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Does Pre-operative Education Increase Activity Participation and Decrease Perceived Arm Dysfunction in Breast Cancer Patients?

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Does Pre-operative Education Increase Activity Participation and Decrease Perceived Arm Dysfunction in Breast Cancer Patients?

Presented in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Occupational Therapy

Eastern Kentucky University
College of Health Sciences
Department of Occupational Science and Occupational Therapy

Stephanie Rexing 2021

EASTERN KENTUCKY UNIVERSITY
COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

This project, written by Stephanie Rexing, under direction of Anne Fleischer PhD, MPH, OT/L, CLT-LANA, Faculty Mentor, and approved by members of the project committee, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF OCCUPATIONAL THERAPY CAPSTONE

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Certification

We hereby certify that this Capstone project, submitted by Stephanie Rexing, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the project requirement for the Doctor of Occupational Therapy degree.

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Executive Summary

Background: Currently there is sufficient evidence indicating safety with upper extremity resistive exercise among those at risk for developing breast cancer related lymphedema. However, there is insufficient evidence of the benefits of pre-operative lymphedema prevention education, upper body strengthening exercises, and strategies to continue or resume physically demanding activities that breast cancer survivors need to do, want to do, or are expected to do.

Purpose: This project described the impact pre-operative education has on activity participation, and perceived upper extremity function among individuals diagnosed with breast cancer compared to those who do not receive pre-operative education. The capstone project aimed to (a) describe and compare activity participation rates among individuals diagnosed with breast cancer who attended pre-operative education and those who did not attend pre-operative education and (b) describe and compare perceived arm function among individuals diagnosed with breast cancer who attended pre-operative education and those who did not attend pre-operative education.

Theoretical Framework: Data gathered within this observational study was organized by the Person, Environment, Occupation, and performance model to illustrate the factors impacting the individual with breast cancer's ability to perform occupations that were important to them.

Methods: A static group comparison research design was used to compare breast cancer survivors' perceived arm function and activity level among those seen pre-operatively and postoperatively and post-operatively only. Disability, Arm, Shoulder, Hand (DASH) assessment and Activity Card Sort-modified (ACSm) scores were graphically compared and described.

Results: Among those survivors seen pre-operatively and post-operatively, DASH scores indicated higher perceived arm function when compared to those seen post-operatively only. Additionally, ASCm overall activity participation scores were higher among those survivors who were seen pre-operatively and post-operatively versus those seen post-operatively only.

Conclusions: This pilot study illustrated that it was feasible for occupational therapy to provide lymphedema prevention education, upper body exercises and strategies to safely complete physically demanding activities pre-operatively. The findings from this small sample are promising. There is a need for further research with a larger population to determine if preoperative occupational therapy is associated with higher rates of participation in physically demanding activities and greater perceived arm function.

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Jerod and the boys, as well as my parents and family

Thank you for all your constant support and motivation along this journey. Thank you for always lending a listening ear and cheering me on. Although this journey is ending there are many more ahead and I know with your support I will not fail.

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DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

CERTIFICATION OF AUTHORSHIP

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Title of Submission: Does pre-operative education increase activity participation and decrease perceived arm dysfunction in breast cancer patients?

Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.

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Date of Submission: 5/4/21

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Section 1: Nature of Project and Problem Identification

Introduction

As of January 1, 2019, there were greater than 3.8 million women with a history of breast cancer residing in the United States (U.S.) (DeSantis et al., 2019). Breast cancer survival varies by stage at diagnosis (DeSantis et al., 2019). The overall five-year breast cancer survival rate for patients diagnosed during 2009-2016 was 98% for stage I, 92% for stage II, 75% for stage III, and 27% for stage IV (DeSantis et al., 2019). Improved prognosis can be partially explained by the variety of treatment options which can include one of or a combination of the following: surgical removal of a tumor and/or reconstruction, radiation, chemotherapy, hormone therapy, and immunotherapy (ACS, 2020). In 2016, nearly one half of individuals diagnosed with earlystage breast cancer (stage I or II) underwent breast-conserving surgery with adjuvant radiation therapy, and one-third underwent mastectomy (DeSantis et al., 2019). Approximately 18% of individuals diagnosed with early-stage disease received treatment that included chemotherapy (DeSantis et al., 2019). Most of the individuals with stage IV breast cancer are treated with palliative/noncurative-intent treatment: 56% received radiation/chemotherapy alone, and 26% received no treatment (DeSantis et al., 2019).

Unfortunately, cancer treatment or cancer itself may cause some or many of the following side effects: pain, fatigue, skin and nail changes, nausea, changes in appetite, changing body image, limitations in every day physical functioning, lymphedema, and sleep problems (Ramani et al., 2017). Side effects may vary from person to person based on the age and general health condition of the individual, type of treatment, and amount of treatment (Ramani et. al., 2017). One of the side effects of cancer treatment is lymphedema, which is due to damage to the lymphatic system resulting in an accumulation of interstitial fluid in the affected limb (Zuther &

Norton, 2013). Specifically, surgery and radiation, which are common treatments for breast cancer, can damage lymph vessels and/or lymph nodes (Viehoff et. al., 2015). Outside of cancer treatment, lymphedema can also be caused congenitally by having (a) fewer or no lymph vessels and/or nodes, (b) too big or small lymph vessels or (c) nonfunctioning lymph nodes or vessels (Viehoff et al., 2015).

As survivor rates of individuals diagnosed with breast cancer rise, cancer-related treatment side-effects, including breast cancer-related lymphedema (BCRL), will also increase (Haley-Emery & Schmitz-Johnson, 2014). Otsby et al. (2018) reports that 10 to 30 percent of breast cancer survivors develop BCRL, and it is the most common reason for disability and occupational performance impairments (Nguyen et al., 2017). Shingaki et al. (2013) report occupational performance impairments range from minor to significant difficulties in completing basic activities of daily living (ADLs) such as bathing, dressing, and grooming (Tretbar et al., as cited in Baxter et al., 2017) and instrumental activities of daily living (IADLs) such as child care, leisure participation, grocery shopping and meal preparation, heavy household cleaning, and yard maintenance (Radina & Armer, as cited in Baxter et al., 2017).

To reduce the risk for lymphedema and its associated negative health outcomes, lifelong lymphedema self-care practices are required by breast cancer survivors (Ridner et al., 2016). Bosompra et al. (as cited in White et al., 2015**)** report there is "an urgent need for lymphedema prevention and management education for all breast cancer survivors" (p. 162). This was echoed in the White et al. (2015) study that demonstrates one-quarter of the survivors reporting they were unaware of their risk for developing lymphedema. Raising the awareness of lymphedema and self-care techniques are wanted and needed by individuals who will or have undergone breast cancer treatment (Sherman & Koelmeyer, 2013). The first step is teaching them how to

identify the early signs and symptoms of lymphedema, such as aching and mild swelling, and knowing the importance of notifying a physician when these early signs and symptoms occur. Next, lymphedema risk reduction self-care management strategies should be taught which include avoiding excessive heat and reducing the risk of upper body trauma and infection. (Sherman & Koelmeyer, 2013). Unfortunately, risk reduction self-care management strategies are not routinely taught to those receiving treatment, which has resulted in late treatment (Sherman & Koelmeyer, 2013).

Several researchers have suggested incorporating protocols into standard of care for breast cancer patients. Haley-Emery and Schmitz-Johnson (2014) insist that clinicians must begin integrating a proactive approach to assessment and intervention of BCRL. Researchers suggest a surveillance model with uniform assessment criteria (Haley-Emery & Schmitz-Johnson, 2014). Pre-operative baseline circumferential measurements, in addition to, postoperative circumferential measurements that are repeated four times per year would enable the clinician to identify BCRL early and allow an opportunity for patient education (Haley-Emery & Schmitz-Johnson, 2014).

Researchers suggest that the development of a consistent lymphedema prevention protocol for breast cancer survivors including learning the lymphedema signs and symptoms, and methods for prevention (Hanna et al., 2017). Another group of researchers noted in their research that not only do individuals with breast cancer need to be made aware of their risk for development of BCRL, but information must be presented to them in a way that makes sense to them (Sherman et al., 2018). In a study where women were surveyed regarding their preferences for BCRL education, most women preferred one-on-one private sessions with a healthcare

provider (White, et al., 2015). However, there continues to be disagreement of when this education should be provided, such as before or after surgery (White, et al., 2015).

In addition to education regarding lymphedema risk-reduction management, research has indicated exercise is beneficial for individuals during and after breast cancer treatment (Gho et al., 2014). Exercise has the potential to address physical needs of an individual with breast cancer by improving strength and cardiorespiratory fitness, reducing fatigue, decreasing heart and circulatory disease, and decreasing cancer recurrence risk (Gho et al., 2014). Research has also demonstrated that exercise can improve the emotional and psychological outcomes of individuals with cancer by improving self-esteem, decreasing levels of anxiety and depression, and improving quality of life (An et al., 2020). One factor limiting these individuals from exercise is kinesiophobia--the fear of movement—which results in shoulder restrictions, reduced strength, and depression (Can et al., 2019). Factors contributing to kinesiophobia are upper body pain, numbness, restricted shoulder range of motion, and fear of lymphedema during and after breast cancer treatment (Can et al., 2019).

Zuther and Norton (2013) note that the overall health benefits of regular exercise cannot be ignored and especially among those individuals with lymphedema or those who are at risk for lymphedema. When instituting an exercise program for maximal function, exercises are meant to improve lymph circulation (Zuther & Norton, 2013). However there has been some concern among breast cancer survivors regarding the safety in resuming physical activity following breast cancer treatment (Schmitz et al., 2010). To address the concern that exercise, or physical activity leads to lymphedema, researchers examined the impact of incremental progressive weightlifting and found it did not increase the risk for developing BCRL (Schmitz et al., 2010). Currently

there is sufficient evidence indicating safety with upper body resistive exercise among those at risk for developing BCRL (Schmitz et al., 2010), but there is insufficient evidence of the benefits of pre-operative education, including participation in upper body physical activities.

Problem Statement

Currently little is known about the a) level of activity participation and b) perceived arm function among individuals diagnosed with breast cancer who did or did not receive preoperative lymphedema education.

Purpose of the Project

The purpose of this project is to describe the impact pre-operative education has on activity participation, and perceived upper extremity (UE) function among individuals diagnosed with breast cancer compared to those who do not receive pre-operative education.

Project Objectives

The objectives of this research project are to describe and compare activity participation rates, and perceived arm function among individuals diagnosed with breast cancer who attended pre-operative education and those who did not attend pre-operative education.

Theoretical Framework

The guiding model for this research project is the Person, Environment, Occupation, and Performance (PEOP) model. This top-down and client-centered model focuses on an individual's performance, participation, and well-being (Cole & Tufano, 2020). The focus of this model is the interconnection among person/intrinsic factors, environment/extrinsic factors, and occupation leading to successful occupational performance. The authors of the model included four components to help the occupational therapist apply it: narrative story, personal factors,

occupational factors, and environmental factors (Cole & Tufano, 2020). In line with these components are core terms: occupation, occupational performance, narrative, person factors and environment.

Occupations consist of the activities, tasks, and associated roles, an individual both desires or needs to complete within their daily lives (Baum et al., as cited in Cole & Tufano, 2020**)**. Occupational performance is the completion of those meaningful occupations through interaction between the person and the environment (Baum et al., as cited in Cole & Tufano, 2020)**.** Baum et al. (as cited in Cole & Tufano, 2020) note that occupational performance is seen as doing and this enables participation and engagement in everyday life contributing to wellbeing.

Occupational performance is a result of a dynamic interaction of the person performing the occupation within an environment (Cole & Tufano, 2020). Occupational dysfunction arises when limitations and restrictions occur within the individual and/or their environment or the occupation itself (Cole & Tufano, 2020). The PEOP directs the OT to view occupational performance within a complex system where the client is at the center (Baum et al., as cited in Cole & Tufano, 2020).

Gathering subjective data about the client is part of the narrative process that provides the individual's perception of the current situation (Cole & Tufano, 2020). Additionally, the narrative focuses on the interests, needs, choices, attitudes, motivation, and individual's perceptions of the past, current, and future (Cole & Tufano, 2020). The OT can utilize the individual's attitude and motivation to determine if the patient will be appropriate for specific interventions as well as determine what the individual aims to accomplish with therapy to allow the OT to create individualized interventions. For instance, if an individual suggests a goal of

returning to work, the OT will focus treatment interventions on improving the individual's function to reach that goal. An individual's work requirements, their attitude and/or motivation, and economic need to return to work vary among individuals with the same goal. Through the narrative, the therapist learns from the individual why they want, need, or are expected to return to work along with the occupational performance demands. From this knowledge, the therapist can collaborate with the individual to develop treatment interventions that are centered around the person and their individualized needs.

Within this model, the person is comprised of many personal or intrinsic factors that influence an individual's capabilities (Cole & Tufano, 2020). These factors include neurobehavioral, physiological, cognitive, psychological, and spiritual. Neurobehavioral factors describe their ability to use adaptive and/or compensatory responses. Physiological factors include the physiologic mechanisms that influence endurance, flexibility, movement, and strength (Cole & Tufano, 2020). Cognitive factors are an individual's ability to learn and remember information (Cole & Tufano, 2020). Psychological factors are those processes that are internal for the person and used to influence what he or she may do, an individual's sense of self, and how their actions are interpreted (Cole & Tufano, 2020). Lastly spiritual factors are those individual experiences that contribute to personal understanding about themselves and their place in the world (Cole & Tufano, 2020).

The environment or extrinsic factors may either support or limit performance, well-being, and/or occupational performance (Cole & Tufano, 2020). Within this model, the environment includes the physical and natural, culture, social determinants, social support, social capital, education and policy, and assistive technology. The built or physical environment is made by people and may include assistive technology devices and tools and appliances whereas the

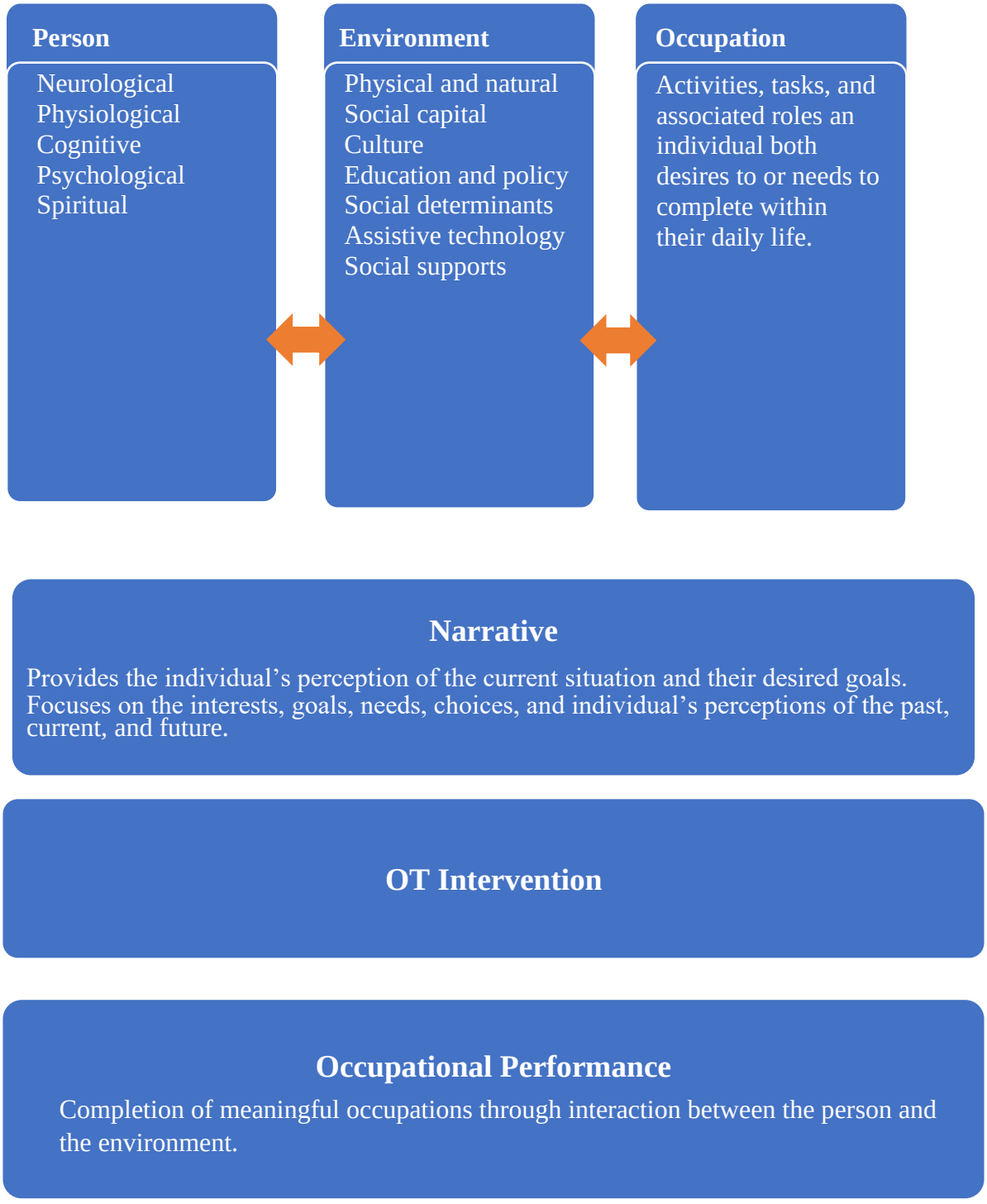
natural environment includes features of geography that cannot be modified including terrain, climate, and hours of daylight (Cole & Tufano, 2020). The cultural environment includes values, beliefs, customs, decision making, and economic characteristics and behaviors that are passed from one generation on to another (Cole & Tufano, 2020). Social determinants of health encompass both the social and economic systems responsible for health inequities that include the social and physical environments and health services (Cole & Tufano, 2020). Social capital is the level in which members within a community and/or society cooperate and support one another for mutual benefit ultimately leading to health and social cohesion while social support includes an individual being a part of a greater whole that results in a sense of belonging (Cole & Tufano, 2020). Health, education, social, and public polices includes those policies and access, funding, advocacy, and political organization that might enable or hinder an individual's occupational performance (Cole & Tufano, 2020). Assistive technology includes any piece of equipment or product system that is used to increase, maintain, and/or improve an individual with disabilities' function (Cole & Tufano, 2020).

The PEOP was used as a guiding model for this research project. The researcher organized the data collected within the PEOP model to illustrate the factors impacting the individual's ability to perform occupations that are important to them (Figure 1). Occupational therapy interventions provided were directed toward these factors to improve the individual's ability to perform the desired occupation without increasing their risk for BCRL.

Significance of the Study

This study will describe the perceived arm function and activity participation among individuals diagnosed with breast cancer who are seen pre-operatively and post-operatively and those seen post-operatively only.

Figure 1. PEOP Model



Section Two: Literature Review

Breast Cancer Survivorship

Breast cancer survivors are growing in number (Baxter et al., 2017). According to the SEER data obtained from 2010 – 2018, 90% of women survive breast cancer for five years or greater. Siegel et al. (2020) indicate there were an estimated 276,480 new breast cancer cases in 2020 which includes 30% of female diagnosed cancers with 42,170 deaths. New female breast cancer cases have been rising on average 0.3% each year over 2008-2017 (U.S. Department of Health and Human Services, 2020). Despite this increase in new female breast cancer cases the death rate for female breast cancer has dropped by 40% since 1989 (Siegel et al., 2020).

Early diagnosis and new treatments are contributing to the increasing number of breast cancer survivors (Baxter et al., 2017). Additionally, these survivors are living "normal" life spans resulting in more individuals living with cancer-related impairments (Baxter et al., 2017). Fortunately, survivorship care is an evolving field striving to recognize, understand, and manage issues that arise in the posttreatment phase (Chiu & Nichol, 2018). Additionally, survivorship care aims to prevent the development of acute or chronic impairments (Shah et al., 2016). Some breast cancer survivors experience significant and long-lasting impacts to their physical, emotional, and psychological health (Chiu & Nichol, 2018). To meet this demand, post-treatment visits are dedicating more time to identifying and addressing these impairments which can impact their physical, emotional and psychological health. Common impairments addressed in survivorship care include UE lymphedema, posttreatment pain, and cancer recurrence (Chiu & Nichol, 2018), which are a result of chemotherapy, radiation, and/or surgery (Ramani et al., 2017). These impairments can lead to changes in occupations, and result in occupational participation deficits (Ramani et al., 2017).

Occupational Participation

Palmadottir (2010) found occupational participation to have a restorative power in aiding individuals with breast cancer manage the side effects of breast cancer treatment. Within their research, occupations aided women in taking control of their lives by allowing them to organize time, manage emotional distress, and gain some control of their own health (Palmadottir, 2010). This control over their health reinforced the survivor's sense of health and normality and encouraged them to go on with their lives (Palmadottir, 2010).

Lymphedema

Up to 80% of breast cancer survivors experience at least one breast cancer-related side effect and some may persist after the end of treatment (Can et al., 2019). Among these sideeffects for breast cancer survivors is damage to the lymphatic system which can result in a lifetime risk for developing BCRL (White et al., 2015). Individuals with a history of ALND have a 20% risk for developing BCRL as compared with a 5% risk among those who had sentinel lymph node biopsy (Disipio et al., 2013).

Breast cancer survivors who develop BCRL will need to know what types of treatment that are available (Ostby et al., 2018). The gold standard for treating lymphedema is Complete Decongestive Therapy (CDT) (Zuther & Norton, 2013). CDT is made up of two phases (Zuther & Norton, 2013): (a) Phase I includes manual lymphatic drainage (MLD), compression bandaging, skin care education and lymphatic flow arm exercises (Ridner et al., 2015) and (b) Phase II includes wearing a compression garment and/or self-bandaging, completing self-MLD, caring for skin, and completing UE exercises (Ridner et al., 2015). Phase II becomes part of the individual's daily self-care routine to reduce the risk of the lymphedema progressing and

acquiring associated negative health outcomes, such as infections or non-healing wounds (Ridner et al., 2015).

Unfortunately, Ostby et al. (2018) found suboptimal self-management rates among those with BCRL. The researchers hypothesized this was due to a lack of health care provider education customized to survivor needs (Ostby et al., 2018). Within their research, Ostby et al. (2018) identified the lack of education about lymphedema treatment and risk reduction strategies as barriers to self-management of BCRL.

In addition to the research by Ostby et al. (2018), Lu et al. (2015) completed research including lymphedema patient education combined with exercise to determine if it reduced the risk for developing BCRL. The researchers' results indicated that patient education beginning within the first week post-surgery followed by physiotherapy was effective in reducing the risk of lymphedema in women who underwent ALND, with only 7.7% of the survivors developing upper-limb lymphedema (Lu et al., 2015). These results were compared to the 18.6% who developed upper-limb lymphedema who received neither education nor physiotherapy and the 15% who developed upper-limb lymphedema who received education alone (Lu et al., 2015).

Puscas and Tache (2015) suggest that exercise is vital in both the recovery after breast cancer surgery as well as prevention and treatment of lymphedema. Physical activity has been noted to increase lymph volume from 2 liter/24 hours to 3 liter/24 hours (Puscas & Tache, 2015). This acceleration of the lymphatic circulation assists in prevention of lymph stasis and lymphedema (Puscas & Tache, 2015). Additional benefits of exercise in individuals who are undergoing or who have completed cancer treatment are the following: (a) improved quality of life, (b) improved ability to complete everyday tasks, (c) reduced risk for falls, (d) better managed weight, (e) improved body image and self-esteem, (f) reduced fatigue, stress, anxiety,

and depression, (g) reduced risk of sarcopenia (muscle wasting), (h) reduced osteoporosis, (i) reduced cardiovascular disease and diabetes, (j) improved blood flow and reduced risk of blood clots, (k) improved lymphatic flow, and (l) reduced cancer recurrence (Quaglio et al., 2019). Additionally, An et al. (2020) found that breast cancer patients who consistently exercised after treatment reported having a better quality of life, fewer treatment-related symptoms, better psychosocial factors, and improved physical fitness compared to those who were not exercising. Regardless of what exercise survivors completed, the results were the same suggesting that consistent exercise participation is associated with both maintenance and improvement in physical and mental health (An et al., 2020). Researchers suggested a combination of aerobic and resistance exercise during and after treatment for individuals with breast cancer (An et. al., 2020).

Patient-Reported Outcomes

The International Classification of Functioning, Disability, and Health (ICF) (as cited in Swisher et al., 2010) note that activity limitations are difficulties in which an individual might have in performing activities or tasks while participation restrictions are problems an individual may encounter within life situations. Disability is a combination of impairments, activity limitations, and participation restrictions (Swisher et al., 2010). Within the breast cancer population, Swisher et al. 2010 notes activity limitations and participation restrictions have been studied less often than impairments. A hypothesized reason for this is the possible difficulty in finding appropriate tools for measuring activity limitations and participation restrictions (Swisher et al., 2010). Harrington et al. (2014) suggest patient-reported outcome measures should be used to assess breast cancer survivor's difficulty in upper extremity activities and participation in daily roles. Disability of Arm, Shoulder and Hand (DASH) questionnaire and Activity Card Sort

modified (ACSm) are two patient-reported outcome measures that have been effectively used with the breast cancer population.

Disability of Arm, Shoulder, and Hand. The DASH questionnaire is commonly used to measure patient-reported outcomes for the upper body among those with a history of breast cancer (Harrington et al., 2014). Harrington et al. (2014) completed an extensive literature review of the patient-reported UE outcome measures for women with breast cancer and found the DASH most useful in assessing patient-reported upper extremity function in breast cancer survivors. Through their extensive search of the literature, Harrington et al. (2014) noted the DASH was found to have construct validity distinguishing between a group of breast cancer survivors versus healthy controls. Additionally, the DASH demonstrated the ability to distinguish between a group of breast cancer survivors with BCRL and a group of breast cancer survivors without BCRL (Harrington et al., 2014).

Additional studies using the DASH with breast cancer patients includes Swisher et al. (2010) study to determine the type and severity of upper limb problems following breast cancer treatment as well as how those impairments impacted self-reported participation in daily activities. Swisher et al. (2010) reported that this was the first study to use the DASH to quantify UE-related disability and determine the specific nature of the impairments, activity limitations, and participation restrictions among breast cancer survivors. Swisher et al. (2010) found a high prevalence of shoulder, arm, or hand impairments, and self-reported activity limitations and participation restrictions among individuals who had breast cancer surgery.

Another group of researchers, Miedema et al. (2011) completed a study regarding arm mobility and its impact on physical activity and recreation among breast cancer survivors using the DASH. Researchers concluded that arm pain, range of motion (ROM) and lymphedema

significantly predicted breast cancer survivors' difficulties with participation in recreation activities (Miedema et al., 2011). Researchers also discovered that 43 months after breast cancer surgery there were a number of women still experiencing pain and ROM restrictions largely impairing participation in recreational activities (Miedema et al., 2011).

Activity Card Sort modified (ACSm). The Activity Card Sort (ACS) is a patient reported outcome measurement tool that assesses an individual's participation in instrumental, social, and low-and high-demand leisure activities, as well as asking respondents to list their five most important activities (Baum & Edwards, 2008). The ACS has recently been used by Schreuer et al. (2020) in a longitudinal study to compare women's participation in daily activities at the subacute phase to their participation five years after diagnosis as well as to explore factors associated with participation in daily activities at follow-up. Researchers used the ACS to assess participation in daily activities of survivors and found that long-term symptoms, especially physical and cognitive symptoms, restricted women's participation in daily activities five years following diagnosis (Schreuer et al., 2020).

Lyons et al. (2010) has used a modified version of the ACS, the Activity Card Sort modified (ASCm), to study survivors with stem cell transportation to measure activity resumption. The ACSm utilizes a checklist rather than the traditional card sort (Lyons, 2010). Fleischer and Howell (2016) utilized the ACSm in their study comparing breast cancer survivors' resumption of previous activities at the beginning and end of radiation treatment, and 3-months and 6-months after treatment. The researchers found that the breast cancer survivors activity resumption was different at each time point (Fleischer & Howell, 2016). Additionally, the researchers discovered that breast cancer survivors did not return to their baseline level of social activities (Fleischer & Howell, 2016).

Problem Solving Approach

Schulman-Green et al. (2011) suggest that individuals who have had breast cancer and want to engage in occupations that they need to do, want to do, or are expected to do after breast cancer diagnosis and its treatment, must learn how to manage treatment-related impairments. Problem-solving treatment (PST) assists individuals who were diagnosed with cancer generate and evaluate various solutions for challenges they face when participating in occupations (Lyons et al., 2012). Within PST, the occupational therapist does not suggest specific solutions to occupational performance problems, rather teaches them to use a six-step problem-solving approach so they become an active director of their recovery (Lyons et al., 2012).

The PST method has been used in research to demonstrate its value in treatment of breast cancer patients. One group of researchers completed a randomized control trial in which women who were unable to perform a valued activity were taught they can (1) change something about their personal skills, (2) change the environment in which the activity is performed, or (3) change the nature and steps of the activity itself (Lyons et al., 2012). Lyons et al. (2012) found that women chose a variety of activity challenges with the most common being exercise and instrumental activities of daily living (IADLs). The goal of the majority of the sessions was for women to adapt a particular, familiar activity or set of activities that the women were already doing (Lyons et al., 2012). Surprisingly to the researchers, nearly a third of the sessions focused on finding a new activity to add to a woman's daily routine (Lyons et al., 2012). Researchers proposed that these findings indicate women's desire to set goals and make changes across a variety of areas in their lives while undergoing chemotherapy (Lyons et al., 2012).

Summary

Breast cancer survivors must learn to manage at least one cancer treatment related impairment (Can et al., 2019; Chiu & Nichol, 2018; Schulman-Green et al., 2011), such as upper extremity lymphedema and pain, and the changes these impairments have on occupational participation (Ramani et al., 2017). Despite this knowledge, many therapists only assess for the presence of impairments, not the impact on function. Harrington et al. (2014) suggested therapists evaluate the individual's difficulty in completing upper extremity activities and participation in daily roles.

The DASH is a measurement tool that has been used to evaluate individuals with breast cancer perceptions of their upper extremity function (Harrington et al., 2014), and the ACSm compares occupational participation before cancer diagnosis with their current occupational participation levels (Baum & Edwards, 2008). Each of these assessment tools have been used within various studies evaluating breast cancer survivor's function (Davies et al., 2015; Harrington et al., 2014; Davies et al., 2013; Miale et al., 2013; Swisher et al., 2010; Schreuer et al., 2020; Fleischer & Howell, 2017; Baum & Edwards, 2008) but have not been used within the same study. By utilizing the DASH and the ACSm within the same study, occupational therapy lymphedema prevention education can be directed toward the high-demand activities identified by the individual before and after breast cancer surgery. Specifically, a home program will be collaboratively developed to incrementally return to these high-demand activities based on the evidence incremental strengthening activities can increase function and reduce the risk of lymphedema (Palmadottir, 2010; Schmitz, et al., 2010).

Section Three: Methods

Research Query

The capstone project aimed to (a) describe and compare activity participation rates among individuals diagnosed with breast cancer who attended pre-operative education and those who did not attend pre-operative education and (b) describe and compare perceived arm function among individuals diagnosed with breast cancer who attended pre-operative education and those who did not attend pre-operative education.

Project Design

The project design was a static group comparison. Static group comparisons are most often used when answering a descriptive question such as what happened after a phenomenon occurred and/or compared to the control group, what happened after a phenomenon occurred (DePoy & Gitlin, 2015). In this study the independent variable was individualized pre-operative BCRL prevention including, education, home program, and adaptations and/or modifications of high-demand physical activities. The dependent variables were survivor's activity participation level and perceived UE function as measured by the ACSm and the DASH.

Setting

The study took place within a clinic at the Owensboro Health Wound Healing Center where individuals with breast cancer receive occupational therapy.

Inclusion/Exclusion Criteria

Survivors were included in the study if they were English-speaking, had been diagnosed with breast cancer within the last six months and evaluated and/or treated by an occupational therapist no greater than six months post-operatively. Survivors were excluded from this study if

they had received any previous formal lymphedema education by an occupational therapist or physical therapist.

Survivors were those individuals with breast cancer who had been referred to occupational therapy pre-operatively and/or post-operatively from general or plastic surgeons, radiation oncologists, and/or oncologists within the Owensboro Health system.

Project Methods

Data Collection

After Institutional Review Board (IRB) approval was granted, standard of care OT evaluation measures and clinical notes were extracted from 12/9/20 – 1/20/21 and additional measures were collected 1/21/21 - 2/24/21. After data was collected, each individual was provided a unique code. Evaluation measures included the DASH questionnaire, the ACSm checklist, and active range of motion (AROM) measurements. Clinical notes included type of cancer and stage, type of surgery, ALND versus SLND, number of nodes removed, and current radiation therapy or chemotherapy. Lastly field notes included observations of caregivers, survivor's perceived interest in topic, concerns expressed by caregiver and/or survivor, survivor's work status, and if occupational therapy follow-up was needed.

Standard Occupational Therapy Interventions

Standard of care for individuals with breast cancer occurs in two different routes (1) a pre-operative occupational therapy evaluation with post-operative follow-up or (2) a post-operative occupational therapy evaluation and treatment. Those individuals who received pre-operative OT completed both the ACSm and the DASH assessments and had the following physical evaluations completed: (a) arm limb volume calculated by using circumferential measurements of the hand, wrist, forearm, below elbow, above elbow, and upper arm at regular

intervals using a tape measure and (b) bilateral active shoulder flexion, abduction, adduction, and internal and external rotation AROM using a goniometer.

After completion of these assessments, they were reviewed and recorded by the OT. Next, individualized lymphedema prevention education, home exercise program, and possible adaptations and/or modifications of high demand physical activities were provided to each survivor. Individualized lymphedema prevention education included (a) risks for developing lymphedema, (b) risk reduction strategies, (c) symptoms of lymphedema, and (d) treatment for lymphedema. A post-operative home exercise program (HEP) was prescribed based on the specific surgical procedure the individual was planning to undergo. Each HEP had previously been pre-approved by the referring general and plastic surgeons within the Owensboro Health system. After the education was provided, the OT and survivor collaboratively developed activity participation goals and discussed strategies to meet these goals using the six steps of the problem-solving approach as a guide (Lyons, et al., 2012). The steps include (1) identifying high demand activities that are important to the individual and what component(s) of the activity will require modification and an incremental plan to return to it, (2) setting a goal that is behavioral, observable, achievable, and general, (3) brainstorming multiple solutions that could help meet the goal, (4) identifying the advantages, and disadvantages for each potential solution, (5) creating and implementing an action plan that addresses when and how the solution will be implemented, including what resources might be needed, and a "plan B" to address foreseeable barriers to executing the solution, and (6) assessing how well the problem was solved by the action plan (Lyons et al., 2012 p 33-40). Post-operative follow-up appointments were scheduled for re-assessment and treatment.

Those individuals who returned for post-operative OT after receiving pre-operative OT completed the ACSm and the DASH assessments and had circumferential arm measurements and AROM measurements retaken. These assessment scores and measures were compared to those taken pre-operatively. Assessment results and goal progression were discussed with the individual. Goals were adjusted as needed. Problem solving session was conducted to develop strategies to increase activity participation and complete HEP. Follow-up appointments were scheduled for those who had unmet therapy goals.

Those individuals who only received post-operative OT completed the ACSm and DASH assessments and had the following physical evaluations completed: (a) arm limb volume calculated by using circumferential measurements of the hand, wrist, forearm, below elbow, above elbow, and upper arm at regular intervals using a tape measure and (b) bilateral shoulder AROM—flexion, abduction, adduction, and internal and external rotation using a goniometer.

After these assessments were reviewed and scored by the OT, individualized lymphedema prevention education, home exercise program and possible adaptations and/or modification of high demand physical activities were provided to each survivor. Individualized lymphedema prevention education included (a) risks for developing lymphedema, (b) risk reduction strategies, (c) symptoms of lymphedema, and (d) treatment for lymphedema. A postoperative HEP was prescribed based on the specific surgical procedure the individual underwent. These HEPs had previously been pre-approved by the referring general and plastic surgeons within the Owensboro Health system. After the education was provided, the OT and patient collaboratively developed activity participation goals and discussed strategies to meet these goals using the six steps of the PST as a guide. Follow-up appointments were scheduled for those with therapy goals.

Field Notes

Field notes were recorded after each visit and were de-identified. Notes included therapist's observations, such as, caregiver involvement during the session, survivor's perceived interest in the topic, and caregiver's and survivor's concerns expressed. Any deviations from the above standard protocol were recorded.

Data Analysis

The following data was extracted from the medical record and deidentified: demographics, cancer type, stage, bilateral shoulder AROM, and bilateral arm limb volume, and ACSm and DASH scores. Descriptive statistics, figures and charts were used to summarize and illustrate the individuals seen pre-operatively and post-operatively, and individuals seen post-operatively only.

Important activities listed within the ACSm were categorized by instrumental activities of daily living (IADLs), social participation, and low- and high-demand leisure activities. Field notes and problem-solving session notes were thematically analyzed.

Instruments Used

As noted previously the ACSm has been utilized to measure activity participation and the DASH has been utilized to measure perceived UE function among breast cancer survivors.

ACSm

The ACSm is a modified version of the original assessment tool, the ACS. The ACS was developed in order to measure activity engagement in the following four domains: instrumental activities (i.e., driving, paying bills, childcare), low physical-demand leisure (i.e., puzzles, quilting, photography), high physical-demand leisure (i.e., bicycling, woodworking, hiking), and social activities (i.e., volunteer work, visiting with friends, traveling) (Baum &

Edwards, 2008). There are three different versions of the ACS for (a) community-dwelling, healthy older adults; (b) older adults in a nursing facility; and (c) people recovering from a medical event (Baum & Edwards, 2008). When used with individuals recovering from a medical event, the ACS scoring reflects the percentage of activities that an individual has retained during recovery (Baum & Edwards, 2008). Additionally, the ACS can be used longitudinally to track an individual's progress in returning to a prior level of function after a health event (Baum & Edwards, 2008). The ACS has been tested for both reliability and validity in adults and older adults both with illness as well as in individuals with multiple sclerosis, cerebral vascular accident, and Alzheimer's disease (Baum & Edwards, 2008; Everard et al., 2000). The one-week test-retest reliability coefficient is r=0.9 and internal consistency of the four domains is greater than $\alpha = 0.7$ (Baum & Edwards, 2008).

The ACSm, the modified version of the ACS, is a measurement tool that assesses an individual's participation in occupational performance of instrumental, social, and low-and highdemand leisure activities, as well as asking respondents to list their five most important activities (Lyons et al., 2010). Survivors were provided with 80 activities and asked to assign these activities to one of five categories: (a) never done, (b) do now as often as before breast cancer treatment, (c) do less or differently than before breast cancer treatment, (d) have not done since breast cancer treatment, or (e) new activity (Lyons et al., 2011). The ACSm is then scored the same as the ACS. The total score and four domain scores reflect the percent of activities retained since the medical event by dividing current activities by previously done activities (Lyons et al., 2011). A score of zero would indicate the respondent is not doing any of their pre-medical event activities nor have they added any new activities whereas a score of 100 would indicate the respondent is performing at their pre-medical event level (Lyons et al., 2011).

The ACSm was first used by Lyons et al. (2010) in their study of activity resumption after stem cell transportation. The ACSm was established as an alternative approach to administering the ACS when the tool was used in a self- administered checklist format over time to describe activity resumption after a medical event, in this case stem-cell transportation (Lyons et al., 2010). Researchers were able to describe activity resumption of those recovering from stem cell transportation. The ACSm was used again by Fleischer and Howell (2017) to describe activity resumption of breast cancer survivors from the beginning of radiation therapy until 6 months afterwards.

DASH

The DASH is a self-report questionnaire utilized in assessing function and symptoms in upper extremity musculoskeletal conditions (Cheville et al., 2008; Hudak et. al., 1996). The 30-items assess physical functioning (i.e., home management, ADLs/self-care and recreational activities), social functioning (family and occupation), and psychological function (self-image) (Cheville et al., 2008; Hudak et. al., 1996). Respondents use a Likert scale to classify items along the continuum of 1 “no difficulty” to 5 “severe difficulty” (Davies et al., 2013). To determine total score, the following calculation is used: [total score = (sum of *n* responses)/*n*-1 x 25)], *n* is the number of completed responses (Cheville et al., 2008; Hudak et al., 1996). Scores can range from 0 to 100, with 0 indicating no disability and 100 is severe disability (Davies et al., 2015).

The DASH has been found to have strong internal consistency when assessing physical and social functioning as well as associated psychological issues among breast cancer survivors (Davies et al., 2015). The DASH has additionally been found to be a reliable measure of physical, social, and psychological functioning of the upper limb in breast cancer survivors with lymphedema (Davies et al., 2015).

Ethical Considerations

The study was approved by the Eastern Kentucky IRB and the Owensboro Health Research Review Committee (OHRRC).

Informed Consent

Informed consent was waived and not obtained from the survivors. Informed consent was waived because the research did not utilize any personal identifiers and the research did not include an experimental intervention. The research was completed as an analysis of current standard of care and was considered observational.

Confidentiality

All paper documentation/information is being stored in a lockbox. Paper documentation and information includes field notes and assessment tools. Upon completion of this project, paper and electronic documentation will be stored by the faculty mentor for three years in a locked office or within a password protected computer. After this time, the mentor will destroy the paper and delete electronic documentation.

Section Four: Results and Discussion

Demographics and Medical History

There were five total survivors included in the research project. Table 1 shows the survivors' demographics. Survivors were seen at various points within their cancer treatment (Table 2); and they demonstrated varying levels of upper extremity function and expressed unique sets of valued activities (Figures 2-6). Three of the five survivors were seen preoperatively for occupational therapy evaluation. Of these three survivors, cancer treatment had not been initiated and each were preparing for surgery. Two of these three survivors were seen post-operatively for follow-up; however, one survivor's surgery was rescheduled outside the data collection period. The remaining two survivors were seen for initial occupational therapy evaluation post-operatively. One survivor had a right breast segmentectomy and axillary lymph node dissection with four lymph nodes removed and radiation. The other survivor received neoadjuvant chemotherapy followed by a left breast mastectomy with immediate placement of tissue expanders and axillary lymph node dissection with 11 lymph nodes removed. This survivor will receive radiation therapy.

Physical Function

Two of the five participants had their dominant upper extremity affected. As seen in Table 3, three of the five participants had no deficits in AROM at initial evaluation. BC01 had deficits in AROM post-operatively; whereas, BC05 had baseline deficits that did not change from pre-operative visit to post-operative visit.

Perceived Arm Function

For those participants seen for evaluation and re-assessment, BC01, BC03, and BC05, DASH scores declined (see DASH results in Table 4), indicating a perception of improved function in their upper extremities.

ACSm Results

Each survivor provided a unique list of important activities within the ACSm (Figures 26). Although the list of activities was unique, the occupations of social participation and low demand leisure were common among all five survivors. One of the 5 survivors indicated the occupation of instrumental activity of daily living as important and another one indicated the high demand leisure occupations as important (Figure 7).

For the survivors seen both pre-operatively and post-operatively overall ACSm scores, indicating activity participation, declined in IADL, low demand leisure, and social participation with participation in high demand leisure activities remaining the same. This is demonstrated in Figure 8. However, as noted in Figure 9, overall activity participation was higher among those survivors who were seen pre-operatively and post-operatively versus those only seen postoperatively.

Table 1. Survivor Demographics

Survivor	Age	Race	Gender	Marital Status	Working Status	Co-Morbidities	Type of Cancer	Stage	Type of Surgery
BC01	73	White	Female	Married	Retired	Osteoarthritis, sleep apnea, reflux, s/p laminectomy, and 'left wrist procedure'	Invasive Ductal Carcinoma, Grade 2	IV	Mastectomy
BC02	61	White	Female	Married	Working, Full Time	Thyroid disease	Invasive Ductal Carcinoma, Grade 2	IA	Segmenectomy
BC03	58	White	Female	Single	Working, Full Time	Diabetes, hypertension, diaphragmatic hernia, GERD, and prior bladder surgery; cystopexy around 2003	Invasive Ductal Carcinoma, Grade 2	IA	Segmenectomy
BC04	79	White	Female	Widowed	Retired	Hypertension, reflux, heart disease, and some element of kidney disease	Invasive ductal Carcinoma; grade 1	IA	Scheduled Lumpectomy
BC05	82	White	Female	Widowed	Retired	Diabetes, hypertension, COPD, hypothyroidism, fibromyalgia, stage IV renal failure, bilateral kidney stones, and hypercholesterolemia	Ductal carcinoma in situ (DCIS) of Right breast; no invasion	0	Lumpectomy

Table 2. Survivor's Type of Cancer and Surgery and Treatment Course

Survivor	**Type of Cancer**	**Type of Surgery**	**Sentinel or Axillary Lymph Node Dissection (SNLD/ALND)**	**# of Lymph Nodes Removed**	**Plastic Surgery**	**Radiation**	**Chemotherapy**
BC01	Invasive Ductal Carcinoma, Stage IV	Left Breast Mastectomy	ALND	11	Tissue expander placed; post-radiation reconstruction planned	Planning to begin radiation at start of care; undergoing radiation at time of reassessment; concluded at last contact with patient via telephone	Neoadjuvant – immunotherapy along with carboplatin/Abraxane based chemo – in addition after 4 cycles to receive Adriamycin/Cytoxan
BC02	Invasive Ductal Carcinoma, Stage IA	Right Breast Segmenectomy	SNLD	4	No	Yes; concluded	Adjuvant endocrine therapy with anastozole
BC03	Invasive Ductal Carcinoma, Stage IA	Left Breast Segmenectomy with a repeat Left Breast Segmenectomy	SNLD	6	No	Yes; beginning March 1st	Hormone therapy – f/u with oncologist 4/19/21

BC04	Invasive ductal Carcinoma, Stage IA	Planning for Left Breast Lumpectomy	Planned SNLD – surgery moved to 3/11	Unknown	Planning for oncoplastic surgery at time of L breast lumpectomy with reconstruction prior to radiation	Unsure; Anticipated	Unsure – has yet to meet with Oncology
BC05	Ductal carcinoma in situ (DCIS) of Right breast; no invasion; Stage 0	Right breast lumpectomy with preoperative seed localization	No nodes dissected	None	No	Unsure – appt with radiation oncology 3/11/21	Unsure – surgeon suggested endocrine therapy; appointment with oncologist 3/4/21

Figure 2. BC01 PEOP Model

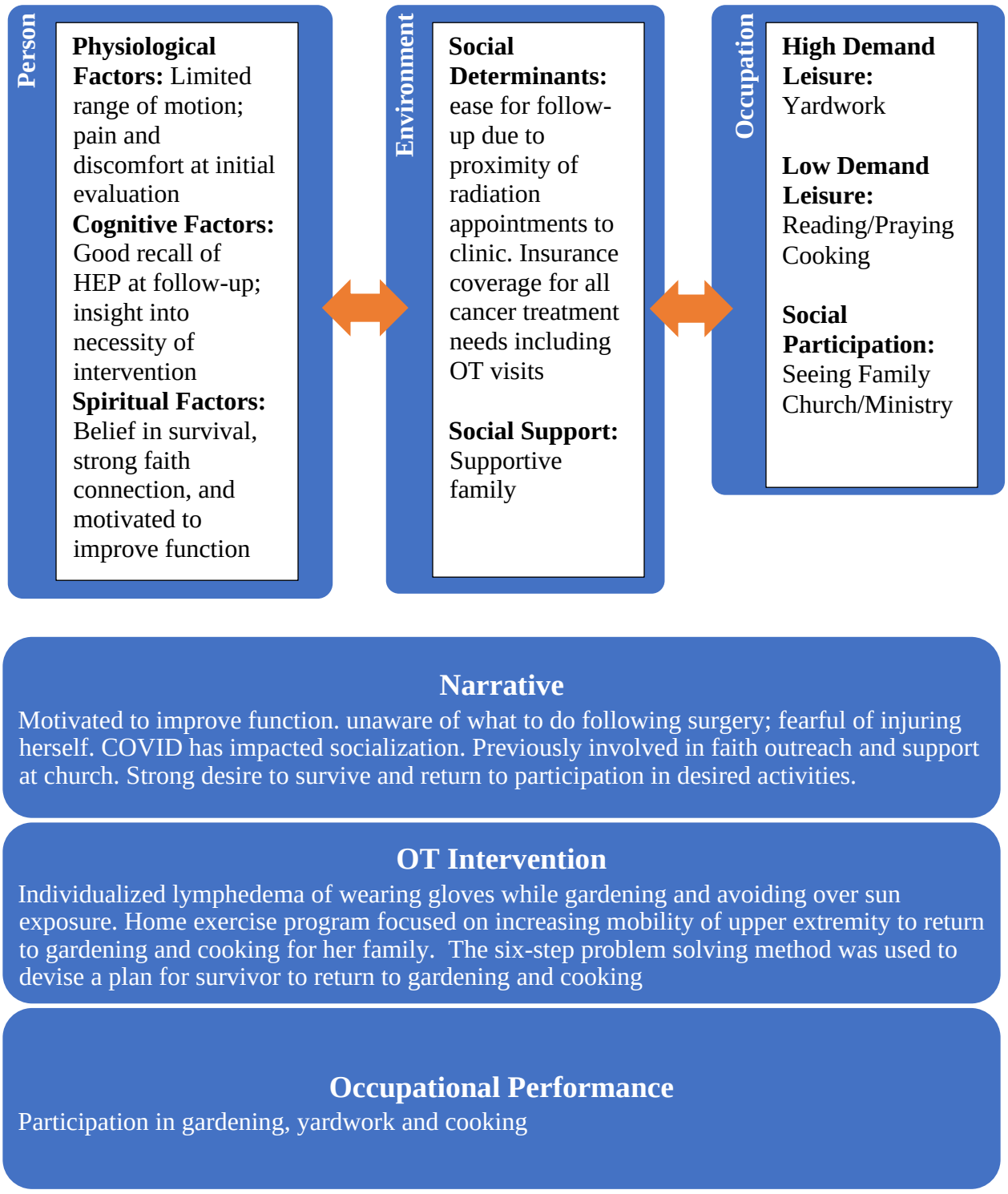


Figure 3. BC02 PEOP Model

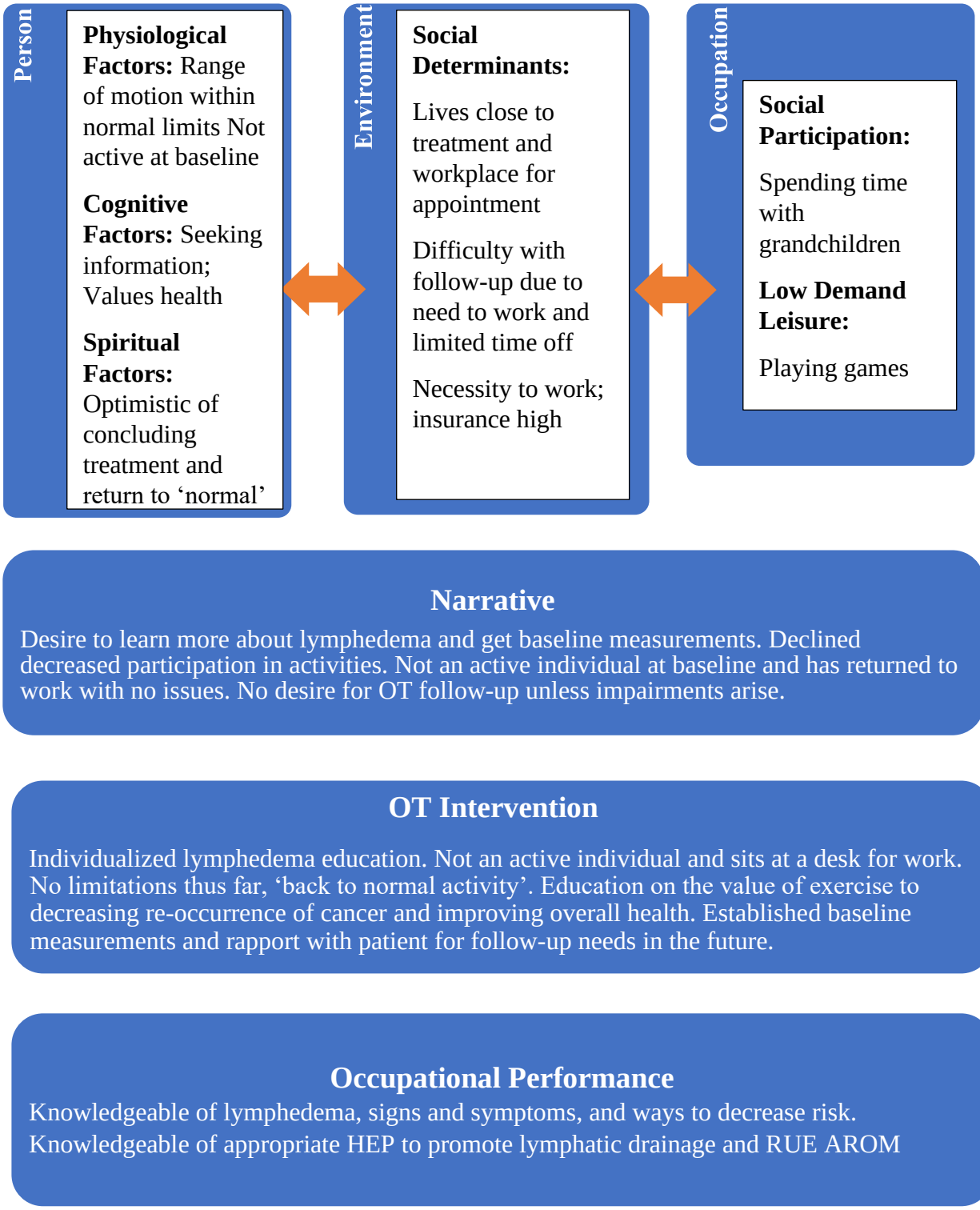
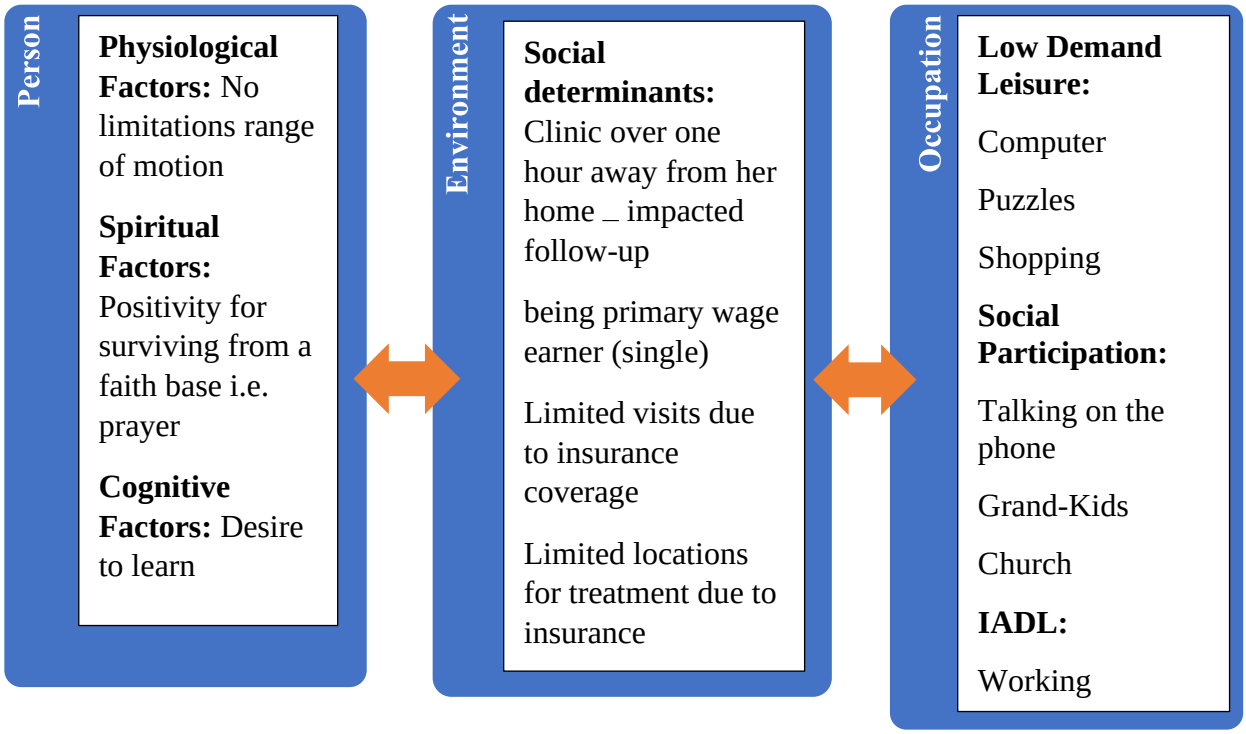


Figure 4. BC03 PEOP Model



Narrative

Support from aunt, who is a breast cancer survivor. Work necessary; desired to resume work as soon as possible. Required 2nd surgery, delay in OT follow-up. At re-assessment she was back to work.

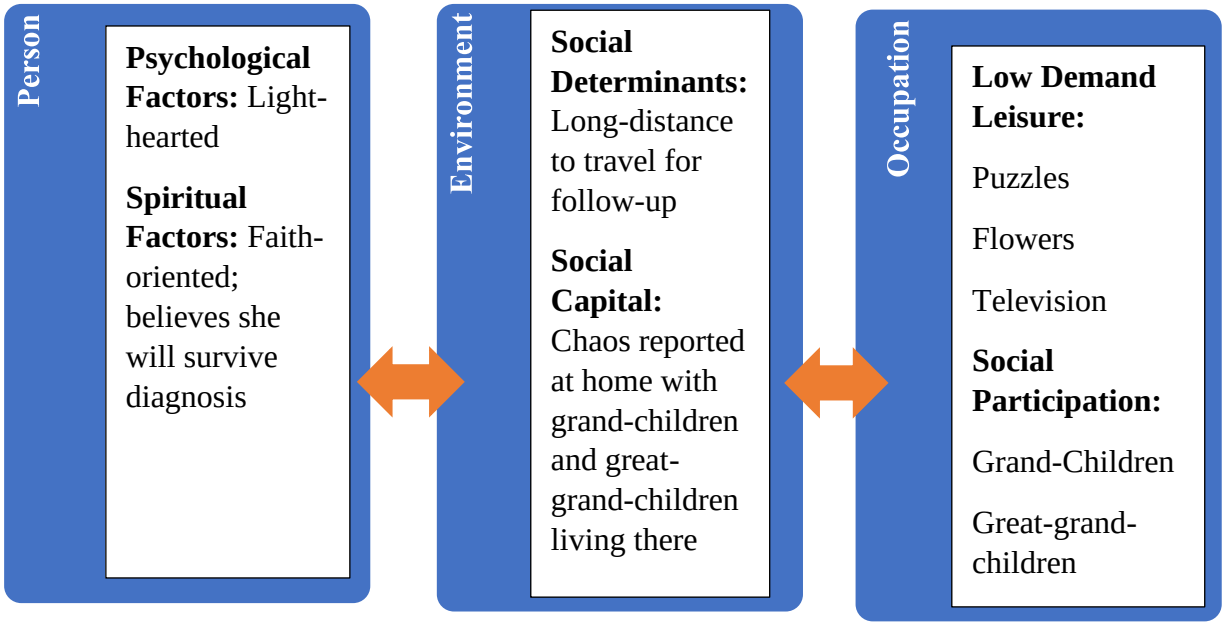
OT Intervention

Individualized lymphedema education, focus on return to work. HEP, focused on maintaining mobility following surgery. Problem solving strategies to formulate a plan for survivor's return to work post-op.

Occupational Performance

Return to work with use of one problem solving strategy

Figure 5. BC04 PEOP Model



Narrative

Less active over the last few years due to age; socialization within church. Limited due to COVID with her ability to participate in social activities requiring leaving her home. Family is supportive however there is a lot of chaos in her home.

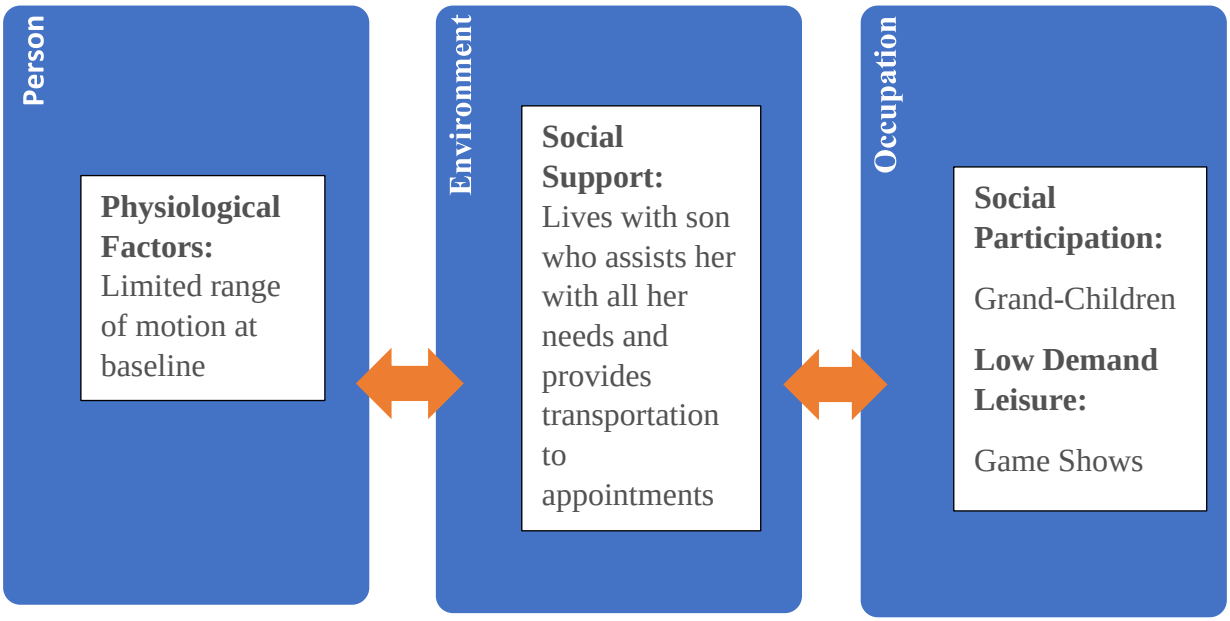
OT Intervention

Individualized lymphedema education. Minimal activity at baseline. No impairments, however, problem-solving strategies were discussed with the possibility of impairment after treatment. Individualized HEP, focused on maintenance of range of motion. Patient had planned to return post-op however her surgery was moved.

Occupational Performance

Participation in desired activities i.e. puzzles, flowers, television, grand-children and great grand-children

Figure 6. BC05 PEOP Model



Narrative

Very sedentary with minimal activity. Lives with son who is available to assist as needed and she relies heavily on him. Previously enjoy traveling and worked as a social worker, now she mostly watches television and sits in her recliner.

OT Intervention

Individualized lymphedema education. Minimal activity at baseline and disinterested in education. Individualized HEP was focused on maintenance of range of motion. Problem solving strategies for maintenance of activity however patient with no high-demand activities listed.

Occupational Performance

Participation in desired activities gameshows and grand-children

Table 3. Survivors Visit Type, Upper Extremity Hand Dominance, and Range of Motion at Evaluation and Reassessment

Survivor	**Initial Visit**	**Dominant Upper Extremity Affected**	**Active Range of Motion @ Pre-Op Evaluation**	**Active Range of Motion @ Post-Op Evaluation**	**Active Range of Motion @ Follow-Up**
BC01	Post-Op	No	N/A	• Flexion 111° • Abduction 90° • External Rotation WNL • Internal Rotation WNL	• Flexion 150° • Abduction 140° • External Rotation WNL • Internal Rotation WNL
BC02	Post-Op	Yes	All shoulder movement WNL	N/A	N/A
BC03	Pre-Op	No	All shoulder movement WNL	All shoulder movement WNL	
BC04	Pre-Op	No	Pre-Op Evaluation: All shoulder movement WNL	N/A	N/A
BC05	Pre-Op	Yes	• Flexion 145° • Abduction 110° • External Rotation WNL • Internal Rotation WNL	• Flexion 145° • Abduction 120° • External Rotation WNL • Internal Rotation WNL	

Table 4. Survivor DASH Scores at Pre-Operative, Post-Operative, and Re-assessment

Survivor	DASH Score Pre-Op	DASH Score Post-Op	DASH Score Re-Assessment
BC01	N/A	55	31.67
BC02	N/A	1	N/A
BC03	1	0	N/A
BC04	25	No post-op f/u	N/A
BC05	35	30	N/A

Figure 7. Survivors' Important Occupations

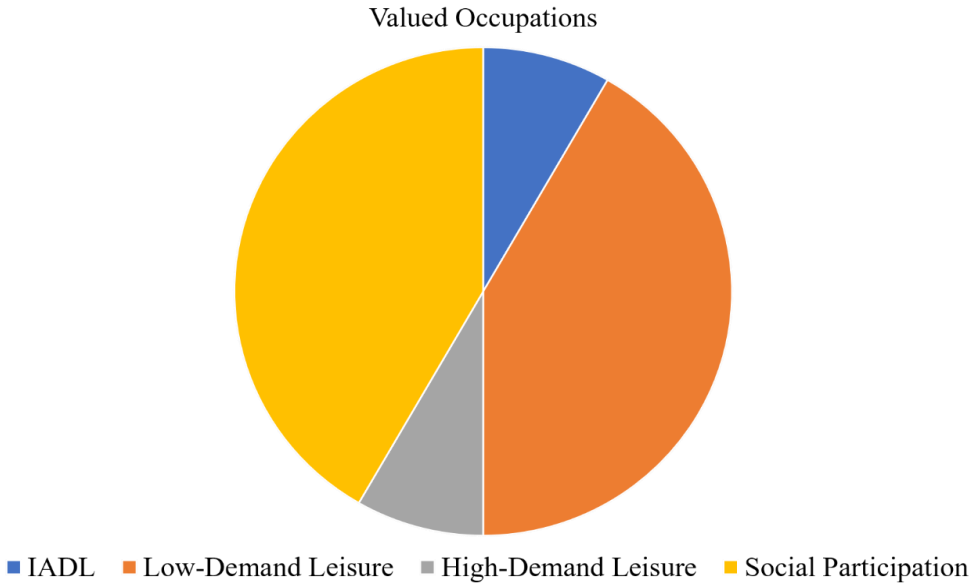


Figure 8. Listed Important Occupations Pre-Operatively Versus Post-Operatively

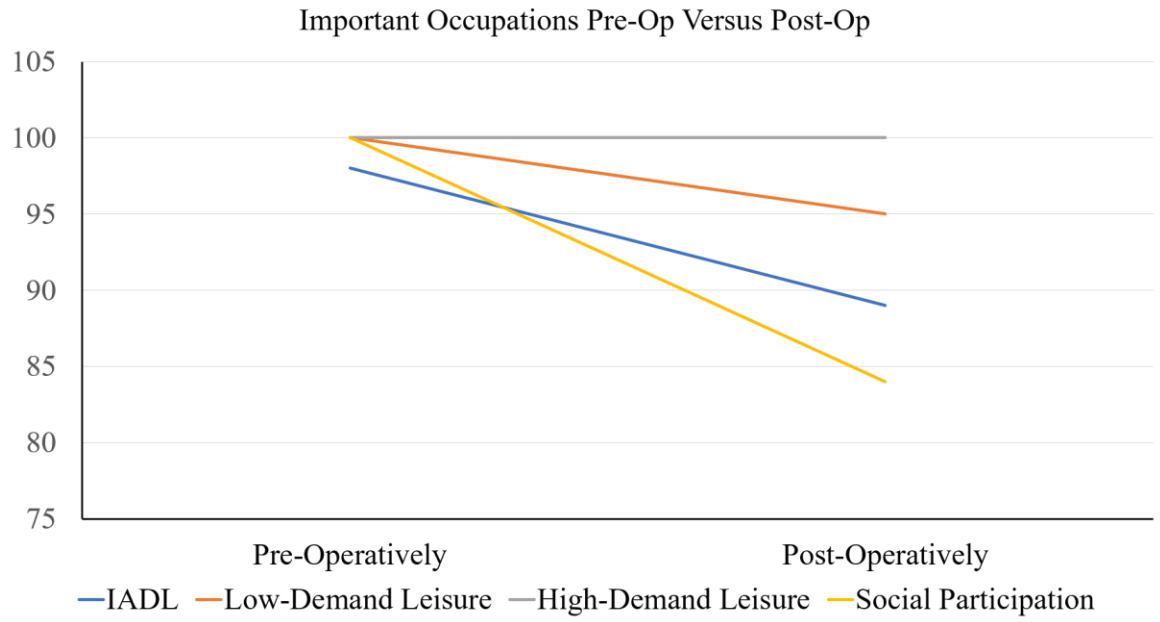
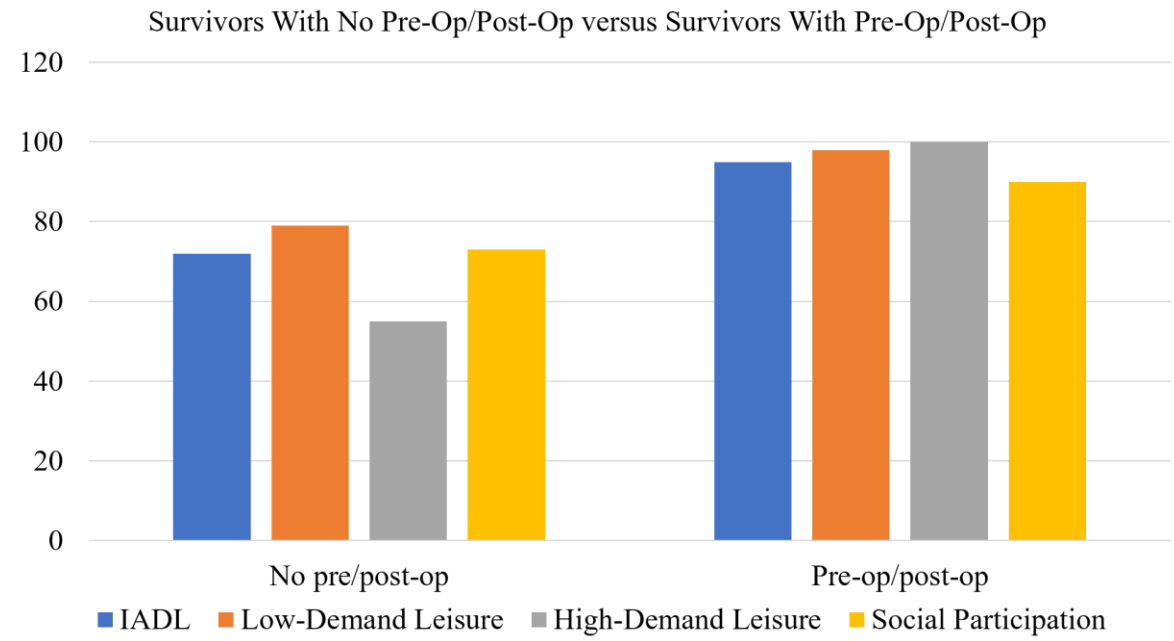


Figure 9. ACSm Scores of Those Survivors With No Pre-Operative Visit Versus Those With Pre-OperativeaAnd Post-Operative Visit



Occupational Therapy Visits

BC03 was seen pre-operatively for initial occupational therapy evaluation and maintained her level of activity participation post-operatively; however, BC05 demonstrated a decrease in activity participation post-operatively compared to preoperative assessment. BC01 was seen for initial occupational therapy evaluation post-operatively and demonstrated an increase in activity participation during a follow-up appointment visit.

Figures 10-15 demonstrate each survivor's individual ACSm scores in each occupational category: IADLs, low-demand leisure activities, high-demand leisure activities, and social participation (also represented in Tables 5-7). Activity participation did not consistently increase or decrease post-operatively. BC03 did however maintain her level of activity participation postoperatively. She stated "after surgery I knew what I could do, and I was able to continue to do the things that were important to me". However, BC05 demonstrated a decrease in activity participation in all four categories despite being seen pre-operatively. BC01 who was seen postoperatively for initial evaluation demonstrated an increase in high-demand leisure activities and social participation activities during her follow-up visit, which were listed as important occupations. BC01 stated "I wasn't sure what I was able to do, now I know what I can do".

Figure 10. Evaluation Versus Re-assessment Overall ACSm Scores Per Survivor

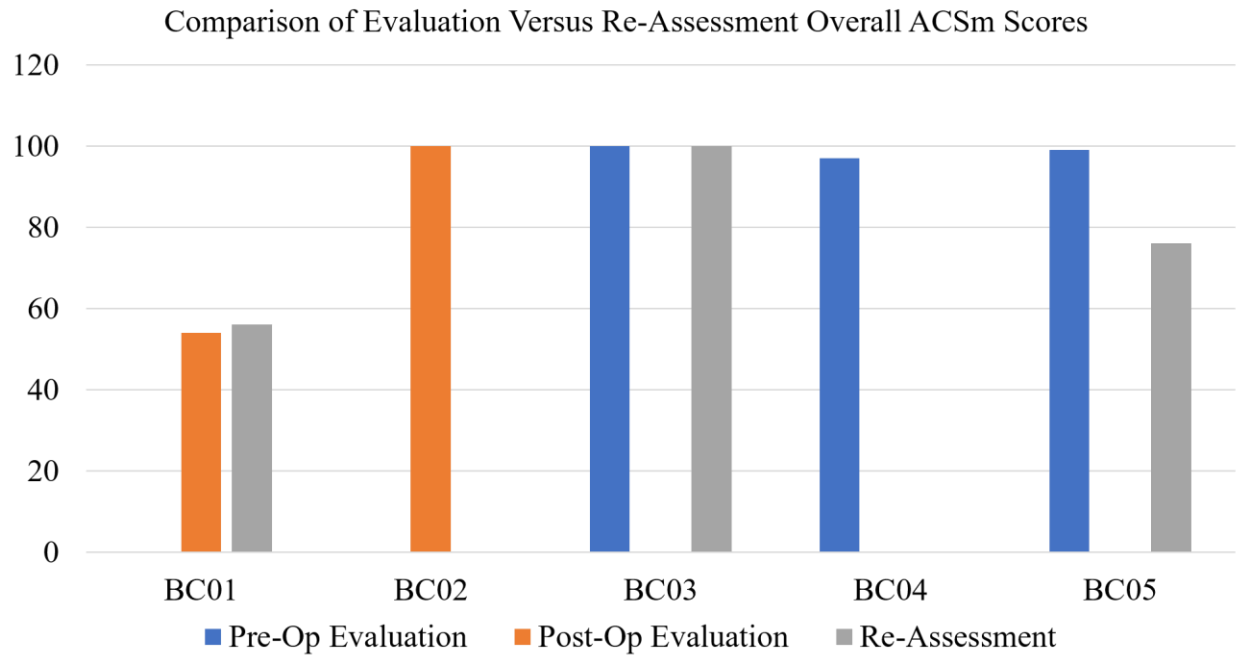


Figure 11. BC01 ACSm Score by Occupation: Evaluation vs Re-assessment

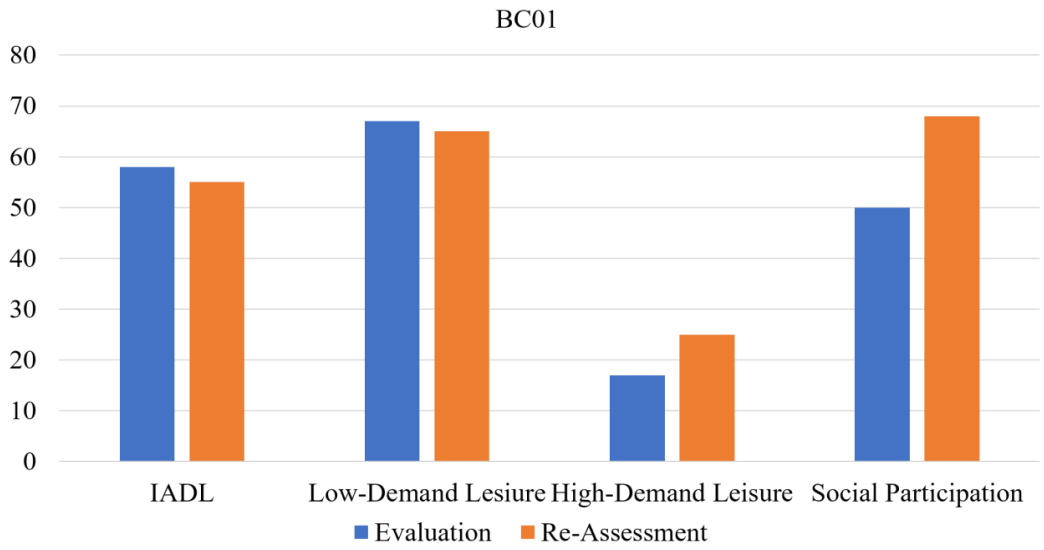


Figure 12. BC02 ACSm Score by Occupation: Evaluation

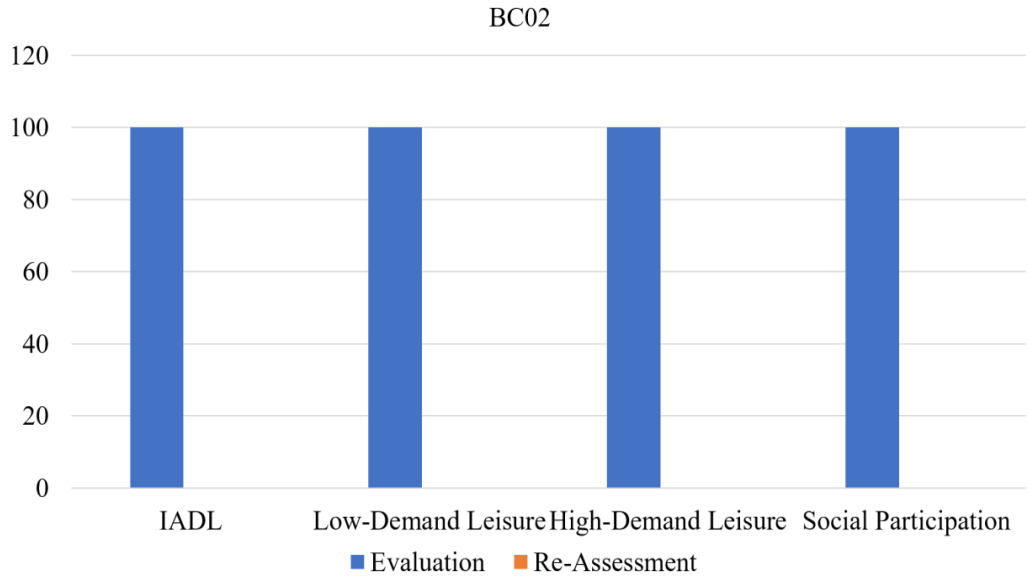


Figure 13. BC03 ACSm Score by Occupation: Evaluation vs Re-assessment

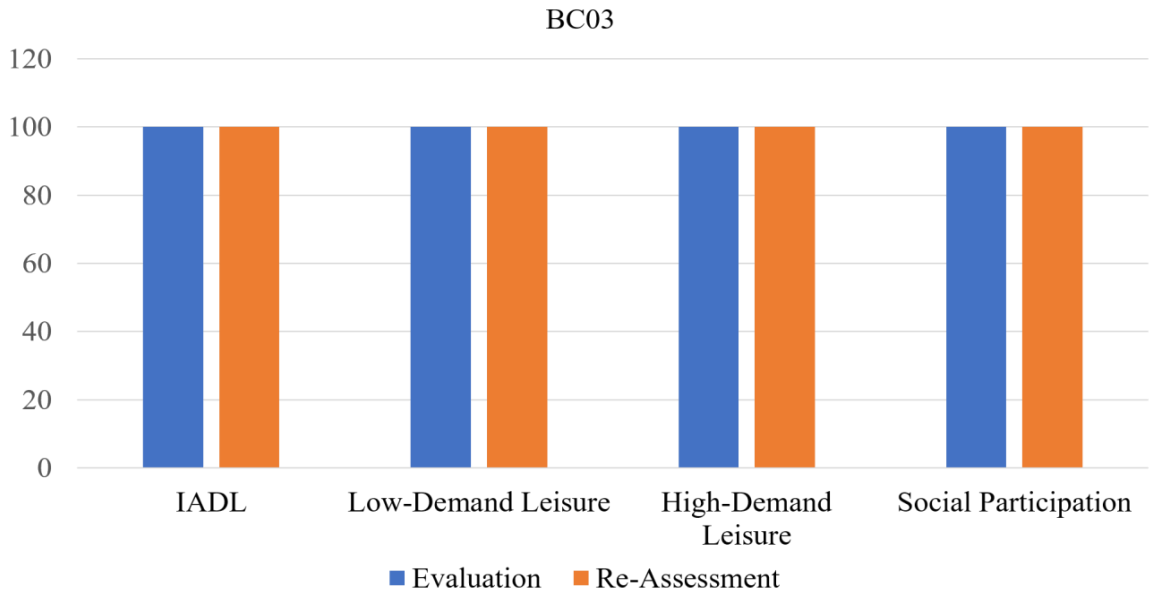


Figure 14. BC04 ACSm Score by Occupation: Evaluation

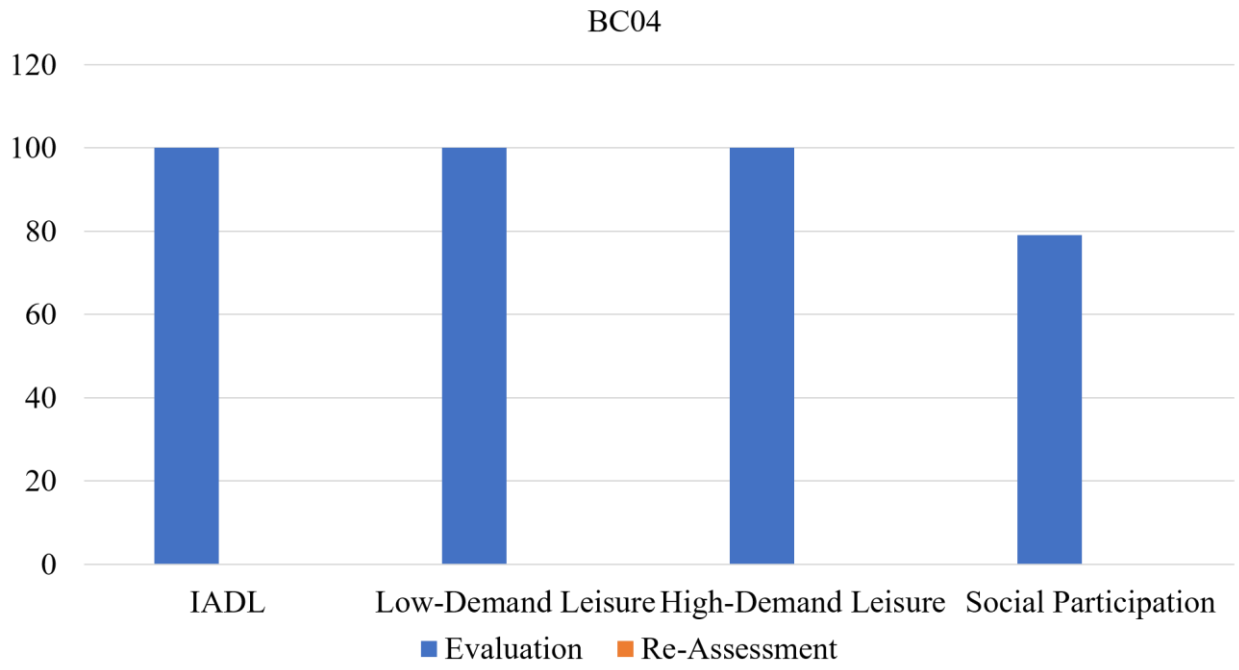


Figure 15. BC05 ACSm Score by Occupation: Evaluation vs Re-assessment

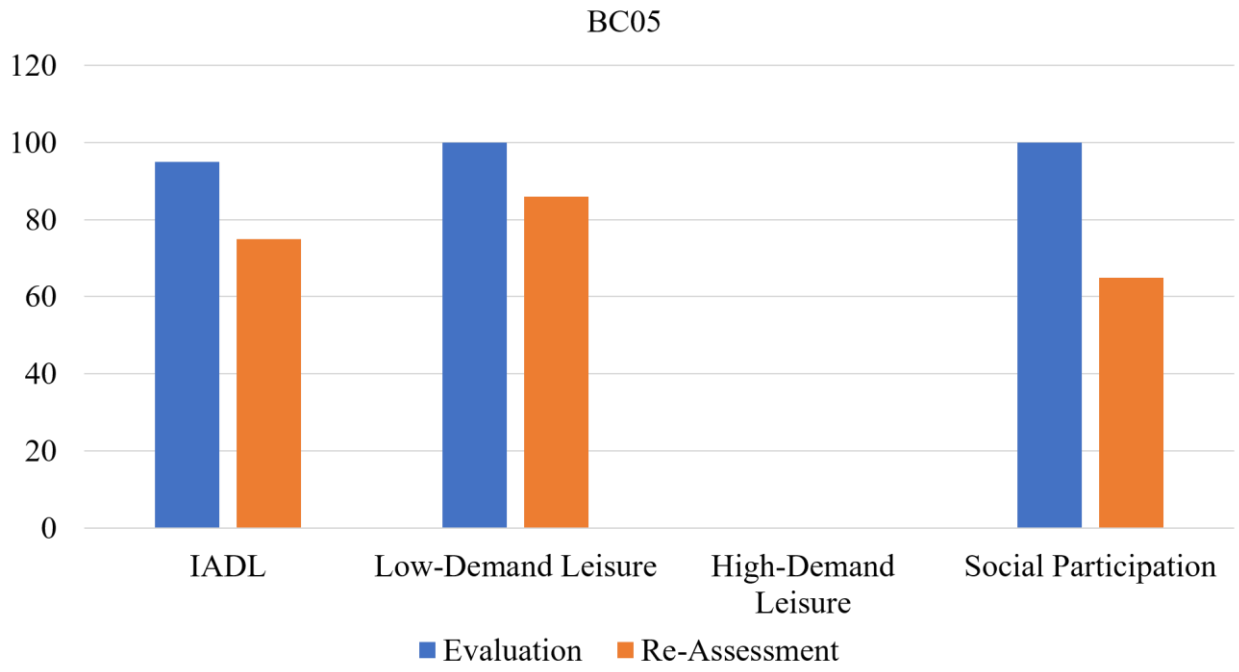


Table 5. Survivor Overall ACSm Score at Evaluation and Follow-up

Survivor	**Overall ACSm Pre-op**	**Overall ACSm Post-op**	**Overall ACSm Follow-up**
BC01	N/A	34.5/64 – 54%	38/68 – 56%
BC02	N/A	77/77 – 100%	N/A
BC03	42/42 – 100%	53/53 – 100%	N/A
BC04	48.5/50 – 97%	N/A	N/A
BC05	38.5/39 – 99%	25/33 – 76%	N/A

Table 6. Survivor ACSm Scores Per Activity at Initial Evaluation

	Initial Evaluation			
Survivor	**Instrumental Activities of Daily Living (IADLs)**	**Low-Demand Leisure**	**High-Demand Leisure**	**Social Participation**
BC01	10.5/18 – 58%	15.5/23 – 67%	1.5/9 – 17%	7/14 – 50%
BC02	20/20 – 100%	28/28 – 100%	14/14 – 100%	15/15 – 100%
BC03	15/15 – 100%	14/14 – 100%	4/4 – 100%	9/9 – 100%
BC04	16/16 – 100%	24/24 – 100%	3/3 – 100%	5.5/7 – 79%
BC05	9.5/10 – 95%	18/18 – 100%	0	11/11 – 100%

[1] Initial evaluation was post-operatively

Table 7. Re-assessment Survivor ACSm Scores Per Activity

Survivor	**Instrumental Activities of Daily Living (IADLs)**	**Low-Demand Leisure**	**High-Demand Leisure**	**Social Participation**
BC01[1]	10.5/19 – 55%	15.5/24 – 65%	2.5/10 – 25%	9.5/14 – 68%
BC02	N/A	N/A	N/A	N/A
BC03	16/16- 100%	20/20 – 100%	5/5 – 100%	12/12 – 100%
BC04	N/A	N/A	N/A	N/A
BC05	9/12 – 75%	9.5/11 – 86%	0	6.5/10 – 65%

[1] Follow-up re-assessment was a visit after her post-operative initial evaluation

Themes

Three themes emerged when analyzing the fieldnotes (Table 8): (a) role of a supportive family, (b) interest and need for lymphedema education and home program, and (c) eager to return to "normal activity".

Role of Supportive Family

All five of the survivors reported having a supportive family. BC01 stated, “I don’t know what I would do without my family, they are helping me through all of this and are my reason for continuing”. BC03 said “without my aunt answering all my questions and supporting me I don’t know if I would be able to go through this”. BC05 reported, “my son takes me to all my appointments and is able to help me with anything I am unable to do on my own”.

Interest and Need for Lymphedema Education and Home Exercise Program

Four of the five survivors noted they were strongly interested in learning more about lymphedema and safe exercise. BC01 stated, “I am going to do whatever I have to in order to get better, I’ve got to get back to being active”. BC02 reported, “I want to know how I can prevent lymphedema, what I need to look for, and where to go if I get it”. BC03 said, “I need to do whatever I can to get my arm moving after surgery so I can return to work”.

Eager to Return to Normal Activity

Four of the five survivors were still in treatment at time of initial evaluation visit and/or were being seen prior to treatment initiation. These four survivors were all focused on concluding treatment and returning to their level of normal activity. BC01 said, “I am ready to beat this cancer so I can get back to enjoying life”. BC03 reported, “I want to get through treatment so I can know I am able to work and provide for myself”. BC04 stated, “I am ready to get this surgery over with so I can know I am going to survive”.

Table 8. Occupational Therapist's Field Notes

Survivor	**Caregiver Involvement**	**Perceived Interest in Topic**	**Concerns Expressed**	**Work Status**	**Follow-up**
BC01	Her family is very involved with her recovery and helpful. Survivor shows researcher pictures of her family at Christmas gathering in matching pink shirts her son had bought to support her during her recovery of breast cancer.	Survivor is very interested and involved in OT evaluation. Survivor passionate about 'doing whatever it takes to improve function of UE" in order for her to complete radiation.	Being able to return to desired activities including yardwork, cooking, and her previously active lifestyle at time of evaluation. At time of reassessment patient motivated to conclude radiation and voiced concerns regarding plastic surgery and how that will impact her UE motion.	Retired Prior to COVID and Breast Cancer diagnosis patient was involved with non-pay ministry and volunteer work at church.	Yes, Patient was seen 3 times for follow-up and a Re-Assessment
BC02	Survivor has supportive family per her report.	Survivor desires to learn more about lymphedema otherwise is not concerned with any limitations nor right upper extremity function.	Survivor has no concerns. Survivor voices no limitations or impairments. Survivor declined need for follow-up.	Working is a necessity. Survivor works for Owensboro Health in the Engineering & Maintenance Department as a work-order specialist taking calls and putting work orders into computer.	No

BC03	Survivor has a supportive aunt with lymphedema and safe through breast cancer. She was able to ask questions and gain guidance from her aunt.	Survivor is interested in learning about experience doing exercises post-op. Survivor is wearing a shirt, at both visits with this OT, that contains all her grandchildren's names.	Survivor reports she is ready for surgery to be over and be through treatment in order to resume daily life. At time of post-op reassessment, survivor does not have any functional impairments and she feel that her exercises are going well.	Working is a necessity. Survivor is a waitress at a local diner in her hometown.	Yes. Post-op of second surgery
BC04	Survivor reports a supportive family. Survivor lives with her daughter and son-inlaw; however, she reports that there is a lot of chaos in her home due to her granddaughter moving home with her small children and her grandson is still living at home.	Survivor is interested in learning about safe activity following surgery at pre-op evaluation.	Survivor is focused on surgery and recovery with no immediate concerns other than 'getting rid of the cancer'.	Retired	Moved surgery to beyond data collection period
BC05	Patient lives with son who came with her to the evaluation. Son appears supportive. At	Survivor did not seem concerned with exercises nor lymphedema at	Survivor focused on having surgery at time of pre-op evaluation.	Retired	Yes. Post-op of surgery.

	follow-up appointment survivor came with granddaughter who is supportive and attentive to survivor. They were going to lunch and shopping after appointment.	postop evaluation nor reassessment.	At post-op reassessment, survivor was not concerned with edema in right hand as she stated that it has improved and the function of her right hand was good.		

Discussion

The objective of this research project was to describe activity participation rates and perceived arm function among individuals diagnosed with breast cancer who attended preoperative education compared to those who did not attend pre-operative education. The research included two queries: (1) what are the similarities and differences of individuals who had breast cancer and their activity participation rates among those who attended pre-operative education and those who did not attend pre-operative education? and (2) what are the similarities and differences of individuals who had breast cancer and their perceived arm function among those who attended pre-operative education and those who did not attend pre-operative education?

Post-Operative Occupational Therapy

For BC01 who was initially seen post-operatively for occupational therapy, she reported that she had been limited in her ability to garden, complete yardwork and cook due to fear of moving her left UE. BC01 stated “I was too scared to move my arm due to pain and I wasn’t comfortable with what was safe.” Kinesiophobia may have been a factor leading to her difficulties completing these activities. Some researchers have linked kinesiophobia to an increased risk for upper extremity lymphedema, depression, anxiety, and decreased upper extremity functioning in breast cancer survivors (Can et al., 2019). Researchers suggest that survivors should be encouraged to increase their physical activity incrementally to reduce the risk of kinesiophobia and lymphedema (Can et al., 2019).

BC01 might have benefited from pre-operative occupational therapy to learn how to safely return to her desired high-demand physical activities sooner. Researchers have suggested that individuals who have had breast cancer and want to engage in desired occupations must learn

how to complete them while managing treatment-related impairments (Schulman-Green et al., 2011). One strategy is for breast cancer survivors to return to desired physically demanding activities sooner and without developing lymphedema is to see them pre-operatively. During this visit, survivors could develop compensatory strategies to return to these activities immediately and also develop an incremental plan to physically return to them as they did pre-operatively (Lyons et al., 2012).

Pre-operative Occupational Therapy

Pre-operative occupational therapy may provide skills for breast cancer survivors to return to their physically demanding activities sooner and without developing lymphedema; however, this will only occur if the survivor sees the connection between the strategies learned during the visit and returning to physically demanding activities. Additionally, not all breast cancer survivors may desire being physically active, which can put them at risk for developing lymphedema later (Sander et al., 2019). This was illustrated in this study. BC03 indicated that the pre-operative education, exercises, and problem-solving session helped her return to work quickly and she applied this content because she financially needed to return to work. In contrast, BC05 expressed little interest during the preoperative visit in learning how to prevent lymphedema and returning to any physically demanding activity. When she returned for her post-operative visit, she reported that she had not completed any of the lymphedema prevention exercises and expressed no interest in resuming pre-breast cancer diagnosis activities.

Themes

Role of Supportive Family

Among all survivors described in this study, family support played an important role in their breast cancer journey which is consistent with the findings of other researchers. Family

involvement has been associated with survivors experiencing higher levels of hope and less cancer-related stress (Akbari et al., 2019; Hoeck et al., 2014).

Interest and Need for Lymphedema Education and Home Exercise Program

Individuals within this observational study appeared to understand the need to include lymphedema prevention strategies into their daily life. This was consistent with Sherman & Koelmeyer's (2013) findings that reflected that breast cancer survivors wanted and needed lymphedema prevention self-care techniques. Additionally, Otsby et al. (2018) reported that breast cancer survivors want accurate lymphedema prevention education and self-care management strategies prior to deciding their breast cancer treatment. Our findings are not consistent with many breast cancer survivors. White et al (2015) found that one-quarter of breast cancer survivors reported that they were unaware of their risk for developing lymphedema; therefore, these survivors would not have known that there was a need to learn about lymphedema.

Eager to Return to Normal Activity

The same four of the five survivors that reported an interest and need for education and HEP also noted they were eager to return to normal activity. Their interest in returning to normal activities is consistent with the findings of Palmadottir (2010). She found that participating in occupations aided women in taking control of their lives which then reinforced the survivor's sense of health and normality (Palmadottir, 2010).

Strengths and Limitations

Strengths

The static group comparison design is most useful in answering the descriptive question, "what happened after a phenomenon occurred" (DePoy & Gitlin, 2015, p. 144). In the capstone

project the design allowed the researcher to descriptively compare the two groups of survivors who received standard of care OT within two different pathways. The study design potentially has an advantage over a pre-test/posttest design because it allowed the researcher to compare pre-operative education and activity levels with those who did not attend a pre-operative visit.

Limitations

There were certain limitations in this research study that must be considered. First, static group comparison is unable to demonstrate causal relationships and is unable to answer predictive questions due to inadequate control of study conditions, which leads to the potential for bias (DePoy & Gitlin, 2015). Additional limitations of this research project included (1) a short data collection period; and (2) COVID-19, which resulted in less willingness of the patients to attend extra outpatient visits and engage in social participation.

Implications for Practice

Researchers have demonstrated valuable benefits of occupational therapy interventions throughout the continuum of care; but there is a need to illustrate the possible benefits of occupational therapy interventions prior to treatment (Braveman et al., 2017; DeIuliis & Hughes, 2012; Hunter et al. 2017a;). Occupational therapy could play a critical role both in understanding what roles and occupations that breast cancer survivors want, need, or are expected to continue after treatment and in supporting the development of physically active habits and routines (DeIuliis & Hughes, 2012; Harcrow et al., 2020; Hunter et al., 2017a; Hunter et al., 2017b; Cross, 2019).

To address the need of developing physically active habits and routines, this study aimed to describe the impact of pre-operative education focusing on maintaining or resuming important occupations, particularly those that are physically demanding. Additionally, lymphedema

prevention education and exercises were provided so survivors could safely begin to include this within their daily routines pre-operatively and continue with them post-operatively. Through this pilot study, the researcher observed a trend among those who were seen pre-operatively to participate in more activities post-operatively compared to those only seen post-operatively. If this trend were found to be significant in more rigorous studies in the future, developing physically active routines and habits could become part of breast cancer pre-habilitation programs.

Future Research

Current results are promising; however, further research is still needed to demonstrate if there are significant differences between activity participation and perceived arm function in breast cancer survivors seen pre-operatively versus post-operatively with a larger population of breast cancer survivors over an extended time.

Conclusion

This study aimed to determine the impact of pre-operative education on activity participation rates and perceived arm function among individuals diagnosed with breast cancer who attended pre-operative education compared to those who did not attend pre-operative education. The current study was promising. In this small sample there was a trend illustrating the possible benefits of pre-operative occupational therapy visit which includes (1) lymphedema prevention education, (2) baseline shoulder range of motion and arm limb volume measurements, (3) home exercises, and (4) strategies to continue important high-demand physical occupations.

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Appendix: IRB

Institutional Review Board (IRB)/Independent Ethics Committee (IEC) Authorization Agreement

Name of Institution or Organization Providing IRB Review (Institution/Organization A):
Eastern Kentucky University
Federalwide Assurance (FWA) #: FWA00003332

Name of Institution Relying on the Designated IRB (Institution B):
Owensboro Health, Inc.
FWA #: 00001887

The Officials signing below agree that Owensboro Health, Inc. may rely on the designated IRB for review and continuing oversight of its human subjects research described below:
(*check one*)

(___) This agreement applies to all human subjects' research covered by Institution B's FWA.

(_X_) This agreement is limited to the following specific protocol(s):

Name of Research Project: Does Pre-operative Education Increase Activity Participation and Decrease Perceived Arm Dysfunction in Breast Cancer Patients?
Name of Principal Investigator: Stephanie Rexing
Sponsor or Funding Agency: N/A Award Number, if any: N/A
Protocol #: 3700

(___) Other (*describe*):

The review performed by the designated IRB will meet the human subject protection requirements of Institution B's OHRP-approved FWA. The IRB at Institution/Organization A will follow written procedures for reporting its findings and actions to appropriate officials at Institution B. Relevant minutes of IRB meetings will be made available to Institution B upon request. Institution B remains responsible for ensuring compliance with the IRB's determinations and with the Terms of its OHRP-approved FWA. This document must be kept on file by both parties and provided to OHRP upon request.

Signature of Signatory Official (Institution/Organization A):

Date: 1/28/2021

Print Full Name: Gustav A. Benson Institutional Title: Institutional Official

Signature of Signatory Official (Institution B):

Date: 2/24/2021

Print Full Name: John Hackbarth Institutional Title: CFO

Owensboro Health

Institutional sign off

Sponsor: Owensboro Health, Inc.
Protocol: *Does pre-operative education increase activity participation and decrease perceived arm dysfunction in breast cancer patients?*
Investigator: Stephanie Rexing
Date: 11/17/2020

I, Alice Bruce, give my approval for Owensboro Health submission "Does pre-operative education increase activity participation and decrease perceived arm dysfunction in breast cancer patients?" to Eastern Kentucky IRB for exempt determination or approval.

Thank you,

Alice Bruce, BS, CCRP
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