the study by Ananian et al. (2004), the sample of women who chose mastectomy had a first degree relative with a history of breast cancer. A prospective study by Hatcher, Fallowfield, & A'Hem (2001) found that women who underwent prophylactic mastectomy did so due to their belief that it would greatly decrease their risk of developing breast cancer. Hatcher and colleagues state in the discussion that women who choose prophylactic mastectomy often have inaccurate perceptions of their actual risk of disease. Therefore, Hatcher emphasizes that women need to meet with genetic counselors to ensure that their surgical decisions are based on accurate perceptions.

Fear

Fear is a concept several researchers correlated with women's surgical decisions in their studies related to breast cancer (Ananian et al., 2004; Kraus, 1999; Mastaglia & Kristjanson, 2001; Ward et al., 1989). Ananian and colleagues state that fear of surgery was an important concern for women choosing mastectomy. This fear of surgery prevented the women from opting for reconstruction either before or after their mastectomy. Kraus found that fear of recurrence and radiation therapy were common factors among the women who chose to have a mastectomy. In Mastaglia and Kristjanson's retrospective study, women stated fear of cancer recurrence, fear of further surgery, and fear of dying from cancer were factors for choosing mastectomy. Women who chose breast conserving surgery also stated fear of recurrence and dying from cancer were factors that led them to their decision. Ward et al. also identified three most important factors for the surgical decision among all participants in the study. One factor was fear of recurrence and the other two factors of equal importance were avoiding a second surgery and physician's

preference. Furthermore, Ward found the breast conserving group identified fear of losing a breast as an important factor for their surgical decision.

Preferred Role in the Decision Making Process

A common variable recognized in the review of literature is the women's role in the decision making process. There are varying degrees in which a woman desires to participate in the surgical decision following a diagnosis of breast cancer (Beaver, Luker, Owens, Leinster, & Degner, 1996; Halkett et al., 2005; Harcourt & Rumsey, 2001; Mastalgia & Kristjanson, 2001; Reaby, 1998). A British study conducted by Beaver et al., stated that women diagnosed with breast cancer are being encouraged more frequently to be involved in the decision regarding their treatment. Beaver et al further state that the extent to which women feel comfortable with surgical decision making needs to be determined. The results from Beaver and colleagues show that women diagnosed with breast cancer prefer to have the physician make the final treatment decision. One explanation may be that breast cancer, as a life threatening illness, may limit the women's decision-making ability (cited in Beaver et al; Kraus, 1999). Researchers with similar findings agree that women may find the choice of treatment stressful due to the news of the breast cancer diagnosis impairing their ability to think clearly (Pierce, 1993; Fallowfield, Hall, Maguire, Baum, & A'Hern, 1994).

Possible influences impacting the participation in the decision-making process include the presence of support people, the reaction to the breast cancer diagnosis, and the physician's opinion (Halkett et al., 2005). Halkett and colleagues also found that the physician involved in a woman's treatment decision may have personal beliefs that will impact the woman's final choice. Ward et al. (1989) found that women who perceived themselves as an active participant

in the decision making process had a positive adjustment to their breast surgery treatment choice. In a retrospective study, Mastalgia and Kristjanson (2001) found that women who underwent breast-conserving surgery stated that the physician's preference impacted their final decision for surgical option, whereas women who underwent modified radical mastectomy stated the physicians' preference was not a factor.

Conclusion

The literature review identifies several factors that influence the surgical treatment choice among women with breast cancer. The review supports body image, family history, demographics, fear, and preferred role in the decision making process as important points to consider when women are faced with the breast cancer diagnosis. However, the majority of the studies conducted were retrospective. Ward et al. (1989) makes note that retrospective bias is a concern with these types of studies, and is uncertain that the responses would have been similar if the participants were seen prior to their surgery. Ananian et al. (2004) similarly stated that there have been no reliable prospective surveys to assess body image importance prior to surgery. Harcourt and Rumsey (2001) suggest that gaps in the existing research literature such as the majority of retrospective studies, need to be addressed. "Research in this field needs to be prospective and multicentered" (Harcourt & Rumsey, p. 485). These implications for future research have justified the need and development of this research question, "What factors influence surgical treatment decision-making at the time of diagnosis for women with breast cancer?"

Chapter III

Methodology

Research Design

This study follows a prospective mixed mode design which includes a blending of qualitative and quantitative data. The descriptive qualitative portion of the study used phenomenology to understand the experiences of the study participants. The descriptive quantitative portion of the study used independent and dependent variables to compare frequency of participant responses. A mixed mode design is beneficial in theory generating studies (Polit & Beck, 2004). The investigators believe their study has the potential to be theory generating.

There are several advantages to implementing a mixed mode design. Polit and Beck (2004) state that combining qualitative and quantitative data is a complementary relationship using both words and numbers. Implementing both methods can possibly reduce the limitations that a single approach could encounter. A mixed mode design is also multidimensional and can illustrate not only statistics, but also the experiences and emotions of the participants (Polit & Beck).

Setting and Sample

The study was conducted in an outpatient oncology office in a mid-Michigan teaching hospital. The study used a nonprobability sampling design. A purposive sampling method was used in order to choose subjects who will most represent the topic being researched (Polit & Beck, 2004). Subject participation included women ages 18 or older. The inclusion criterion was a positive stage I or stage II invasive breast cancer diagnosis prior to the surgical treatment for

cancer. The exclusion criteria included any invasive breast cancer diagnosis and stage III or stage IV breast cancer (Appendix B). The sample for this study was women selected from an oncology surgeon's office after they had been diagnosed with breast cancer, but prior to the surgical treatment. This is purposive because all of the potential subjects were diagnosed with breast cancer and facing the decision of what type of surgical treatment to undergo. Polit and Beck state that this type of sampling does not provide an objective method for "assessing the typicalness" of the chosen subjects (p. 294). However, purposive sampling was an effective method to answer the research question because all subjects were at the same stage of their cancer treatment as well as seeing the same surgeon.

The purposive sampling method was used over an interval from September 2008 through January 2009 to draw a sample of 10 participants. There were no refusals from those who met the inclusion and exclusion criteria. Of those sampled, 10 women were asked to participate and all 10 women agreed with 3 scheduled for MRM surgery and the other seven scheduled for BCS.

Procedure

Written permission to conduct this study was obtained from the Institutional Review Board (IRB) of the acute care institution and from the IRB of the University of Michigan (Appendix C). The patients of Dr. Raouf Mikhail, oncology surgeon, were asked to be participants in the study. Permission from Dr. Mikhail was granted (Appendix D). All women who consult Dr. Mikhail regarding breast surgery are given the results of their biopsies from their primary care physician. At the initial consult with Dr. Mikhail, they receive the Michigan Department of Community Health (2003) booklet, "Breast Cancer: What you need to know before treatment" as required by Michigan State law. They are then scheduled for an

appointment with the Nurse Navigator at Hurley Medical Center. The Nurse Navigator was not engaged in this study. The patient's appointment with the Nurse Navigator is to discuss the pathophysiology of the type of breast cancer the women have been diagnosed with, available surgical treatment options, and education regarding what to expect during and after surgery. The Nurse Navigator gave the women a flyer (Appendix E) about the study at this appointment using the script (Appendix F) provided by the researchers. After their time with the Nurse Navigator, the women were asked if they would like more information about the study that was in the flyer they received. If the woman said yes, the researcher entered the room. It is at this time that the subjects were given the "Letter of Introduction" (Appendix G) and asked to participate in this study. After questions were answered and the informed consent (Appendix H) was signed, the researcher handed out the demographic sheet (Appendix I) and open-ended question (Appendix J) to the participant. The participants were asked at this time if they would prefer to write their own thoughts and feelings in response to the open-ended question, or to verbally state their responses to the researcher while she took notes.

The privacy and confidentiality of each participant was maintained. No identifying information was given on the data collected. The participants were consecutively coded with numbers and letters to identify surgical choice: 1L, 2L, 3L, 4L, 5L, 6L, 7L, 1M, 2M, 3M. The data obtained from these participants was rich in quality and recurrent statements were identified to achieve data saturation. The informed consents were kept separate and no names were linked to the data collected. Interviews were conducted in a private room with no interruptions.

The researcher ensured constancy of research conditions by being the sole presenter of the informed consent, demographic data collection sheet and open ended question sheet to all participants. There were no interruptions during the time of data collection. By using one setting,

all the participants received information from the same physician and Nurse Navigator including review of the “green” booklet.

Instruments

The “Factor List” (Appendix A) was specifically developed by Ward, Heidrich and Wolberg (1989) to measure the factors that women consider when choosing what type of breast cancer surgery they will undergo as treatment. Prior to this 1989 study, a tool to measure these concepts was not available. The authors established content validity for the instruments used in their study. Content validity is the degree that the items in an instrument represent the content for the concepts that are being measured in the study (Polit & Beck, 2004). Content validity for the 16-item factor-list was assessed by asking an oncology surgeon and nurse specialist to ensure the list of items covered all possible factors. The study does not include a content validity index.

Dr. Sandra Ward (personal communication, October, 2007) granted permission to use and adapt this 16-item Factor list in this prospective study. Because the original study was retrospective, the questionnaire given to the women was written in past tense. The items had to be reworded to state the factors as a preoperative reason for choosing the surgery. Also, the original study used the Factor list in a questionnaire. In this study, the adapted Factor list served as the framework to examine the extent to which prospective (pre-op) content analysis supported Ward’s retrospective(post-op) findings. Having more than one study that used the Factor List tool increased the reliability of the instrument for retrospective studies (Ward, Heidrich & Wolberg, 1989; Mastaglia & Kristjanson, 2001). This study has the potential to extend the validity of the Factor List by examining content validity of the factors preoperatively.

A pen, paper, and the researcher are the instruments used in this study. A demographic data sheet (Appendix I) was given to each participant. The data included on the demographic survey include age which will be reported as mean. Categorical data such as ethnicity, insurance, marital status, education, employment, and family history of breast cancer will be reported as percentages. A question regarding the participant's current satisfaction with her breast appearance is the last question on this survey and uses a Likert-type scale. The Likert scale ranges from 1 to 5, with 1 meaning highly dissatisfied, 3 meaning neutral, and 5 meaning highly satisfied. This variable is ordinal treated as interval and will be expressed using mean and standard deviation.

A sheet of paper with one open-ended question was given to each participant (Appendix J). The question, "What thoughts and feelings have you experienced since your diagnosis of breast cancer that have guided you to your surgical treatment decision?" was read aloud by the researcher. Participants were asked by the researcher if they preferred to write their responses or verbalize them to the researcher and have her take notes. One participant chose to verbalize her responses to the researcher who assumed the expected qualitative researcher role described by using the phrase "researcher as instrument" (Polit & Beck, 2004, p. 225). This process was helpful to eliminate the problems of different reading and writing capabilities of the participants.

Variables

The dependent variable was the surgical decision that the women chose as treatment for breast cancer: Modified Radical Mastectomy (MRM) or Breast Conserving Surgery (BCS). The independent variables were the recurring themes determined through content analysis of participant responses to the open-ended question. Other independent variables included

demographic data, such as age, marital status, insurance, employment, and ethnicity, as well as family history of breast cancer, current bra size, and current satisfaction of breast appearance.

Data Analysis

Descriptive statistics, percentages, means, and standard deviations were used for the demographic variables in this study. Fisher's Exact was used to examine the relationship between actual breast satisfaction and type of surgery. Content analysis was used to analyze the narrative data from the open ended question for major categories across subjects. No transcribing of data was done because the investigators reviewed the raw data directly.

Content analysis is the process of analyzing the narrative data for recurring themes or patterns (Polit & Beck, 2004). The thoughts and feelings that the participants either wrote or verbalized to the researcher were analyzed for possible recurring themes. Polit and Beck (2004) define a theme as a recurring regularity that becomes apparent during an analysis of qualitative data. Ward's adapted Factor List (Appendix K) was used as a tool to categorize the data. Prior to the data analysis, the researchers reviewed the Factor List to develop cue words for each numbered factor that would signal the presence of the factor. However, as the Factor List was analyzed, it was determined that the cue words were already present in each of the statements. Once identified, the adapted Factor List was used as a categorization scheme with corresponding codes to organize and sort the data. There were instances when the factor list items were insufficient and did not match the raw data that needed to be coded. Each researcher independently wrote down the items that did not fit into the adapted Factor List and began making additional factors. After all the data were sorted and organized, patterns and themes were identified.

Reliability and Validity

The researchers have used methods to ensure the trustworthiness and credibility of the data and analysis. Inter-coder reliability is the degree to which the researchers agree about their ratings for the themes and categories when reviewing the participant's narrative portion of the study. The co-investigators independently reviewed each participant's response, coded the findings, and compared findings to assess level of agreement. After the co-investigators agreed with ratings of the narrative statements, the thesis Chair reviewed their work. The feedback from the Chair supported findings of the co-investigators. The Chair also agreed that the content analysis was easily understood. This is called investigator triangulation which reduces the possibility of biased interpretation. The content analysis and interpretation can benefit from different perspectives (Polit & Beck, 2004).

Researcher credibility also adds to the strength of the study. Diane Welker, RN, MS, ANP-BC, the content expert of the study, is a Nurse Practitioner with years of oncological experience. She was employed as Nurse Navigator at a breast cancer center and has a great amount of experience counseling women with breast cancer throughout their treatment. She was also key in the development of the breast cancer center where this study took place. The researchers also have years of oncological experience and have counseled and treated many women going through breast cancer from diagnosis through treatment. Janet Barnfather, PhD, RN has competed for and received funding for studies at the local, state and national levels. In part, her expertise includes past studies with patients who are hospitalized and have oncology problems. Dr. Barnfather has developed an expertise in conducting and teaching clinical nursing research related to her lead role in qualitative research data analysis for two funded projects: a

State of Michigan project and a National Institutes of Health project. The experience of these individuals provided this study with researcher credibility.

Chapter IV

Results

Demographic Data

There were a total of 10 participants in this study. The demographic data (Appendix H) were collected and included: marital status, education, insurance, employment, ethnicity, family history of breast cancer, type of surgical treatment, age, current bra size and satisfaction with current breast appearance. The demographic characteristics of the participants are included in Table 1. The mean age for the total population was 59.5 years (S.D. = 15.57). The mean age of the 7 participants who chose BCS was 63.3 years (S.D. = 15.77). The mean age of the 3 participants who chose MRM was 50.7 years (S.D. = 13.32). Most of the sample was Caucasian (n=7, 70%) while 30% was African American.

Table 1: Demographic Characteristics of Participants (N = 10)

	Number	%
Marital Status		
Single	1	10
Married	6	60
Divorced	1	10
Widowed	2	20
Education		
Less than High School Diploma	1	10
High School Graduate	1	10
Some College	1	10
Associates Degree	4	40
Bachelors Degree	1	10
Graduate Degree	1	10
Other	1	10
Insurance		

Full Coverage	9	90
Partial Coverage	1	10
Employment		
Full Time	5	50
Part Time	2	20
Retired	3	30
Ethnicity		
White	7	70
African American	3	30
Family History of Breast Cancer		
Yes	4	40
No	6	60
Type of Surgical Treatment		
Breast Conserving Surgery (BCS)	7	70
Modified Radical Mastectomy (MRM)	3	30
Age		
40 – 49	4	40
50 – 59	2	20
60 – 69	2	20
80 - 89	2	20
Bra Size		
B	2	20
C	3	30
D	2	20
DD	1	10
DDD	1	10
Unknown	1	10
Breast Satisfaction		
1 = Highly Dissatisfied	0	0
2 = Dissatisfied	1	10
3 = Neutral	5	50
4 = Satisfied	2	20
5 = Highly Satisfied	2	20

Each demographic characteristic was analyzed independently and compared by surgical treatment choice as illustrated in Tables 2 through 10. Table 2 shows 100% of the MRM group were married. The participants in the MRM group all had college degrees, while the BCS group ranged from less than high school to a graduate degree (Table 3). All participants had insurance coverage. All of the participants in the MRM group (100%, n=3) had full coverage, and 6 out of 7 in the BCS group had full coverage (Table 4). None of the individuals were unemployed. Those currently not working were retired (Table 5). Two participants from each group identified a family history of breast cancer (Table 7). One MRM participant did not write an answer for current bra size (Table 9). Approximately 43% (n=3) of the BCS participants were either highly satisfied or satisfied with their current breast appearance while the MRM participants reported a much lower rate (33%, n=1). Fisher's Exact test revealed no significant relationship between demographic variables and actual breast satisfaction (Table 11).

Table 2: Surgical Treatment Decision and Marital Status

	BCS (n = 7)	BCS % of n	MRM (n = 3)	MRM % of n
Single	1	14.29	---	---
Married	3	42.86	3	100
Divorced	1	14.29	---	---
Widowed	2	28.57	---	---

Table 3: Surgical Treatment Decision and Education

	BCS (n = 7)	BCS % of n	MRM (n = 3)	MRM % of n
Less than HS	1	14.29	---	---
HS Diploma	1	14.29	---	---
Some College	1	14.29	---	---
Associates Degree	2	28.57	2	66.67
Bachelors	---	---	1	33.33

Degree				
Graduate Degree	1	14.29	—	—
Other	1	14.29	—	—

Table 4: Surgical Treatment Decision and Insurance

	BCS (n = 7)	BCS % of n	MRM (n = 3)	MRM % of n
Full Coverage	6	84.71	3	100
Partial Coverage	1	14.29	—	—

Table 5: Surgical Treatment Decision and Employment

	BCS (n = 7)	BCS % of n	MRM (n = 3)	MRM % of n
Full Time	4	57.14	1	33.33
Part Time	1	14.29	1	33.33
Retired	2	28.57	1	33.33

Table 6: Surgical Treatment Decision and Ethnicity

	BCS (n = 7)	BCS % of n	MRM (n = 3)	MRM % of n
White	5	71.43	2	66.67
African American	2	28.57	1	33.33

Table 7: Surgical Treatment Decision and Family History

	BCS (n = 7)	BCS % of n	MRM (n = 3)	MRM % of n
Yes	2	28.57	2	66.67
No	5	71.43	1	33.33

Table 8: Surgical Treatment Decision and Age

	BCS (n = 7)	BCS % of n	MRM (n = 3)	MRM % of n
40 – 49	2	28.57	2	66.67
50 – 59	2	28.57	—	—

60 – 69	1	14.29	1	33.33
80 – 89	2	28.57	—	—

Table 9: Surgical Treatment Decision and Bra Size

	BCS (n = 7)	BCS % of n	MRM (n = 3)	MRM % of n
B	1	14.29	1	33.33
C	3	42.86	—	—
D	2	28.57	—	—
DD	1	14.29	—	—
DDD	—	—	1	33.33
Unknown	—	—	1	33.33

Table 10: Surgical Treatment Decision and Current Breast Satisfaction

	BCS (n = 7)	BCS % of n	MRM (n = 3)	MRM % of n
1 Highly Dissatisfied	—	—	—	—
2 Dissatisfied	1	14.29	—	—
3 Neutral	3	42.86	2	66.67
4 Satisfied	1	14.29	1	33.33
5 Highly Satisfied	2	28.57	—	—

Table 11: Type of Surgery and Actual Breast Satisfaction Crosstabulation* (N=10)

		Type of Surgery		
		BCS	MRM	Total
Actual Breast Satisfaction	Satisfied/Highly Satisfied	3	1	4
	Neutral/Dissatisfied	4	2	6
	Total	7	3	10

*Fisher's Exact $p = NS$

Research Question: “What factors influence the surgical treatment decision-making at the time of diagnosis for women with breast cancer?”

Themes Identified on the Adapted Factor List

Table 12 presents the participants’ responses as coded using the adapted factor list included in Appendix K (Ward, Heidrich, & Wolberg, 1989). The researchers had a 71.43% initial agreement rate and had coded 10 out of 14 responses similarly. After discussing the other ratings, the researchers collectively agreed upon the remaining 4 ratings. The participants were consecutively coded with numbers and letters to identify surgical choice in the order they were interviewed: 1L, 2L, 3L, 4L, 5L, 6L, 7L, 1M, 2M, 3M. Of the 12 categories included on the factor list, only 5 were identified in the participants’ responses (41.67%). These 5 categories include physician’s opinion, other acquaintance with mastectomy experiences, fear of side effects from chemo and radiation, length of recovery, and fear of recurrence as influences regarding type of surgical treatment chosen.

Physician’s Opinion

The physician’s opinion had the highest occurrence of responses with 9 out of 10 (90%) participants stating that this was an impact in surgical treatment choice. All of the MRM participants (n=3, 100%) and 85.61% (n=6) of the BCS group stated this as a factor. This theme was clearly demonstrated by the following participant responses:

1L) “Dr. Mikhail...agreed a lumpectomy would be a good choice for me. Dr. Mikhail guided me to this step right here because I was really lost as to what to do.”

2L) “Specialist talking. Felt really lucky that had 2 really good specialists”

3L) “I have great doctors...I’m a judge not a doctor...I believe in doing what doctors tell you... Dr Mikhail says this is the way to go so this is the way to go.”

5L) “Dr highly recommended for age”

6L) “after discussion, I feel it is the right thing to do”

7L) “the Dr. recommended lumpectomy so I am going with that”

1M) “information from doctor...have relied a lot on what docs have said from radiologists on”

2M) “physician recommended due to other smaller tumors”

3M) “he said there are four spots in there that are poorly differentiated...difficult to do lumpectomies and get it all out...didn’t hesitate when he suggested that”

Fear of Side Effects from Chemo and Radiation

Fear of side effects from chemo and radiation feelings was coded as the second highest factor across all participants with a total response rate of 20% including 1 MRM (33.33%) and 1 BCS (14.29%) participant. This theme refers to the participant’s desire to avoid chemo and radiation and is supported by the following participant responses:

7L) “I do not want chemo”

2M) “some fear of upcoming treatments...avoid future surgeries (possible chemo and radiation)...praying don’t have to do chemo”

Other acquaintance with mastectomy experiences, length of recovery and fear of recurrence all had a total response rate of 10%. Fear of recurrence and other acquaintance with mastectomy experience were both stated by 1 MRM (33.33%) participant and zero BCS participants. Conversely, length of recovery was stated by 1 BCS (14.29%) participant and zero MRM participants.

Other Acquaintance with Mastectomy Experiences

1M) “friend who had a mastectomy Dr Mikhail did...helps that she had someone”

Length of Recovery

4L) “I feel that a lumpectomy is the best decision for me because it is the least invasive for me, quicker healing time and all around best fit. I will be able to return to my life faster and plan my holidays”

Fear of Recurrence

2M) “hopefully heading off cancer in other breast also”

Table 12: Factors/Themes Identified in Participants' Responses to the Open Ended Question Using Adapted Factor List (Ward, Heidrich, Wolberg, 1989).

Factor	Participants with Factor Present	Total # of Responses (N = 10)	Total % of Responses	# of BCS Responses (n = 7)	% of BCS Responses	# of MRM Responses (n = 3)	% of MRM Responses
1. Knowing the survival Rate is equal for mastectomy and breast conserving surgery will impact my surgical decision.	***	***	***	***	***	***	***
2. The physician's opinion will impact my surgical decision.	1L, 2L, 3L, 5L, 6L*, 7L*, 1M, 2M, 3M*	9	90	6	85.71	3	100
3. Other acquaintances with mastectomy experiences will impact my surgical decision.	1M*	1	10	***	***	1	33.33
4. Other acquaintances with breast conserving experiences will impact my surgical decision.	***	***	***	***	***	***	***
5. My partner's feelings will impact my surgical decision.	***	***	***	***	***	***	***
6. Concerns related to arm mobility and strength will impact my surgical decision.	***	***	***	***	***	***	***
7. Fear of side effects from radiation and chemotherapy will impact my surgical decision.	7L*, 2M	2	20%	1	14.29	1	33.33
8. Length of recovery following surgery will impact my surgical decision.	4L	1	10%	1	14.29	***	***
9. Fear of losing a breast will impact my surgical decision.	***	***	***	***	***	***	***
10. Fear of recurrence will impact my surgical decision.	2M	1	10%	***	***	1	33.33
11. Fear of dying from cancer will impact my surgical decision.	***	***	***	***	***	***	***

New Factors/Themes Identified

There were instances that the factor list items were insufficient and did not match the raw data that needed to be coded. Each researcher independently wrote down the items that did not fit into the factor list and began making additional factors. The researchers had an 86.21% initial agreement rate and had coded 25 out of 29 responses similarly. After discussing the other ratings, the researchers collectively agreed upon the remaining 4 ratings. Collectively comparing the items, 10 new categories were developed as presented in Table 13. These categories include fear (nonspecified), information given, personal decision, involved support system, strong faith/spirituality beliefs, previous experience with someone with breast cancer, guidance from the nurse navigator, trust (nonspecified), age, and fear of subsequent surgeries were all identified within the participants' responses to the open-ended question.

Fear (nonspecified)

Of these 10 new categories identified, 60% of the participants stated fear was an influence in their surgical treatment decision which included 4 (57.14%) BCS participants and 2 (66.67%) MRM participants. This fear was not specified, and could not therefore, be placed in numbers 7, 9, 10 or 11 on the adapted factor list. These statements were not clear regarding the fear that the participants were feeling and were expressed through the following:

1L) "scared"

2L) "scared"

3L) "scared, scared...terrified"

4L) “I have worked in the medical field for over 25 years, sometimes we know too much that it scares us to death and not enough to comfort us”

2M) “anxiety”

3M) “can’t imagine being so tied to breasts I would risk my breast”

Involved Support System

Of the total sample (N=10), 60% of the participants also stated that having an involved support system was an important influence in leading the decision for surgical treatment: 4 (57.14%) were BCS participants and 2 (66.67%) were MRM participants. The support theme was demonstrated through direct response statements or participant accompanied by a support person. Responses from the participants were:

3L) “my brother is a doctor and he is in agreement...wonderful family”

4L) nurse researcher observation of patient accompanied by husband and daughter and requested them to stay during data collection

5L) nurse researcher observation of patient accompanied by granddaughter, patient relaxed and laughing with granddaughter

6L) nurse researcher observation of patient accompanied by granddaughter

1M) “discussed with family...having friend as support to help you listen...”
observation of close friend with participant during data collection

3M) “I have many years ahead of me with my husband (who is wonderful!)”

Information Given

Information given was stated by 40% (n=4) of the participants in response to the open-ended question as supported by these statements:

2L) “reading information provided...I don’t feel scared asking questions, they made me feel very comfortable...gave me the info”

4L) “everyone gave me the info to make my decision confidently”

6L) “after discussion, I feel it is the right thing to do”

1M) “information from doctors...I read the green book several times...looked on internet...took upon self [*sic*] to find pathology of nodes, called and asked before first post op appointment”

Personal Decision/Choice

Across the total sample, all BCS participants (n=3, 30%) responded about their role in making a personal decision regarding surgical treatment. This theme is described through statements that show women felt their own choice and decision was important in the decision making process:

2L) “let me make my decision”

4L) “everyone gave me the info to make decision confidently”

6L) “beautiful to have chance to have caught it in time and have a choice”

Strong Faith/Spirituality

Within the sample, 30% (n=3) of the participants identified the theme of spirituality or faith when discussing factors that impacted their surgical treatment decision. This theme is supported with these participants' responses:

3L) "blessed because God is reminding me I have everything...faith in choice"

6L) "I thank my Creator for life...much greater profound respect for the care of my body and life in general...feel it is a little valley I will pass and be fine and then get ready to face next obstacle"

nurse researcher observation made that participant was very positive and spiritual

2M) "praying don't have to do chemo"

Previous Experience with Someone With Breast Cancer (nonspecified)

This theme was developed due to the participants' not specifying what surgical treatment their acquaintance chose and therefore, could not be placed in the adapted factor list items 3 and 4. The participants' responses (n=2, 20%) coded into this new theme were:

5L) while talking to granddaughter participant stated, "Remember Dorothy, didn't have a thing done and she just died"

1M) "friends who have had similar experiences with breast cancer..."

Fear of Subsequent Surgeries

The majority of the participants (66.67%, n=2) in the MRM group stated that fear of more surgery was a factor in their surgical treatment decision. This theme is supported by their statements:

1M) “would not want to experience a third surgery if I did not have breast removed”

2M) “avoiding future surgeries”

There were three additional factors identified in the narrative responses. These factors were only stated one time by one participant. Although not recurring, the researchers felt the factors were important because the participants were expressing their personal feelings. One factor identified by a participant was trust. She expressed this in stating, “I know Dr. Mikhail and Dr. Mikhail’s family, and I know he is a great doctor and I trust him.” A second factor identified by a participant was age. She expressed this through the statement, “if I were a younger person, it would be a different story.” The third factor identified by one participant was the guidance of the Nurse Navigator through the statement, “the Nurse Navigator was very helpful.”

Chapter V

Discussion

Theoretical Framework Related to Findings

The results illustrate that this theory-generating study has the potential to expand on the Factor List developed by Ward, Heidrich, and Wolberg (1989). Important themes were identified from the total sample using the Adapted Factor List. The physician's opinion had the highest occurrence of responses with 90% of the participants stating that this was an impact in surgical treatment choice. It was not surprising to see this theme emerge because physicians are the experts regarding the available treatment options and take on the responsibility of prescribing and providing the treatment to their patient (Halkett et al., 2005). Due to the emotions of denial, fear and loss of control during this life changing time, women may desire to take on a more dependent role with the physician (Charles, Gafni, & Whelan, 1999). The factor with the next most frequent occurrence (20%) was fear of side effects from chemo and radiation. Length of recovery and fear of occurrence were reported at a much lower rate (10%). It seems that the Adapted Factor List was best at capturing an important theme, but was less useful in learning about the experiences of the participants.

For prospective use, the Adapted Factor List was not a sufficient tool because it did not capture all themes identified by the participants. This study does, however, serve as a building block for others. Findings support that the Adapted Factor List did not account for 10 identified themes in the sample (Table 12). Among these 10 new themes, the two equally high percentages (60%) were Fear (nonspecified) and Involved Support System. Halkett et al, (2005) recognize support as a factor that can influence the experience of the decision making process regarding

surgical treatment. When examining and comparing these themes by type of surgery, both remained the highest for all identified 10 new themes. In addition, Fear of Subsequent Surgeries was equally high at 66.67% for the MRM group only.

Using the qualitative approach allowed women to express their individual thoughts and feelings in regard to the decision making process. Conversely, the original Factor List limited the women's responses to the items on the list. There was no area for them to expand on their thoughts. This information could have been missed and would be unknown if new themes were not identified. There is support that the Adapted Factor List needs to be expanded to include more factors as evidenced by the 10 new themes revealed with this study.

Implications of the Results

The implications of the results of this study have great potential related to practice, research, and policy. Regarding practice, it is the hope of the researchers that the results from this study will assist healthcare providers in better understanding the experiences that women go through when faced with breast cancer, and to ultimately facilitate the surgical treatment decision making process for patients with breast cancer. The investigators know of no other prospective study in this area making it a theory-generating study. It is a huge stepping stone for further studies to expand and learn more about women's perspectives during their fight with breast cancer. Sharing findings from this study can help gain awareness and support for further needed studies in this area. Nurse practitioners have networks that impact policy at state and national levels. Health policy can be influenced through setting professional agendas and promoting interest groups in organizations such as Michigan Council of Nurse Practitioners and the

American Academy of Nurse Practitioners. Results will also help to support the evolving role of breast cancer centers and breast cancer nurse navigators.

Limitations

The primary limitation of the study was that participants were from one physician and one site. The majority of the sample was Caucasian (70%). This homogenous sample limits the ability to generalize the findings to various populations. Sample size is another limitation. If the sample were larger, results may have been more generalizable for the quantitative portion of the study. Although the qualitative data provided rich information., a larger sample size could assist in understanding more about the deeper meaning of the participants' experiences.

Alternative Explanations for the Findings

There were areas not considered in this study that could have possibly had an impact on the findings. Co-morbidities of the participants were not assessed. As with all cancer patients, the treatment decision is influenced by current health status and any other health problems an individual has. The amount or type of information that the participant was exposed to regarding breast cancer surgery was not included in the data. The women may have also had various previous experiences with cancer in their lifetime, either personally or through a family member or friend. Family history of breast cancer may have not been accurately depicted. It was unknown if there was a "true" family history with a first degree relative (i.e., mother, sister, aunt) because this was not specified by the participants. Any of these factors could have affected the way the women responded in this study.

Recommendations for Further Research

Subsequent research in the area of pre-op surgical decision making by women with breast cancer is a must. This study, being the first prospective study with this topic known to the authors, has great potential for expansion. Further research should consistently include a prospective design with larger sample sizes from more than one setting with diverse populations and various physicians. Although the relationship between current breast satisfaction and type of surgery was not significant in this study, it may be due to the small sample size. Studies should focus more on qualitative approaches before quantitative studies are conducted because a major benefit is the strong potential to gain knowledge that could otherwise remain unknown. More open ended questions would facilitate sharing of thoughts and feelings during this extremely emotional and challenging time. It would also be interesting to know more demographic data such as the particular occupation the participants have. Perhaps individuals working in the healthcare field may have had experiences that affected their decision making process.

Although this study does provide insight into the breast cancer decision making experience, clinicians must be cautioned that the findings need to be replicated in subsequent prospective studies before making major decisions based on these findings alone. Replication of this study should include a more diverse clinical setting to gain a deeper insight to the breast cancer experience among a more diverse population.

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Appendix A

The Factor List (Ward, Heidrich, & Wolberg, 1989).

1. Fear of recurrence
2. Avoiding a second surgery
3. Physician's preference
4. Fear of dying from cancer
5. Side effects of radiotherapy
6. Others MRM experiences
7. Others BC experiences
8. Another's preference
9. Fear of radiotherapy
10. Arm mobility or strength
11. Same survival rate for both
12. Losing a breast
13. Inconvenience of radiotherapy
14. Partner's feelings
15. Breast reconstruction
16. Amount of pain involved

Appendix B

The Stages of Breast Cancer

Inclusion Criterion

Stage I	The tumor is between 0-2cm in size. The lymph nodes are negative for presence of cancer and there is no evidence of metastasis.
Stage II	The tumor is small (2-5 cm) with 1-3 positive lymph nodes or large (greater than 5cm) with negative lymph nodes.

Exclusion Criterion

Stage III	The tumor size can vary from undetectable to greater than 5cm with more than 4 positive lymph nodes under the arm or chest wall. No distant metastasis.
Stage IV	The tumor can be any size with any number of positive lymph nodes. Distant metastasis present.

(National Comprehensive Cancer Network, 2009).

Appendix C

University of Michigan IRB Approval Letter

To: Dr. Janet Barnfather

From: Marianne McGrath

Cc:

Janet Barnfather

Deborah Dimond

Elizabeth Holifield

Diane Welker

Subject: Initial Study Approval for [HUM00013599]

SUBMISSION INFORMATION:

Study Title: Dimond/Holifield: Breast Cancer and Factors Influencing the Decision-Making Process

Full Study Title (if applicable):

Study eResearch ID: [HUM00013599](#)

Date of this Notification from IRB: 3/3/2008

Initial IRB Approval Date: 2/23/2008

Current IRB Approval Period: 2/23/2008 - 2/22/2009

Expiration Date: Approval for this expires at **11:59 p.m. on 2/22/2009**

UM Federalwide Assurance (FWA): FWA00004969 expiring on 5/10/2009

OHRP IRB Registration Number(s): IRB00000248

NOTICE OF IRB APPROVAL AND CONDITIONS:

The IRB Flint has reviewed and approved the study referenced above. The IRB determined that the proposed research conforms with applicable guidelines, State and federal regulations, and the University of Michigan's Federalwide Assurance (FWA) with the Department of Health and Human Services (HHS). You must conduct this study in accordance with the description and information provided in the approved application and associated documents.

APPROVAL PERIOD AND EXPIRATION:

The approval period for this study is listed above. Please note the expiration date. If the approval lapses, you may not conduct work on this study until appropriate approval has been re-established, except as necessary to eliminate apparent immediate hazards to research subjects. Should the latter occur, you must notify the IRB Office as soon as possible.

IMPORTANT REMINDERS AND ADDITIONAL INFORMATION FOR INVESTIGATORS**APPROVED STUDY DOCUMENTS:**

You must use any date-stamped versions of recruitment materials and informed consent documents available in the eResearch workspace (referenced above). Date-stamped materials are available in the "Currently Approved Documents" section on the "Documents" tab.

RENEWAL/TERMINATION:

At least two months prior to the expiration date, you should submit a continuing review application either to renew or terminate the study. Failure to allow sufficient time for IRB review may result in a lapse of approval that may also affect any funding associated with the study.

AMENDMENTS:

All proposed changes to the study (e.g., personnel, procedures, or documents), must be approved in advance by the IRB through the amendment process, except as necessary to eliminate apparent immediate hazards to research subjects. Should the latter occur, you must notify the IRB Office as soon as possible.

AEs/ORIOs:

You must inform the IRB of all unanticipated events, adverse events (AEs), and other reportable information and occurrences (ORIOs). These include but are not limited to events and/or information that may have physical, psychological, social, legal, or economic impact on the research subjects or other.

Investigators and research staff are responsible for reporting information concerning the approved research to the IRB in a timely fashion, understanding and adhering to the reporting guidance (http://www.med.umich.edu/irbmed/ae_orio/index.htm), and not implementing any changes to the research without IRB approval of the change via an amendment submission. When changes are necessary to eliminate apparent immediate hazards to the subject, implement the change and report via an ORIO and/or amendment submission within 7 days after the action is taken. This includes all information with the potential to impact the risk or benefit assessments of the research.

SUBMITTING VIA eRESEARCH:

You can access the online forms for continuing review, amendments, and AEs/ORIOs in the eResearch workspace for this approved study (referenced above).

MORE INFORMATION:

You can find additional information about UM's Human Research Protection Program (HRPP) in the Operations Manual and other documents available at: www.research.umich.edu/hrppp.



Marianne McGrath

Chair, IRB Flint

Appendix D

Approval Documentation

To Whom it May Concern:

I, Dr. Mikhail, have read the background information, literature review, and planned methodology for the study.

"What factors influence the surgical treatment decision-making for women with breast cancer?" I approve of this study and agree with the planned methodology and grant permission to Deborah Dimond and Elizabeth Hollifield, both graduate students at the University of Michigan-Flint, to conduct this study with my breast cancer patients at Hurley Medical Center.

Sincerely,

A handwritten signature in black ink, appearing to read 'Raouf Mikhail', with a long horizontal line extending to the right.

Dr. Raouf Mikhail
G-1075 North Ballenger Highway
Flint, MI 48503
(810) 238-1118

Appendix E

Breast Cancer Decision Making Study Flyer

The diagnosis of breast cancer is a life changing event.

Be part of an informative breast cancer research study:

- Have you been diagnosed with Stage I or II breast cancer and are in the process of deciding upon the type of surgical treatment you will have?
- Would you be willing to share your experience and perspectives about the decision for surgical treatment for your breast cancer?

If you answered YES to these questions, you are eligible to participate in an informative breast cancer research study.

The purpose of this research study is to assess the woman's perspective and what factors affect her decision making process for breast cancer surgical treatment. The information gathered in this study will be beneficial to healthcare providers to better understand this difficult and emotional decision for woman with breast cancer. Participation will receive a \$20 gas card.

The study is being conducted with Dr. Raouf Mikhail's patients at Hurley Medical Center.

Please call Deborah Dimond, RN BSN and Graduate Nurse Practitioner Student at the University of Michigan-Flint Nursing Department at (810)730-6235 or Elizabeth Holifield, RN BSN and Graduate Student at the University of Michigan-Flint at (810)624-1592 for more information.

You will be asked if you would like more information regarding this study at your next appointment at Hurley Medical Center. If you decide you would like further information, Deborah Dimond or Elizabeth Holifield will be available to answer any questions you may have. If you decide you would not like further information, your care will not be affected in any way.

Appendix F

Oral Script

Nurse Navigator Visit With Patient

“Two University of Michigan-Flint graduate students are conducting a research study at Hurley with Dr. Mikhail’s breast cancer patients. I am including a flyer in your packet for your review. I cannot answer any questions about the study, but if you are interested after reading the flyer, there will be an opportunity to speak with one of the students today.”

Nurse Navigator Visit With Patient After Time Given to Read

“Did you have an opportunity to read the flyer regarding the research study conducted by the two University of Michigan-Flint graduate students?”

If the patient says “yes”, reply:

“Would you be interested in meeting with Deborah or Elizabeth for more information? They are here and can answer any questions you may have.”

If the patient says “no”, reply:

“Here is the flyer describing the study. If you are interested, you can meet with one of the students for information about the study. They are here and can answer any questions you may have.”

Appendix G

Letter of Introduction to Participant

Dear Patient,

Deborah Dimond, RN, BSN and Elizabeth Holifield, RN, BSN, both enrolled in the research courses of the Nurse Practitioner program at the University of Michigan Flint, are conducting a research study titled, “What factors affect the surgical treatment decision-making process for women with breast cancer?” at Dr. Raouf Mikhail’s office from May 2008 through August 2008. Any patient who has signed the informed consent will be able to participate. Participation is completely voluntary and will not affect care provided in any way.

If you would like more information, please contact Deborah Dimond and Elizabeth Holifield who would be glad to speak with you about the research study. Contact information provided below.

Sincerely,

Deborah L. Dimond, RN, BSN, U of M- Flint Student

dholden@umflint.edu

(810) 730-6235

Elizabeth Holifield, RN, BSN, U of M- Flint Student

adamholifield@bellsouth.net

(810) 624-1592

Appendix H

Informed Consent

**TITLE: Factors that Affect the Surgical Decision-Making Process among Women
with Breast Cancer**

PRINCIPAL INVESTIGATORS:

Deborah Dimond, RN BSN

Dimond4ever@sbcglobal.net

(810)730-6235

Elizabeth Holifield, RN BSN

adamholifield@bellsouth.net

(810)624-1592

Why is my consent being requested?

Deborah Dimond, RN, BSN and Elizabeth Holifield, RN, BSN, both enrolled in the research courses in the Nurse Practitioner program at the University of Michigan-Flint will conduct a research study titled: Factors that affect the surgical treatment decision-making process among women with breast cancer. The study will take place at Hurley Medical Center from February 2008 through June 2008.

What is the purpose of the study?

This study will investigate what factors are important to women with breast cancer and whether these factors have an influence on the surgical decision for breast cancer treatment. This study will be beneficial for health care providers to understand the experience that you are going through, and may ultimately facilitate the surgical treatment decision making process for patients with breast cancer.

What will my involvement in this study entail?

At your second scheduled appointment following your initial meeting at Hurley Medical Center, you will be asked to write down or verbalize any personal thoughts you have had since your diagnosis of breast cancer that have brought you to your decision about the type of surgical treatment you will have. You can write your own thoughts and feelings or share them with the researcher who will write them for you. Your written permission is required before you can participate in the study. In addition to providing your thoughts and feelings to the above question, those who choose to participate will also be asked to complete a demographic data sheet. Participation in this study will take approximately 15 minutes of your time. You will only be asked to complete the demographic data sheet and write or verbalize your thoughts and feelings at this one point in time. No follow up or contact is necessary unless there are questions you wish to discuss.

What are the risks involved with this study?

There are no foreseeable risks to participate in this study unless you feel it will increase your stress at this emotional time. Deborah or Elizabeth will spend as much time as you may need to discuss your concerns or uncomfortable feeling. Deborah and Elizabeth can also provide appropriate referrals to professional resources as needed. Your participation in this study is completely voluntary.

What are the benefits of this study?

Although you may not receive direct benefit from your participation, others may ultimately benefit from the knowledge obtained in this study. There are no costs to you resulting from your participation in the study. Participants in this study will receive a \$20 gas card after signing the informed consent to thank you for your time.

Will my information given be kept unidentified?

You will not be identified in any reports on this study. Records will be kept confidential to the extent provided by federal, state, and local law. However, the Institutional Review Board and university responsible for monitoring this study may inspect these records. Following analysis of all data, the demographic data sheet and all other information you provided will be destroyed.

If you agree to take part in this research study, please sign and date this form and bring it to your follow-up appointment at Hurley Medical Center. If you have any questions, please call the researchers, Deborah Dimond (810)730-6235 or Elizabeth Holifield (810)624-1592. Further questions can also be directed to Dr. Janet Barnfather, chairperson of the study, at (810)742-3420, or Diane Welker, content expert of the study, at (810) 257-7346. Should you have questions regarding your rights as a research participant, please contact the Institutional Review Board, Sally Conley, 530 French Hall, 303 E. Kearsley Street, Flint, MI 48502-1950, (810) 762-3383 phone, sjconley@umflint.edu. The Hurley Medical Center Institutional Review Board (810) 257-9974 can also answer any questions you may have regarding your rights as a research participant.

VOLUNTARY CONSENT

Your participation in this project is voluntary. Even after you sign the informed consent document, you may decide to leave the study at any time without penalty or loss of benefits to which you may otherwise be entitled. Your care and treatment will not be affected by your participation in this study in any way. One copy of this document will be kept together with the research records of this study. Also, you will be given one copy to keep.

All of the above has been explained to me and I have been given the opportunity to ask questions and have those questions answered. I understand that, throughout my participation in this research study, I am encouraged to ask any additional questions I may have. Deborah Dimond and Elizabeth Holifield will answer any further questions I may have concerning the study. I hereby consent to participate in the study.

Patient Signature

Date

Witness Signature

Date

Appendix I

Demographic Data Sheet

Check all that Apply

1. Marital Status:

Single _____ Married _____ Divorced _____ Separated _____ Widowed _____

Single, Living with Another _____

2. Education:

Less than High School Diploma _____ High School Graduate _____ Some College _____

Associates Degree _____ Bachelors Degree _____ Graduate Degree _____ Other _____

3. Insurance:

Full Coverage _____ Partial Coverage _____ None _____

4. Employment:

Full Time _____ Part Time _____ Unemployed _____ Retired _____ Other _____

5. Ethnicity:

White _____ African American _____ Hispanic _____ Indian _____ Asian _____

Other _____

6. Family History of Breast Cancer:

Yes _____ No _____

7. Type of Surgical Treatment you are undergoing for Breast Cancer:

Mastectomy _____ Lumpectomy _____

Your Age: _____

Current Bra Size: _____

Rate the following question from 1-5, 5 = highly satisfied, 3 = neutral, 1 = highly dissatisfied

Satisfaction with Current Breast Appearance: 1 2 3 4 5

Appendix J

Open-Ended Question

Please read the question below and write down any thoughts or feelings. There are no right or wrong answers. This is an opportunity to share how you are feeling. Phrases or single words may be used to describe your feelings to this question:

“What thoughts and feelings have you experienced since your diagnosis of breast cancer that have guided you to your surgical treatment decision?”

Appendix K

Adapted Factor List (Ward, Heidrich, Wolberg, 1989)

Factor	Present in Narrative
Knowing the survival Rate is equal for mastectomy and breast conserving surgery will impact my surgical decision.	
The physician's opinion will impact my surgical decision.	
Other acquaintances with mastectomy experiences will impact my surgical decision.	
Other acquaintances with breast conserving experiences will impact my surgical decision.	
My partner's feelings will impact my surgical decision.	
Concerns related to arm mobility and strength will impact my surgical decision.	
Fear of side effects from radiation and chemotherapy will impact my surgical decision.	
Length of recovery following surgery will impact my surgical decision.	
Fear of losing a breast will impact my surgical decision.	
Fear of recurrence will impact my surgical decision.	
Fear of dying from cancer will impact my surgical decision.	
Satisfaction of current breast appearance will impact my surgical decision.	