Rural Breast Cancer Patients' Experience with a Planned Exercise Program

by

Meghan Sarna

A field study submitted in partial fulfillment of the requirements of the degree of
Master of Science in Nursing
Saginaw Valley State University

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Approved for content and format by:

Karen Brown-Fackler, EdD, RN, CN
Associate Professor of Nursing
Field Study Chairperson

_____ _____
Date Signature

Kathleen Glaza, MSN, RN
Clinical Nurse Specialist
Field Study Committee Member

_____ _____
Date Signature

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by

Meghan Sarna

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Abstract

The purpose of this qualitative study was to understand the experiences of participants in a cancer specific program for patients living in a rural area. Seven women were interviewed using open-ended questions and guided by the theory of unpleasant symptoms. Data was analyzed by developing a categorization of schemes and codes to search for patterns, themes and subthemes. Findings were factors that altered the women's participation in the planned exercise program including psychological (depressed mood, fear, uncertainty, accountability, awareness, motivation and confidence) and physiological (fatigue, body changes, weight gain, breast reconstruction and increased energy). There were also situational factors including rural isolation, support system, cost, access to healthcare, social interaction, support group and socialization that had an impact. The findings contribute to a deeper understanding of rural breast cancer patients' ability to engage in a cancer specific exercise program after treatment for cancer with or without adjuvant treatment. It is important for health care providers to understand how exercise can be holistically advantageous for rural breast cancer patients and consistently encourage these women to participate in programs that provide it.

Keywords: Breast Cancer, Rural, Theory of Unpleasant Symptoms, Qualitative study

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Chapter One

Introduction

According to the American Cancer Society (2017), there are more than 3.1 million breast cancer survivors in the United States. Many studies have shown a correlation between exercise and a lower risk of cancer recurrence or death from breast cancer (American Cancer Society, 2017; American Heart Association 2017; Syka, 2015). Rural women diagnosed with breast cancer are more likely to be "sedentary and experience poor health status" (Olsen et al., 2014, p.890). This sedentary status is correlated to rural regions being underserved with healthcare resources and are therefore at risk for increased mortality and morbidity (Vallance et al., 2013). Historically, breast cancer patients were advised to avoid exercise due to the risk of developing lymphedema (Sanders et al., 2012). However, recent studies have shown that exercise has been linked to improvements in overall health, physical function, reduction of unpleasant symptoms and decreased risk of comorbid conditions in breast cancer patients (American Cancer Society, 2017; Vallence et. al., 2017, Wurz et al., 2014).

Despite the benefits of physical activity, only 19%-33% of rural breast cancer patients meet the public health guidelines of physical activity and therefore may not realize the potential health benefits (Olson et al., 2014). Women living in rural areas may feel stigmatized by their cancer diagnosis and report a lower quality of life (Reid-Arndt & Cox, 2010). The coordination and continuity of care provided by health practitioners is an important element for adherence to breast cancer treatment plans, specifically survivor programs that include exercise (Raymen & Edwards, 2010). Due to the lack of studies regarding the experiences of rural breast cancer patients' participation in an exercise program, further studies are needed (American Cancer Society, 2017).

The focus of this study was to understand the experiences of participants in a cancer specific exercise program for patients living in a rural setting. The exercise program being studied was locally sponsored for participants. It was a 10 week, twice a

week, free exercise program offered to cancer patients and instructed by cancer exercise specialists in northern Michigan. The theoretical framework for this study involved unpleasant symptom management and was guided by the Theory of Unpleasant Symptoms (TOUS). This theory was used to help categorize and analyze collected data from open ended interview questions (Lenz et al., 1995). The study population studied consisted of breast cancer patients residing in a rural community in northern Michigan. The county studied was classified as a rural area, designated by the Federal Office of Rural Health Policy (HRSA, 2017). The inclusion criteria included participants who were over 18 years of age, with a breast cancer diagnosis of stage 0-III, and who had surgery for breast cancer with or without adjuvant treatment for cancer. The participants were either currently or previously enrolled in the cancer specific exercise program and had healthcare provider approval prior to joining the program.

According to Rayman & Edwards (2010), women have an 11% chance of being diagnosed with breast cancer in their lifetime and the coordination of care after a cancer diagnosis is important for rural women and primary care providers in order to reduce morbidity and mortality. Since physical activity has been linked to improvements in physical function, quality of life and fatigue in breast cancer patients, exercise programs specific to this population are important. For the purpose of this study, exercise is defined as "a form of leisure physical activity performed on a repetitive basis over an extended period with the intention of improving physical fitness, or the performance or health" (Syka, 2015, p.489).

Chapter Two

Theoretical Framework and Literature Review

Women undergoing treatment for breast cancer may experience a multitude of unpleasant symptoms from standard cancer treatment interventions which can negatively impact their daily life throughout treatment, surgery and survivorship. Common symptoms for cancer patients include "pain, worry, depression, diarrhea, cough, shortness of breath, nausea, weakness, fatigue, fever and confusions" (Nayak et al., 2015, p. 349). By assessing and implementing appropriate interventions, Primary Care Providers (PCPs) can use the Theory Of Unpleasant Symptoms (TOUS) as a framework to help achieve positive patient outcomes (Lenz et al., 1995).

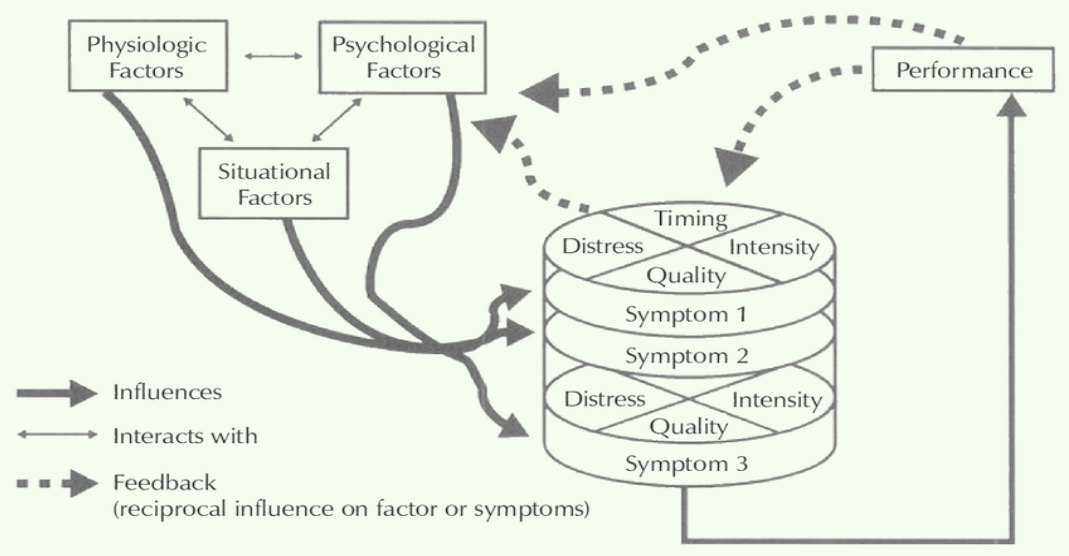
The TOUS was used as a guide for this research to help understand the experience of rural breast cancer patients and the management of unpleasant symptoms related to treatment, surgery or medication while attending a planned exercise program. The TOUS

allowed for the assimilation of multiple symptoms experienced by breast cancer patients in a cancer specific exercise program and served as a conduit for "identifying symptom dimensions that are important to measure" when managing symptoms (Lenz et al., 1997, p.22).

Parsimony was achieved by the TOUS theory by suggesting that some factors influenced the experience of several different symptoms. This would allow for similar interventions useful in alleviating more than one symptom (Lenz et al., 1997, p.14-15). The TOUS also allowed for organization of data into themes.

The main influencing factors in the TOUS model include "physiologic, psychologic and situational factors" (Seung Eun, Vincent & Finnegan, 2017). The symptoms concept consists of four dimensions including intensity, timing, distress and quality (Seung Eun et al., 2017). The final concept, performance, is an "outcome or effect of the symptom experience" which includes functional and cognitive activities that act as a feedback mechanism (Seung Eun et al., 2017, p. 22).

Figure 1. Updated version of the middle-range theory of unpleasant symptoms. Adapted from "the middle-range theory of unpleasant symptoms: an update" by Lenz et al. Copyright 1997 by Aspen Publishers, Inc. Published by Lippincott Williams & Wilkins, Inc.



In this study, the TOUS was adopted to examine the relationship between the major factors and symptoms experienced by rural breast cancer patients and their ability to successfully participate in an exercise program to optimize their health, decrease cancer recurrence and minimize mortality (Syka, 2015). The physiologic domain included the physical impact of changes to the body after major surgery, the psychological factors included the emotional experiences with those changes and the situational factors included perceived barriers to program adherence. The performance outcome is results from attending the exercise program which then serves as a feedback mechanisms for all symptoms and factors experienced which revealed the relationship between each domain.

Literature Review

The data bases CINAHL, MEDLINE and COCHRANE were used to research the topic of breast cancer patients' experience with a planned exercise program in a rural area. The search terms used were breast cancer, unpleasant symptoms, health related quality of life, exercise, and rural health.

Psychological Domain: Rural Breast Cancer Patients. Patients living in rural communities are considered underserved due to the availability of healthcare resources and are at risk for increased mortality and morbidity (Vallance et al., 2013, p. 1080). Rogers et al., studied 483 rural breast cancer patients and discovered that only 19% reached adequate physical activity levels (2009). According to Olson et al., (2014) rural women diagnosed with breast cancer are more likely to be "sedentary and experience poor health status" (p.890). Rogers et al., also discovered that "designing interventions consistent with preferences may lead to programs that are more attractive to patients who are only 'possibly' interested in joining" (2009, p. 418).

According to Vallance et al., (2013) a reduction of symptoms, shorter recovery times and overall health improvements are linked to breast cancer patients engaging in exercise programs. Recent evidence demonstrates that breast cancer patients who

reduced their exercise habits after their diagnosis had a "four times greater risk of dying", compared to breast cancer patients who increased activity after diagnosis (Vallance et al., 2013).

Despite low levels of exercise in rural breast cancer patients, they are more inclined to request information about cancer and beneficial lifestyle interventions (Rogers et al., 2009). According to Vallance et al. (2013) "rural and small-town survivors appear to prefer initiating a physical activity program with other similar aged women, immediately after treatment, at a community fitness center" (p.527).

Physiologic Domain: Unpleasant Symptoms. Many unpleasant symptoms can accompany a breast cancer diagnosis at different treatment stages. According to the National Institute of Health (NIH), pain, depression and fatigue are the most prevalent symptoms that cancer patients will experience (So et al., 2013). These unpleasant symptoms can also affect breast cancer survivors. Physical symptoms such as fatigue, nausea, anxiety, decreased immune function, decreased cardiopulmonary function, neuropathy and joint pain are common in survivors of breast cancer (Sander et al., 2012). Rural breast cancer patients are likely to experience distress and depression because of their cancer diagnosis (Reid-Arndt & Cox, 2010). Decreased well-being and functional well-being along with increased concerns about breast cancer symptoms such as hair loss and lymphedema were also observed in rural breast cancer patients (Reid-Arndt & Cox, 2010). Common sequelae after a breast cancer diagnosis is unwanted weight gain which is correlated with increased levels of estrogen in patients who do not exercise (Homes et al., 2005). Being overweight at the time of the cancer diagnoses and weight gain after a diagnosis is also linked to decreased survival rates (Holmes et al., 2005).

Situational Domain: Barriers to Healthcare. Exercise has continuously been recognized as a successful tool for improving the quality of life for patients with chronic diseases (Mcneely et al., 2006; Syka, 2015). Moderate physical exertion during exercise can also reduce mortality and improve overall survival (Syka, 2015). Vallance et al.

(2013) stated that rural breast cancer patients are at higher risk for decreased quality of life, specifically physical function and fatigue compared to their urban counterparts. Lower reports of quality of life are also linked to concerns about being stigmatized as a cancer patient (Reid-Arndt & Cox, 2010).

According to Wurz et al. (2014), specific internal and situational barriers are prevalent for participants of exercise programs and include distance travelled to exercise facility, scheduling conflicts, and multiple roles or jobs. By understanding the experience of breast cancer patients' participation in a cancer specific exercise program, identifiable factors and symptoms associated in patients will be distinguishably organized using the TOUS model. This study will contribute to the literature regarding rural breast cancer patients' adherence to exercise programs and unpleasant symptom management.

Chapter Three

Methods

Individuals participation in an exercise program designed for breast cancer patients have physiological, psychological and situational factors as well as symptoms that may influence participation, program adherence and completion. This qualitative

study explored the factors and symptoms experience of breast cancer patients living in a rural area and their participation in an exercise program.

Data Collection Method and Protection of Human Subjects

This study was a phenomenological, qualitative design and data was collected from participants of an exercise program in a rural town in northern Michigan. The inclusion criteria were a volunteer, convenience sample of participants including women who were greater than 18 years of age, with a breast cancer diagnosis of stage 0-III, who have had or will have surgery for breast cancer with or without adjuvant treatment for cancer and are currently or were previously enrolled in the exercise program.

Recruitment posters were placed at the exercise facilities with the name and phone number of the researcher (See Appendix A). Participants interested in the study contacted the investigator and a time and date was scheduled for a semi-structured telephone interview that lasted between 15-40 minutes and was recorded on audio tape. Voluntary, confidential participation was emphasized and withdrawal from the study was allowed at any time. Informed consent was addressed by giving participants verbal and written information about the aims of the research followed by obtaining a written consent (See Appendix B). To maintain confidentiality, a description of participant experiences was not labeled with identifiers and codes were used to replace participants so that no one was able to identify the participants who were in the study. The study was approved by the International Review Board (IRB) at Saginaw Valley State University (SVSU).

Instruments and Design

In-depth, semi-structured interviews were conducted with open ended questions that were guided by the Theory of Unpleasant Symptoms (TOUS) (See Appendix C). Using a descriptive phenomenology approach, the data was interpreted by analyzing and describing the interviews. A reflexive journal was maintained to diminish the potentially deleterious effects of preconceptions that might have affected the research process.

Emphasis on the experiences of physiological, psychological and situational factors were evaluated using TOUS to holistically understand what being a breast cancer patient involved in a cancer specific exercise program was like.

The interview began with introductory questions about diagnosis followed by the main research questions that were guided by the TOUS including the factors and symptoms experienced while participating in an exercise program. Neutral probes such as "Can you please explain what you meant?" and "what did you think about when you were answering this question" and "please explain if you experienced any physical health changes since you have completed treatment for cancer" were used to elicit more detail. The semi-structured physiologic domain of the TOUS included questions such as "What are the most important aspects of your physical health". The psychological factors included the experiences women have as a breast cancer patients' and included question: "what motivated you to attend the exercise program?". The situational factors included question: "where there any circumstances that made you miss a class" and "can you walk me through a day when you participated in the exercise program?". The final questions will be: "Is there anything else you would like to tell me?". The performance outcome of the TOUS will be the exercise program which then serves as the feedback mechanisms for all symptoms and factors experienced which will reveal the relationship between each domain.

Trustworthiness

Trustworthiness was enhanced by using rigorous techniques to create clear and accurate descriptions of the participants experience with a cancer specific exercise program. Credibility and authenticity of the data was achieved by review of interview questions findings repeated for the participants to validate. To address transferability, a thick description of participants will be used. Data saturation was reached after seven completed interviews. Dependability and consistency was achieved by maintaining a reflexive journal to address any biases. To address confirmability and objectivity,

researcher bias was prevented by completing a bracketing audit to check for assumptions or previous experiences prior to the interviews.

Data Analysis

Content analysis was conducted and guided by the Theory of Unpleasant Symptoms (TOUS) and the factors previously mentioned to explain and understand the experience of breast cancer patients in an exercise program. Data collected from open ended questions was collected prior to reduction analysis with the use of audio tapes, transcribed verbatim and included any field notes taken. For this phenomenological study, editing analysis was completed by developing a categorization of schemes and codes (first, second & back) to search for patterns, themes and subthemes (Vivar, 2007).

Chapter Four

Findings

The mean age of the sample of participants was 50 years. The reported education levels were a master's degree (n=1), bachelor's degree (n=5) and a high school diploma (n=1). The type of surgery reported prior to participation in the exercise program was lumpectomy (n=3), partial mastectomy (n=1), single mastectomy (n=1), double mastectomy (n=1) and radiation only (n=1). The breast cancer stage of diagnosis ranged from stage I that included four participants, stage II that included one participants, stage III that included one participant and one participant who could not recall her cancer stage. The average distance travelled to the exercise facility from the participants home was 16 miles or 24 minutes. Five participants reported no surgery or treatment within three months of starting the exercise, while two participants reported they had surgery or treatment within the last three months.

The thematic analysis provided a holistic perspective of a rural breast cancer patients' and their experience with a planned exercise program. The TOUS was used to organize open ended questions related to psychological factors and subthemes which included emotions and feelings. The physiological factors and subthemes included body

changes and surgery, and the situational factors and subthemes included cost, support systems and access to healthcare. The themes and subthemes are described in the following sections and presented in Table 1.

Table 1 Themes and subthemes of participation and experience in planned exercise program

	Psychological	**Physiological**	**Situational**
Themes	*Depressed mood* *Fear* *Uncertainty*	*Fatigue* *Body changes* *Range of motion*	*Rural isolation* *Support system* *Cost*
Subthemes	*Accountability* *Awareness* *Motivation* *Confidence*	*Weight gain* *Breast reconstruction* *Increased energy*	*Access to healthcare* *Social interaction* *Support group* *Socialization*

Psychological

Four participants expressed feelings of isolation and uncertainty and also talked about signs or symptoms of depressed mood. They discussed the time in their life in which they were diagnosed with cancer and how they handled the diagnosis. For instance, Terry mentioned "I got the cancer diagnosis and it just pulled the rug right from underneath me and I didn't want to do anything anymore".

Other participants who expressed isolation also expressed uncertainty, nervousness or fear of exercising after having breast surgery. Sally mentioned "I was

nervous to exercise due to weight loss from the chemo, I did decline radiation. The leader was very conscious of my fears and took baby steps until I felt better in order to do a little more at a time". Brenda also mentioned "it felt so good to get into the program knowing what I could and couldn't do in my new body, you know, with my new self". Brenda also stated that "exercising the chest muscles and stuff like that it was just very scary. It was the one part of my body that I just kind got surgery, so it was scary for me to utilize those muscle and things like that, but it was helpful to have the instructor there, coaching me through it. It was just scary".

The participants all reported that the program benefited them in many ways, psychologically. That included confidence, motivation, body awareness, accountability and creating healthy habits that included exercise. Jane mentioned "the main thing I probably took from the program was confidence. That mental confidence and you know, physical that I could do that". Other participants expressed being more aware of their bodies since having breast cancer, Molly expressed "I guess just taking care of myself and being more aware are the most important aspects of my health now. I am more aware of how I feel. It is more on the top of my mind now, whereas it never used to be. I'm always like woah, is this okay, this is new, should I be worried?". Many participants learned that it is important to incorporate exercise into their lifestyle Molly stated "It's just the same as brushing my teeth".

Physiological

All seven of the participants in the planned exercise program reported physiological changes before and after completion of the program. Four participants had no exercise experience prior to the program and one participated stated "having had no gym experience prior to the journey program, there is no way I would have never attempted or tried to work out". The type of surgery each participant experienced was dependent on their overall physiological experience. The participants who had a lumpectomy with lymph node involvement reported range of motion limitations prior to

the exercise program. Jane stated "I feel that the journey program has really helped with my range of motion. It's nice to have a personalized helper to show me what I can and cannot do to get my full range of motion since surgery, so I think that's been a big help". Terry also stated "mobility is a big thing for me and also strength. When I started to recognize after I got cancer how weaker I had become, I realized how much more I needed to focus on strengthening. Strengthening my legs, arms and just getting stronger because when you for cancer treatment, you focus on getting yourself healed from the cancer and that's all you focus on. So, the benefits of the other side of cancer treatment is to say "okay, no I am healed physically this part of the disease, now I'm ready to heal the rest of me and I need to get stronger and II need to be doing these things in harmony with one another, so I can be optimally, at my very best".

Three participants reported a physiological symptom of exhaustion that ranged from moderate to severe. Lack of energy was reported in six of the participants interviewed. Phrases such as "I don't have the stamina that I used to have", "I get tired more easily", "some days I was so fatigued I wasn't able to go", and "I couldn't even walk up a flight of stairs". Positive feedback from six participants who were in the program stated, "during the program I lost weight, and had a lot more energy", and "when I exercise I feel stronger and more alert".

Other positive remarks regarding physiological changes included decreased body weight, increased energy and confidence with ROM. Becky stated, "I gained a ton of weight during treatment, probably because I didn't work out but mostly from the drugs and everything. Getting back into what I could do was important to me. Cancer damages your body so much that you can't really go as crazy as you used to. So, it was helpful to re-learn how to work out safely. I did have lymphedema from the node removal so it helped to have someone monitoring my exercise to ensure that I was doing things correctly to not aggravate or intensify the soreness".

Situational

Many situational factors involved with rural breast cancer patients and a planned exercise program manifested in themes such as isolation, cost, socialization and support systems. On average, distance travelled to the exercise facility from the participants home was 16 miles or 24 minutes. Two participants reported that they would not attend class in the winter if road conditions were compromised. Jane stated "I would only miss a day if I was sick or there was an ice storm or if I couldn't get up my driveway".

Three participants reported that the planned exercise program was a means of support and socialization. Jane also stated "the interaction brought me out of the isolation of being at home, alone. The socialization was with other people who were having similar problems with cancer and so you kind of identified with that support system. It kind of gives you that kick in the butt that you need just to get started rather than just withdraw from any interaction. You know, that self-pity that sets in, you just feel like you're throwing in the towel, like, is this really how my life is going to be now?". Another participant stated, "I look forward to being around other people who are somewhat in my situation". Often times, support groups are offered for breast cancer patients and survivors but one participant explained that support groups were depressing and that the exercise program offered "peer support that was really just fun and it was great being with such a positive group of people that were determined and motivated was great".

The planned exercise program was 10 weeks long and funded by local business owners in the area. During the interviews, there was a common theme amongst three participants regarding the cost of the program and the cost of a gym membership or personal training. Two participants still had young children, while three participants were already retired and collecting a pension. Jane stated "the big thing for me was the cost. When it was free, I couldn't come up with an excuse not to go. I would continue going if it was a reasonable cost. When you're on a fixed income, you have your priorities and at the time, that wasn't one of my priorities". The working mothers

expressed concerns regarding their busy schedules while trying to coordinate the program's specific times. Rhonda would attend a class during her work day and stated "I couldn't really take a lunch due to the schedule constraints with my office, so my time at the gym was really like my lunch hour. I would pack my lunch and generally take something I could eat in my car".

The support from family, friends and employers played a large role in the success of the participants enrollment in the program. Three participants still worked a full-time job. Juggling babysitters, a hectic work schedule and healthcare appointments were identified as barriers to overcome to adequately attend the program.

In summary, all of the participants experienced a change in their physiologic health which simultaneously impacted the psychological and situational aspects experiences by participants before, during and after attending the exercise program. The exercise program was entirely holistic for most participants in treating their unpleasant symptoms from breast cancer and adjuvant treatment interventions.

Chapter Five

Conclusions

Exercise and an active lifestyle is important for breast cancer patients to help minimize unpleasant symptoms related to negative psychological, physiological and situational factors before, during and after cancer treatment with or without adjuvant treatment. Recent evidence shows that exercise is a positive intervention for improving survival after a breast cancer diagnosis and is also useful for improving quality of life (Syka, 2015). Since only 19%-33% of rural breast cancer patients meet the public health guidelines for physical activity, it is likely that they may not realize the potential health benefits of exercise (Olson et al., 2014). The purpose of this qualitative study was to explore the experience of rural breast cancer patients' in a planned exercise program and unpleasant symptom management during treatment and survivorship in one area of northern Michigan.

Overall, the holistic findings supported that women identified multiple themes and subthemes in three domains including psychological, physiological and situational related to attending a planned exercise program. All themes were associated with the TOUS in which the overall outcome resulted from attending the exercise program and served as a feedback mechanism for all symptoms and factors experienced. Parsimony was successfully achieved by the TOUS by suggesting that some factors in each category

(psychological, physiological and situational) influenced the experience of several different symptoms and factors.

Situationally, access to healthcare and wellness centers in rural regions are limited and may be contributing to the low adherence to public health guidelines regarding exercise amongst rural breast cancer patients. Along with extensive commuting miles and compromised road conditions, participants reported missing classes. From a psychological standpoint, rural breast cancer patients experienced feelings of isolation and depressed mood which were improved by socializing and exercising in a planned program specific for cancer patients with other women. Numerous positive physiological changes were reported with the exercise program which included improved range of motion, weight loss, and increased energy.

Most recent evidence demonstrates that breast cancer patients who reduced their exercise habits after their diagnosis had a "four times greater risk of dying", compared to breast cancer patients who increased activity after diagnosis (Vallance et al., 2013). In this field study, four participants had never exercised prior to their cancer diagnosis. Therefore, the coordination and continuity of care provided by health practitioners is an imperative element for adherence to breast cancer treatment plans, specifically survivor programs that includes exercise (Raymen & Edwards, 2010). In conclusion, a planned exercise program for breast cancer patients demonstrates usefulness in holistically, alleviating more than one unpleasant symptom.

There are limitations to this study. There were breast cancer patients who were currently enrolled in the exercise program who if interviewed, may have elicited additional or different themes or subthemes. This was a convenient sample. The population selected was also a limitation in terms of gathering interview data since the designated facility had attracted participants who vacationed in the area in addition to residents. So, the participants may not have been rural residents.

Chapter Six

Implications

There were many aspects of this study that may limit the generalizability of the findings. First, participants were interviewed at different points in the planned exercise program, so symptom experience might have varied due to this. Second, the TOUS guided the questions asked in the open-ended format which may have guided answers in a more favorable manner to the positive outcomes of exercise. Third, this study included various types of cancer and stages with or without adjuvant treatment which may have a wide range of incomparable, unpleasant symptoms. Lastly, this was small qualitative study on one single geographical area.

The usefulness of these findings supports the meaningful use of exercise programs for cancer patients and could aid in grant writing for future program funding in rural regions. It may also be useful for primary care providers or nurse practitioners to prescribe exercise or exercise programs for cancer patients in the future as part of their treatment plan in managing symptoms from a holistic approach.

Target dissemination of findings from this research study could be in a rural nursing journal or holistic nursing journal. Presentation to the facility where the study was done and a presentation to the local nurses association will also be conducted. Exercise and movement is a fundamental component within the American Holistic Nurses Association practice guidelines and encourages nurses to "seek current clinical research regarding special health concerns and the recommendations for therapeutic exercise and movement and make the information available to clients" (Rose & Keegan, 2009, p. 229)

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Appendix A

SAGINAW VALLEY STATE UNIVERSITY

Volunteers Needed!

Are you a breast cancer patient who has or is participating in **The Journey® Program?**

A Saginaw Valley State University graduate nursing student is conducting research to study the experience of women with breast cancer and survivors, who live in this rural area, and have/are participating in the exercise program.

Volunteers are needed to participate in a private interview that will be 45 minutes or less.

- Must be 18 years or older

- Must be previously or currently enrolled in The Journey® Exercise Program
- Must have breast cancer diagnosis of stage 0-III

For further information or if you are willing to schedule an appointment, please contact Meghan Sarna at 612-499-0471 or msarna@svsu.edu

Appendix B

SVSU SAGINAW VALLEY STATE UNIVERSITY.
(989) 964-4000 • From Midland: 695-5325
7400 Bay Road • University Center, MI 48710 • USA
www.svsu.edu

Saginaw Valley State University
Rural Breast Cancer Patients' Experience with An Exercise Program

You are being invited to participate in a research study on rural breast cancer patients' experience with an exercise program. Findings from this study may help health care providers understand the attitudes and expectations of breast cancer patients before, during and after breast reconstruction surgery. You are being asked to participate because you are a breast cancer patient who has been cleared for participation in the Journey Program at Anytime Fitness in Traverse City, Michigan.
The research study involves your participation in an interview which should take about forty minutes or less and will be voice recorded. You will not directly benefit from participation in this study and you will not receive any payment for the interview. Your participation may contribute to the understanding of the experience of breast cancer patients' in an exercise program.

Whether or not you participate in the study is private and any information you provide will be kept confidential. No identifying information will be collected. The researcher will be present in the room until the interview is complete. The interview will take place on a day, time, and place convenient for you where we will have privacy.

Your participation in this study is completely voluntary and you may stop the interview at any time. As in all research, there may be unforeseen risks to the participant. If an accidental injury occurs, appropriate emergency measures will be taken; however, no compensation or additional treatment will be made available. Your participation in this study may involve discussion about surgeries, treatments and emotional experiences which may reveal unpleasant memories or thoughts, therefore support group information will be available. You also have the right to decline to participate at all. Whether you participate or not will not affect your participation in the exercise program.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and reference number in the upper right corner.
If you have questions or concerns about the study, you can contact Meghan Sarna at msarna@mchc.net, 612-499-0471 or Karen Brown Fackler at kmbrown4@SVSU.edu, 989-964-2185 *The participant may also contact the Chair, Human Subjects Institutional Review Board (989-964-7488; irbchair@svsu.edu) if questions or problems arise during the course of the study.*

Subject's Permission
I have read this consent form and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent.

_____ Date_____
Participant signature

_____ Date_____
Witness signature

Any questions about this research or its conduct, and research subjects' rights, and whom to contact in the event of a research-related injury to the subject, should be directed to:

Graduate Nursing Student Researcher, Meghan Sarna, (612) 499-0471, msarna@svsu.edu

Research Advisor, Dr. Karen Brown-Fackler, (989-964-2185), kmbrown4@SVSU.edu

The participant may also contact the Chair, Human Subjects Institutional Review Board (989-964-7488; irbchair@svsu.edu) if questions or problems arise during the course of the study.

[Participants will receive a copy of this consent]

Appendix C

Tool

Begin interview with a few demographical questions:

1. Age
2. Highest education Level
3. Distance travelled to exercise facility (miles)
4. Chemotherapy within last 3 months?

   Yes, No
5. Surgery within last 3 months?

   Yes, No
6. If applicable type of surgery:

   Mastectomy, Double Mastectomy, Lumpectomy, Biopsy
7. Stage of cancer at diagnosis

   Stage I, Stage II, Stage III

Qualitative Interview: Structured, Open ended Questions

Rural Breast Cancer Patients' Experience with a Planned Exercise Program

- Can you walk me through a day when you participate in the exercise program?
- Tell me about your routine exercise prior to your cancer treatment and now?
- When you think of your physical health, what do you think about?
- What are the most important aspects of your physical health?
  - Can you describe how you feel about yourself in that/those areas?
- How have you noticed your physical health change since you have completed the program?
  - What are the similarities and differences?
- What does exercise mean to you now?
  - Why do you say this?
- What motivates you to come to the exercise program?
  - What do you look forward to? What do you not look forward to?
- Can you tell me about any circumstances that would make you miss a class?

The open-ended questions will be arranged to allow for better flow of conversation during the interview.

For each question, the following neutral probes will be used, as needed:

1. What does this item mean to you?
    a. Can you put that question into your own words?
2. How did you arrive at your answer?
    a. What did you think about when you were answering this question?
3. How did you remember that?
    a. How easy or hard for you to remember that?
4. did you formulate your response?
    a. How easy or hard was it for you to find your answer?
5. Go on
6. Can you please explain what you meant?
7. What was that like for you?