

**Occupational Therapists' Role in Reducing the Risk of Breast Cancer Related
Lymphedema Prior to Diagnosis**

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Abstract

Breast cancer related lymphedema (BCRL) is a common complication that occur among breast cancer survivors after surgical or radiation interventions. Nearly 40% of breast cancer survivors develop BCRL, though the International Society of Lymphology (ISL) classifies all those with a compromised lymphatic system as having stage 0 lymphedema. Breast cancer related lymphedema can be debilitating for breast cancer survivors, affecting them physically, mentally, emotionally, socially, and financially. Nevertheless, current literature offers no evidence to support a standard approach to improve management at stage 0 lymphedema. Occupational therapists (OTs) can help breast cancer survivors address BCRL at its early stages in order to improve performance outcomes and survivors' quality of life. A high demand is currently present to educate breast cancer survivors on BCRL and its prevention. This article thus aims to identify best practice in minimizing the risk of developing BCRL beyond stage 0 and distinguish the role of OTs in this practice.

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Introduction

The incidence of breast cancer continues to rise and has become among the most common types of cancer across the United States (Centers for Disease Control and Prevention [CDC], 2019). According to the CDC (2019), the rate of new breast cancer cases in 2016 surpassed any new cases of other types of cancer for both males and females in the United States. Luckily, despite the increase in breast cancer incidence, the 5-year survival rate has increased to 90% due to advances in the technology of early detection and treatment (Narod et al., 2015; CDC, 2019). This means an increase of survivors at risk of experiencing numerous side effects or complications from the treatments they undergo. One of those complications after surgical intervention is breast cancer-related lymphedema (BCRL), which may develop in around 40% of breast cancer survivors (Fu, 2014) and can develop multiple years after cancer intervention (Petrek et al., 2001).

Breast cancer related lymphedema can be a disabling condition that negatively impacts the quality of life among breast cancer survivors (Velanovich & Szymanski, 1997; Penha et al., 2016). BCRL can cause body pain, a negative body image, decreased mental health, decreased overall general health, and impairment in role function due to having a swollen extremity (Velanovich & Szymanski, 1997; Penha et al., 2016). BCRL can increase the financial burden, as breast cancer survivors with BCRL have to pay for office visits with health professionals such as a certified lymphedema therapist (CLT) as well as lymphedema-related products such as compression sleeves compared to those who do not develop BCRL (Dean et al., 2018).

According to Cheville (2020), breast cancer survivors tended to utilize more services to address their breast cancer annually by 30% with the presence of BCRL.

Breast cancer-related lymphedema can negatively impact work capacity, affecting both physical and psychosocial abilities (Boyages et al., 2016; Sun et al., 2020). According to Boyages et al. (2016), about 42% of those with BCRL have reported that their work performance was negatively affected by lymphedema and that the more severe the lymphedema, the worse the impact of the swelling on their work performance. Moreover, Vignes et al. (2020) found that lymphedema impacts the careers of 52.2% of breast cancer survivors with BCRL, particularly those with severely impaired arm movement.

Background

Current literature suggests no presently known cure for lymphedema (Shah et al., 2016), but it suggests positive outcomes of proper management and early education (Dorri et al, 2020; Michelotti, 2019; Shah et al., 2016). While evidence from clinical trials suggests various approaches to BCRL management and emphasizes the benefits of early intervention (Armer et al., 2013, Gillespie et al., 2018, Sun et al., 2016, Hayes et al., 2012, McNeely et al., 2012), there is no evidence from the literature that outlines a standard protocol or approach to improve management at a stage 0 or pre-BCRL phase (Michelotti, 2019). Occupational therapists (OTs) are specialists in health, wellness, and rehabilitation and have the skillset to utilize a holistic approach to lymphedema management and prevention in order to improve and help maximize the quality of life of those with a risk for BCRL (American Occupational Therapy Association [AOTA], n.d.). The purpose of this project is to identify the role of OTs in reducing the risk of BCRL at stage 0 and offer evidence-based practice to guide intervention planning.

Methods

My capstone project involved designing and implementing an educational module that aimed to identify best practices for reducing the risk of BCRL at the stage 0 level and identify the valuable role OTs can have in the risk reduction of BCRL. Exhaustive research was performed for the best practice of risk reduction of BCRL and has been mentioned in the sections below. The inclusion criteria for this research included breast cancer related lymphedema, the management or risk reduction of lymphedema, and articles published within the last 20 years. Exclusion criteria consisted of non-breast cancer related lymphedema. The definition and role of OTs in health care were then identified, followed by highlighting how OTs can play a vital role in each area of the current evidence-based practice to reduce the risk of BCRL at the stage 0 level.

- Outcome measures used included:
 - pretest-posttest measurements of the knowledge of OTs regarding BCRL developed by the first author,
 - a follow-up survey developed by the author to assess the longer-term impact of the information on OTs and their practice (to be implemented in one year).

This educational module was delivered through an AOTA continuing education article. Steps to achieve this include contacting AOTA to learn about the requirements and guidelines for publishing an AOTA CE article, writing and submitting a proposal on the topic of my capstone project, writing and preparing the AOTA continuing education (CE) article and submitting the AOTA CE article for publication. Completion of the project for submission to AOTA is anticipated to be in Fall 2022. Should AOTA not accept this manuscript, this educational module

would be presented as a continuing education course through online platforms such as Summit Professional Education or occupationaltherapy.com.

Evidenced-Based Interventions Supported by Current Literature

Early Education on BCRL

While Dorri et al. (2020) describe a high need for lymphedema education among breast cancer survivors, evidence from Borman et al. (2017) suggests that there is a gap in lymphedema education, with only 19% of patients having received any form of lymphedema information after their breast cancer surgery. Fu et al. (2010) analyzed the importance of patient education by studying the effects of providing patient education about lymphedema on the outcomes of female breast cancer survivors. The authors found that participants who were educated on BCRL were significantly less likely to report arm swelling ($p < .00$). Bland and Kosir (2019) performed a randomized controlled trial on the effects of a structured Breast Surgery Rehabilitation class on patients undergoing surgical intervention for breast cancer. The Breast Surgery Rehabilitation class included information on how to protect the affected extremity from situations such as injury, overheating, infection, overexertion, and constriction. Compared to the control group who did not receive this information, the intervention group scored significantly higher on the quality-of-life assessment called the Functional Assessment of Cancer Therapy – Breast Cancer (FACT-B) ($p = .048$) six months after their mastectomy.

Health care providers lack proper education to offer information to their clients according to a qualitative study by Thomas-MacLean et al. (2005), as eleven out of fifteen participants in the study reported receiving little to no information about BCRL from their health providers. Ridner et al. (2016) also found that breast cancer survivors feel they lack support from their healthcare providers regarding BCRL education. Breast cancer survivors with BCRL may, thus,

develop feelings of disappointment in the lack of BCRL knowledge provided to them by health care professionals (HCP) and may feel neglected by their HCPs (Conway, 2016; Fu & Yang, 2013). Qualitative studies that explored the lived experiences of women who are breast cancer survivors indicated that those who were provided with early education were found to have improved well-being compared to those who were not provided with early education (Conway, 2016). BCRL patients who received professional health care advice were shown to have greater control of their swelling along with an increase in their quality of life (Lin et al., 2020).

According to Temur and Kapucu (2019), the swelling did not occur in breast cancer survivors who received early education and training on BCRL management, but 61.2% of the patients who did not receive this training developed lymphedema. Occupational therapists can encounter clients with a history of breast cancer along the healthcare continuum. They could therefore provide and enhance their patient education about BCRL as an early intervention tool for those with any risk of developing BCRL.

Screenings for Early Detection

Screening for BCRL can help to detect lymphedema at an early stage, which can prevent the severity of lymphedema as well as decrease the risk of lowering quality of life for breast cancer survivors (Armer et al., 2013). Pre-operative assessment of upper limb volume plays a vital role in the early detection of BCRL according to a study by Stout Gergich et al. (2008). The authors of this study proposed a classification model for each stage of lymphedema with corresponding interventions that focus on either preventing or managing BCRL symptoms. They suggested that those who have a 0%-3% limb volume increase post-operatively from their baseline volume should be educated on risk reduction, as well as signs and symptoms of lymphedema. Those with a 3%-5% limb volume increase post-operatively should be educated on prevention of limb

volume progression, as well as prescribed an elastic 20-30mmHg sleeve to wear regularly (Stout Gergich et al., 2008).

Pre-operative limb measurements can also help to determine the diagnosis of lymphedema. The Oncology Section of the American Physical Therapy Association (APTA) developed a clinical practice guideline to guide clinicians in determining measurement significance in the limbs of breast cancer survivors (Levenhagen et al., 2017). The numbers determining measurement significance and thus the need for intervention, however, differ for those with pre-operative measurements. Recommendation discrepancies by pre-operative measurements are as follow:

- L-Dex Scores, or the measurement of fluid status in a limb through electrical signals:
 - For those with no pre-operative limb measurements, the diagnostic L-Dex score for lymphedema is >7.1 ,
 - For those with pre-operative limb measurements, the diagnostic L-Dex score for lymphedema is >10 .
- Limb Volume Measurements:
 - For those with no pre-operative limb measurements, a volume ratio of 1.04 or a calculated volume difference between bilateral extremities of $>200\text{ml}$ is indicative of lymphedema,
 - For those with pre-operative limb measurements, a volume change of 5% or more is indicative of lymphedema (Levenhagen et al., 2017).

Moreover, Sun et al., (2016) found that, without pre-operative measurements, lymphedema can be misdiagnosed in 40%-50% of cases. It is, therefore, necessary for clinicians to obtain pre-

operative measurements for best practice and best outcomes for breast cancer survivors, as well as continue screening post-operatively to determine the need for lymphedema interventions.

Obtaining patient self-report of symptoms of lymphedema may also play a significant role in BCRL detection. A retrospective study by Armer et al. (2003) found one method of early detection of lymphedema to be through self-reported symptoms of it. These self-reported symptoms, such as limb heaviness, swelling, and numbness, were found to be predictive factors in BCRL (Armer et al., 2003).

Therapeutic Interventions and Exercise as Early Intervention for BCRL Prevention

Another important aspect of early intervention to reduce the risk of BCRL in those with breast cancer is a therapeutic intervention. Lacomba et al. (2010) performed a randomized, single-blind trial to study the effects of therapeutic interventions, such as exercises and manual lymph drainage, on breast cancer survivors with a risk of developing BCRL. Both the control group and intervention group in this study received educational strategies on lymphedema management, but the intervention group received additional therapeutic interventions as mentioned above. The authors found that BCRL developed four times more quickly in the control group than in the intervention group. Scaffidi et al. (2012) found a significant reduction of lymphedema symptoms ($p = 0.036$) in breast cancer survivors who received therapeutic services including deep breathing and stretching exercises from day one after breast cancer surgery than those who did not receive the same services. Lu et al. (2015) found that exercise paired with patient education significantly reduced the risk of BCRL in patients with breast cancer ($p = 0.002$) more than patient education only ($p = 0.096$) as compared to no early intervention at all. Resistive exercises were found to be a safe intervention for breast cancer survivors (Hasenoehrl et al., 2020a). In fact, a significant reduction of BCRL was seen in those

who performed resistive exercises, with significant improvements of muscular strength seen in the upper and lower extremities (Hasenoehrl et al., 2020b).

Occupational Therapy Intervention and Modification to Tasks/Occupations to Increase QOL and Decrease Risk of BCRL

The majority of breast cancer survivors return to work after rehabilitation (Hoving et al., 2009). However, Tahan et al. (2010) found that the risk of BCRL increased with certain types of jobs, particularly jobs requiring continuous usage of the affected extremity. According to the study, breast cancer survivors utilizing their hands continuously for more than 1 hour and working at least 8 hours a day for their occupations resulted in significantly worsened BCRL ($p < 0.001$). Authors suggest this may be due to excessive usage of the upper extremity without proper lymphedema management training and controlled exercises to improve muscle strength. Breast cancer survivors may thus find it challenging to return to work (Sun et al., 2017), particularly those who have not received appropriate services to manage and prevent swelling. An aspect of practice in which OT interventions can significantly reduce and manage BCRL is back-to-work education. Vignes et al. (2020) found that workplace adaptations such as workstation ergonomics were made for 26.9% of those with BCRL, particularly those with greater arm-movement impairment, and 86% of those survivors with adaptations were highly satisfied with their work. Further studies are warranted to examine and address this issue. This author suggests using modified work schedules to include breaks from arm movement every 60 minutes, environmental breaks every 60 minutes for those working in hot weather or temperature conditions, as well as adaptive equipment as appropriate at the workplace to prevent the worsening of BCRL. Breast cancer survivors at risk for BCRL development should also undergo a muscle strengthening program to improve the work performance of their affected extremities.

Implications for Occupational Therapy Practice

The risk of breast cancer-related lymphedema (BCRL) is present with any surgical procedure involving lymph node removal. With about 40% of breast cancer survivors developing lymphedema after their oncological treatment (Fu, 2014), oncological rehabilitation programs are multiplying in the United States in response to the growing numbers of breast cancer survivors and their reported impairments (Silver et al., 2018). Yet, there is not a comprehensive standard protocol or interventions that encompass pre-BCRL diagnosis care to minimize the risk of BCRL available at this time. Many OTs, therefore, do not have the proper knowledge and skills to offer effective intervention in the various stages of BCRL. Breast cancer-related lymphedema impairs the functional performance and participation of breast cancer survivors in their occupations and therefore reduces their overall quality of life (Penha et al., 2016). Occupational therapists can utilize a holistic approach to lymphedema management and prevention in order to improve the quality of life of those with a risk for BCRL (AOTA, n.d.).

Evidence from literature is very scarce on the relationship between the risk of lymphedema and duration of performing occupations. Tahan et al. (2010) explored the relationship between the risk of lymphedema and length of performance of tasks and occupations. In this cross-sectional study, Tahan et al. (2010) concluded that those who worked for more than 60 minutes continuously and for more than eight hours in a given day had higher stages of lymphedema, more shoulder limitations on their affected extremity, and a higher need for rehabilitation for their affected shoulder than those working fewer hours and utilizing their affected extremity for less amount of time. Since occupations and work require the use of upper extremities, these results indicate that increased use of hands during work can lead to a higher risk of lymphedema. This study highlights the need for occupational therapists to include

interventions to help their clients with a history of breast cancer return to work safely.

Occupational therapists are equipped to support breast cancer survivors with back-to-work education, assessment of fit including muscle testing and strengthening, as well as task analysis and modification of their work tasks prior to their return to work in order to decrease the risk of BCRL.

Research Conclusion

Breast cancer-related lymphedema is a chronic condition that patients with breast cancer may encounter even years post-surgery, with more severe lymphedema stages and more severe limitations affecting breast cancer survivors who continuously work and use their upper extremities for more than eight hours a day. Due to the majority of breast cancer survivors returning to work, early intervention to address BCRL is key in reducing symptoms (Shah et al., 2016). Currently, no comprehensive standardized program encompassing pre-BCRL diagnosis care to minimize the risk of BCRL are available. Educational resources for OTs and healthcare providers on how to offer early education and effective interventions are also limited. Therefore, this article addresses this gap to identify the importance and management of BCRL at the stage 0 phase in order to reduce the risk of higher level BCRL stages in breast cancer survivors and maximize their outcome and function post-operatively. Occupational therapists can address this through early education about BCRL, therapeutic interventions, early screenings for BCRL pre-operatively and post-operatively, as well as back-to-work education and interventions. Breast cancer survivors can reduce their risk of BCRL, and with this article, OTs can establish their vital role in helping breast cancer survivors claim their lives and live them to their fullest.

Results

This capstone project addressed the need for defining the role of OT in reducing the risk of breast cancer related lymphedema (BCRL) as well as identifying an approach to reducing the risk of BCRL at the stage 0 phase. This project was delivered through an online educational module available for occupational therapists to learn from, and a post-test is available at the end of the educational module to establish the completion and competence of learned material. Prior to submission for publication, current occupational therapists completed a 15-question pre-test and post-test survey online through Survio to determine the effectiveness of the content.

Survey Results

This online survey was submitted on multiple mediums including the AOTA Survey Forum, emails, and social media forums. Only five occupational therapists have completed the survey. Of the five participants, five (100%) completed all survey components. Three participants who have completed the survey were newly graduated (0-1 years' experience) occupational therapists (60%), while one participant was reported to have 3-5 years' experience as an occupational therapist (20%) and another participant reported to have 10+ years' experience (20%). Four participants indicated they are working in the outpatient rehabilitation setting (80%) while one participant indicated they work in academia (20%).

Table 1 summarizes the results of the questionnaires while Table 2 describes the participant demographics. After reading the educational content, all newly graduated occupational therapists were found to have increases in their scores by 7%. The two other participants with at least 3 years of experience, however, had a decrease in their scores by 27% and 7%. The p-value was calculated through a t-test, and results indicated a p-value of $p = 0.39$. Results are therefore not significant ($p < .05$).

Table 1

<i>Participants</i>	Pretest	Posttest	Percentage Change
<i>Participant 1</i>	60%	67%	+7%
<i>Participant 2</i>	40%	47%	+7%
<i>Participant 3</i>	80%	53%	-27%
<i>Participant 4</i>	80%	73%	-7%
<i>Participant 5</i>	60%	67%	+7%

Table 2

<i>Participants</i>	Years of Experience	Work Setting
<i>Participant 1</i>	0-1 years	Outpatient adults
<i>Participant 2</i>	0-1 years	Outpatient adults
<i>Participant 3</i>	3-5 years	Outpatient adults
<i>Participant 4</i>	10+ years	Academia
<i>Participant 5</i>	0-1 years	Outpatient adults

Discussion

The present capstone project identified the role of occupational therapists (OTs) in reducing the risk of breast cancer-related lymphedema (BCRL) at the stage 0 level. A pre-and post-survey was delivered to OTs to determine the effectiveness of the educational module on OTs' knowledge in this subject. Overall, the results of the survey are not generalizable due to the

small sample size. The survey required a larger number of participants to increase the study's power and demonstrate results more closely reflecting current literature, which suggests healthcare workers who received BCRL education had increased BCRL knowledge scores (Tam et al., 2011). The results also differed according to the amount of experience. All of the newly graduated OTs had higher post-test scores (+7%); whereas, the OTs with over 3 years of experience had lower post-test scores (-27% and -7%). This also contradicts results from a study by Tam et al. (2011) that identified an increase in BCRL knowledge with more years of practice ($p = 0.014$). Limitations with the survey may have also caused a ceiling effect with the experienced OTs, resulting in inaccurate results.

Several limitations may have played a role in this conclusion. First, with only five participants, the sample size was too small which greatly reduced the power of the study. Second, participants may have had unidentified time constraints that led to rushing through the survey. This can also explain the discrepancy in results between the newly graduated OTs and the OTs with over 3 years of experience, as newly graduated OTs may not have had time to develop as heavy a caseload as an experienced OT and were thus able to take more time to read and complete the survey. Third, the surveys were delivered online on Survio, which may not have presented the material as organized as it would be through another platform. Finally, 80% of participants reported they work in the outpatient rehabilitation setting, where therapists are more likely to see and treat patients with BCRL. The survey may have attracted those already familiar with BCRL, therefore causing a nonresponse bias.

To address these limitations moving forward, the survey can be delivered through a different platform and made available through additional advertising in order to increase the sample size. An introduction or list of expectations, such as the expected time to complete the

survey, may also decrease the likelihood of participants rushing through answers in their surveys. This educational module can also be advertised to different OT groups online which may attract OTs of different settings to take the survey.

Upon addressing these limitations, the study is anticipated to improve the knowledge of OTs in identifying the role of OTs in addressing stage 0 BCRL. This, in effect, would help to reduce the risk of higher level BCRL stages in breast cancer survivors and maximize their outcome and function post-operatively. Occupational therapists can address this through early education about BCRL, therapeutic interventions, early screenings for BCRL pre-operatively and post-operatively, as well as back to work education. Further studies are warranted to explore the relationship between lymphedema and occupational performance, as well as how OTs can reduce the risk of lymphedema through occupational performance.

Conclusion

Early intervention to address BCRL is key to reducing symptoms (Shah et al., 2016). Therefore, this capstone project addresses this gap by establishing an educational module explaining the importance and management of BCRL at the stage 0 phase in order to reduce the risk of higher level BCRL stages in breast cancer survivors and maximize their outcome and function post-operatively. Occupational therapists can address this through early education about BCRL, therapeutic interventions and exercises such as lymphatic drainage massages and upper extremity stretches, appropriate screening for BCRL pre-operatively and post-operatively, as well as back-to-work education. This project specifically serves the occupational therapy (OT) profession by filling the need for non-certified OTs to know about lymphedema and its early detection in order to reduce the risk of frustration or exacerbation of symptoms from patients. Limitations to this study included a small sample size for the pre and post-test measurements and

a lack of current research regarding OT's role in treating BCRL. Further studies are warranted to explore the relationship between OT services and risk reduction of BCRL, particularly regarding back to work interventions. Breast cancer survivors can reduce their risk of BCRL, and with this educational program, OTs can be the most appropriate professionals to play a vital role in making that happen.

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Appendix A

Pre-test Post-test Exam

- 1) True or False: All breast cancer survivors who have undergone surgical or radiation treatment have stage 0 lymphedema.
 - a. True
 - b. False
- 2) What is NOT a sign of lymphedema?
 - a. Subjective feelings of swelling
 - b. Visible pitting
 - c. Warm to touch
 - d. Limited extremity function
- 3) True or False: There is no cure for lymphedema.
 - a. True
 - b. False
- 4) How long is the risk of BCRL present in breast cancer survivors who have undergone surgical or radiation treatment of their cancer?
 - a. Six months post-treatment
 - b. One year post-treatment
 - c. Ten years post-treatment
 - d. The risk is always present post-treatment
- 5) What is a prominent theme amongst breast cancer survivors?
 - a. Breast cancer survivors feel disappointed in the lack of BCRL knowledge provided to them by health care professionals (HCPs).
 - b. Breast cancer survivors feel they receive BCRL knowledge from HCPs too early and wish to receive this information after their BCRL diagnosis.
 - c. Breast cancer survivors all tend to feel limb heaviness in their upper extremities even six months post-cancer treatment.
 - d. Breast cancer survivors feel a lack of support from their families on managing their BCRL.
- 6) What is NOT an effect related to BCRL?

- a. Decreased quality of life
 - b. Impairment in role function
 - c. Decreased endurance
 - d. Decreased mental health
- 7) True or False: There are many standardized protocols and approaches to treating and improving the management of stage 0 BCRL.
- a. True
 - b. False
- 8) What is NOT considered evidence-based practice in reducing the risk of lymphedema?
- a. Early education on BCRL
 - b. Task modification
 - c. Early screenings
 - d. Greater arm movement during work
- 9) True or False: The majority of breast cancer survivors return to work.
- a. True
 - b. False
- 10) Which group of working breast cancer survivors has an increased risk of developing BCRL?
- a. Those who worked for more than 60 minutes continuously and for more than eight hours a day.
 - b. Those who worked for more than 30 minutes continuously and for more than eight hours a day.
 - c. Those who worked for more than 60 minutes continuously and for more than five hours a day.
 - d. Those who worked for more than 30 minutes continuously and for more than five hours a day.
- 11) True or False: Older breast cancer survivors and those with low physical activity levels were found to more likely experience problems with overall limb function compared to younger breast cancer survivors and those with higher physical activity levels.
- a. True
 - b. False

- 12) What is found to be most satisfactory for breast cancer survivors going back to work?
- a. Shorter working hours
 - b. Workplace adaptations
 - c. Increased pay
 - d. Decreased computer work