THE RETURN-TO-WORK EXPERIENCES OF THAI WOMEN WITH BREAST CANCER-RELATED LYMPHEDEMA

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by
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The undersigned, appointed by the dean of the Graduate School, have examined the

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THE RETURN-TO-WORK EXPERIENCES OF THAI WOMEN WITH BREAST CANCER-RELATED LYMPHEDEMA

Abstract

Purpose This study aimed to examine Thai breast cancer survivors' perspectives on how BCRL affected their employment and related quality of life, as well as the culturally-influenced contextual facilitators and barriers that they faced as they returned to work in Thailand.

Background and Significance: Globally, breast cancer is the most common cancer among women. Women diagnosed with breast cancer undergo breast cancer treatment, and some of them must deal with lymphedema after breast cancer treatments. BCRL may have a negative impact on employment and restrict return to work. After identifying the gaps in the literature, this qualitative research was developed, and it eventually led to the investigation of survivors' individual experiences with BCRL when they returned to work.

Methods: Following informed consent procedures, 13 adult Thai breast cancer survivors with BCRL ages 43-74 were recruited from the community. A grounded theory approach included semi-structured interviews and assessments of work demographics, lymphedema-related changes, interpersonal changes in work, environmental characteristics, and final reflections on the thoughts regarding the future and enduring breast cancer survivors with BCRL.

Results: Data revealed the theoretical model of Return-to-Work Experiences of Thai Women with BCRL could present either challenges or ways of maintaining hope to cope and live with BCRL. This idea of Return-to-Work Experiences of Thai Women with BCRL (Challenges vs Hope) emerged as the core category in the data analysis and emerging core aspects included: (1) changing/adjusting priorities in life after BCRL; (2) challenges of returning to work with

BCRL; (3) seeking availability of resources and support for BCRL; and (4) followed by a resolution as the last core aspect, accepting and living with BCRL.

Discussion and Implications: BCRL appeared to represent a dynamic process for these survivors. Using the findings of this study, future studies will develop evidence-based assessment and intervention strategies to maximize return to work by survivors with BCRL.

Keywords: Breast cancer, lymphedema, survivorship, return-to-work, occupational rehabilitation

CHAPTER ONE

INTRODUCTION

The Problem

Breast Cancer

Breast cancer is a disease in which the breast cells proliferate at an abnormal rate, which may have life-threatening implications. Breast cancer affected 2.3 million people worldwide in 2020, with 685,000 fatalities. As of the end of 2020, breast cancer was diagnosed in 7.8 million women over the previous five years (World Health Organization, 2021), making it the most common cancer in the world. According to statistics from the World Health Organization (2021), over half of breast cancers are diagnosed among women whose risk factors are their gender (female) and age (over 40 years). Thai breast cancer incidence increases by 3% to 7% per year across all regions of the country. In 2020, there were 22,158 new cases of breast cancer and 76,440 cases of five-year prevalence in Thailand (World Health Organization, 2021).

As cancer screening modalities have advanced and led to earlier diagnoses, the life expectancy for breast cancer patients is increasing (American Cancer Society, 2019). As longevity increases, it is important to investigate the cancer treatment complications experienced by breast cancer survivors. Breast cancer causes more disability-adjusted life years (DALYs) in women than any other type of cancer in part due to the years of survivorship (World Health Organization, 2021).

Almost half of all breast cancer incidence and approximately 60% of breast cancer mortality occurs in low- and middle-income countries, including Thailand (Virani et al., 2018). In 2018, the Thai National Cancer Institute reported that one of the major morbidities in Thailand is breast cancer (Virani et al., 2018). Over the past two decades, the incidence of breast cancer in

Thailand is the highest it has ever been, with an age-standardized rate (ASR) of 28.5 cases per 100,000 person-years (PY) (Virani et al., 2018). Breast cancer is the most common cancer among Thai women and is expected to remain one of the leading cancer diagnoses by 2025 (Virani et al., 2018).

Thailand has effectively implemented Universal Health Coverage (UHC) and embedded this national health plan in the 2030 agenda for sustainable development (Lakha et al., 2020). Ideally, UHC means that every person and community have access to health services without suffering financial hardship. All essential quality health services, including health promotion, disease prevention, treatment, rehabilitation, and palliative care, are expected to be included. But despite UHC, many challenges confronting breast cancer survivors in Thailand remain, including the need for additional funding and fine-tuning of resource allocation based on health needs, as well as disparities among health insurance systems (Lakha et al., 2020). Due to Thailand's healthcare delivery system, breast cancer survivors may face increased disease burden and rising expenses of care. These challenges may influence Thai breast cancer survivors with breast cancer-related lymphedema (BCRL) when they return to work.

Surgery, chemotherapy, and radiotherapy are the most common therapies for breast cancer, each of which has its own set of risks and adverse effects. A previous study by Campagen et al (2020) illustrated that clinical outcomes after breast cancer treatment can be divided into seven main aspects: 1) decrease in upper extremity range of motion; 2) decrease in muscular strength; 3) cognitive impairment; 4) decrease in psychological wellness; 5) impairment in activities of daily living; 6) pain; and 7) lymphedema (LE), a protein-rich swelling in the part of the body affected by cancer treatment (Campagna et al., 2020). This present study aimed to provide information on how lymphedema influences Thai breast cancer survivors with BCRL as they return to work.

Breast cancer-related lymphedema (BCRL)

Lymphedema is the accumulation of protein-rich fluid in the interstitial spaces of the affected body part as a result of an occlusion or dysfunction of the lymphatic system (Armer et al., 2010). It is one of the most troublesome complications of breast cancer treatment. Distressing symptoms of BCRL may include sensations of heaviness, swelling, and the risk of localized and systemic infections. Although current changes in breast cancer treatment (such as more conservative breast cancer surgery and minimally invasive surgical techniques due to early diagnosis) have decreased the risk of lymphedema, BCRL remains a major issue for women with breast cancer (Armer & Stewart, 2015; Eaton et al., 2020; Ostby & Armer, 2015). Cancer survivors are at risk for developing BCRL for the rest of their lives, with an incidence rate between 20% and 40% (Armer & Stewart, 2010; ILF, 2020). At 60 months after treatment, LE incidence varied from 43% to 94%, with 2 cm circumferential change at any measured anatomic region being related with the highest probability for lymphedema onset and signs and symptoms being the lowest (Armer & Stewart, 2015).

There are two types of risk factors related to BCRL: cancer treatment and lifestyle. The type of treatment, positive lymph node status, tumor stage at diagnosis, and how many lymph nodes are removed are all treatment-related risk factors (Thomas, 2021). Recent studies also point to the importance of precipitating personal and lifestyle factors, such as physiological behavioral characteristics, as predictors of BCRL (Hayes et al., 2012). There are several modifiable behaviors associated with personal and lifestyle risk, such as having a body mass index (BMI) >25.0 kg/m2 at diagnosis and an inactive lifestyle (DiSipio et al., 2013; Ostby & Armer, 2015; Park et al., 2008; Thomas, 2021).

There are numerous ways BCRL can affect a woman's day-to-day living, from physical discomfort through psychological issues like low self-esteem or depression (Deborah, 2019; Whatley et al., 2016). A survivor's combination of physical and psychological impairments could negatively affect their social lives, leading to isolation due to guilt or shame (Acebedo et al., 2019; Cal & Bahar, 2016; Deborah, 2019). The social, economic, and psychological impacts of lymphedema are widely under-recognized (Stout et al., 2012). Recent studies have illustrated that lymphedema leads to a significant decrease in quality of life, specifically in persons suffering from lymphedema after breast cancer treatment (Jørgensen et al., 2021; Meilani et al., 2020; Penha et al., 2016; Taghian et al., 2014). While the influence of BCRL on breast cancer survivors' quality of life has long been recognized, the impact of lymphedema on breast cancer survivors' work experience has received less attention (Fu, 2008; Sun et al., 2021).

An acute and chronic condition such as BCRL requires professional treatment and self-management. BCRL self-management activities such as manual lymphatic drainage, compression, exercise, and skincare must be performed regularly, usually over a lifetime (Moseley et al., 2007). When treatment is inadequate, lymphedema can result in skin thickening, a sensation of heaviness, loss of normal sensation, impaired function, pain, discomfort, and risk for infection in the affected limb. Psychosocial factors may contribute to poor adherence to BCRL risk-minimization regimens and behaviors, according to recent studies (Ostby & Armer, 2015). The time and energy investment required for self-management activities may impact other aspects of the survivor's life, including family and work roles.

BCRL and Return to Work (RTW)

Women diagnosed with breast cancer undergo a range of breast cancer treatments, and many of these survivors must deal with treatment-related lymphedema. There is some evidence that lymphedema may be associated with negative work outcomes, but there is little published research that investigates the factors underlying this association (Sun et al., 2021). These survivors are then challenged to navigate the return-to-work situation with this chronic condition.

Even though there are recognized potential connections between lymphedema and negative work outcomes, there has until recently been little published research that investigates the precise nature of the association (Sun et al., 2021). Both BCRL and its treatment have direct and indirect effects on work, with environmental and personal factors also influencing the work-return experience (Sun et al., 2021). Few qualitative studies have examined RTW experiences, perspectives, challenges, barriers, and facilitators for BCRL survivors (Cal & Bahar, 2016). Thus, there is a need to fill that gap in the literature and construct a substantive theory of the RTW experiences of breast cancer survivors with lymphedema.

The Rationale for the Study

Breast cancer survivors are confronted with a frightening reality (Cohee et al., 2020; Hansen et al., 2008; Thewes et al., 2016). Diagnosed and treated for a life-threatening condition, survivors may experience debilitating physical and psychosocial treatment-related side effects and challenges. One of the most prominent long-term breast cancer treatment-related complications is lymphedema. BCRL can be associated with physiological, psychological, social, and behavioral changes. These persisting changes may affect the role and function of the survivor in the family unit, socially within the community, and in the workplace environment (Hansen et al., 2008; Neubauer et al., 2017; Sun et al., 2017; Vignes, 2020), with impact on overall quality of life.

The RTW environment is also unknown, including the types of jobs that survivors have, the physical abilities needed to perform employment duties, and the accessibility of workplace accommodations. There are other demographic differences (such as income and living in a rural location), but it is unclear how much of an impact they have on RTW. Understanding the combined effect of treatment effects, demographic differences, and occupational determinants on RTW requires more research (Vidt et al., 2022). To date, there have been few qualitative studies exploring RTW experiences, perspectives, challenges, barriers, and facilitators for survivors with BCRL (Cal & Bahar, 2016). Nor have there been sufficient studies examining the association of BCRL with RTW and quality of life (QOL) in Thailand.

This qualitative research was generated after noting the gap in previous studies; this leads to our exploration of Thai survivors' individual experiences with BCRL when they return to work. A grounded theory approach was applied to explore the experience of return-to-work and work-related barriers and facilitators to BCRL self-management of Thai survivors by using semi-structured interviews with individual participants in the community setting. This study was guided by the following research questions:

RQ 1a): What are the issues and concerns for survivors with BCRL in Thailand when they return to work?

RQ 1b): What are barriers and facilitators among survivors with BCRL in Thailand when they return to work?

RQ 2a): How does BCRL impact work?

RQ 2b): How does BCRL impact work-related QOL?

RQ 3a): How does BCRL self-management impact work?

RQ 3b): How does work impact BCRL self-management?

RQ 4): How does culture in Thailand impact survivors with BCRL when they return to work?

The study aimed to provide a detailed description of the experiences and factors (barriers and facilitators) that influence the Thai breast cancer survivor's return to work and path through life with BCRL. The findings of this study can help support existing and future lymphedema research and self-management interventions by providing a foundational understanding of survivors' experiences and perspectives associated with BCRL, RTW, and QOL in the Thai cultural context.

Conclusion

Chapter 1 introduces this study with attention to the problem of breast cancer, the treatment effect of lymphedema, its potential impact on return-to-work, and the rationale for this qualitative study. Chapter 2 provides the background that focuses on BCRL-related factors that may influence the decision to return to work or make work-related changes following a breast cancer diagnosis and the development of lymphedema. Chapter 3 is the manuscript in process which examines studies of BCRL interventions reported in the literature that have aimed to improve quality of life and physical well-being. Chapter 4 describes the grounded theory research methods applied to explore BCRL self-management and work in the Thai context. Chapter 5 reports the findings from the qualitative pilot study for the dissertation research as a manuscript under review. Chapter 6 reports the dissertation findings in manuscript format. Chapter 7 applies the study findings to nursing practice, education, research, and policy.

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CHAPTER TWO

BACKGROUND

This chapter provides the background that focuses on breast cancer-related lymphedema (BCRL)-associated factors that may be associated with the decision to return to work (RTW) or make work-related changes following the development of lymphedema after a breast cancer diagnosis. Moreover, this chapter summarizes previous literature reporting BCRL challenged with physical, psychological, and socially impacted; self-management; quality of life; return-to-work; and interventions, revealing the gaps from previous studies.

BCRL Experiences

PubMed was searched using the following MeSH terms and keywords: “breast cancer related lymphedema”, “patients experience”, “psychology”, “qualitative research”, “secondary lymphedema”, “psychological impact”, and “burdens, psychological”. Databases to search included: PubMed, MEDLINE, CINAHL (include PsycInfo and PsycArticles), Google Scholar, Scopus, Embase and Web of Science. Twelve qualitative studies were reviewed**,** with all studies exploring survivors’ BCRL experiences. The findings were divided into three subcategories: physical limitations, psychological concerns, and social concerns. Additionally, articles related to BCRL self-management, quality of life, return to work, and interventions were included in this literature review.

Physical limitations

Physical Impairment

The most common physical change associated with BCRL was related to arm morbidity, the outcome most frequently reported in previous qualitative studies (Acebedo et al., 2019; Cal

& Bahar, 2016). Upper-body morbidity referred to symptoms, such as heaviness, swelling, numbness, tingling, pain, or tightness, and functional impairments, such as limited range of motion, changed movement patterns, or altered muscle recruitment in the arm, shoulder, and/or breast, on the affected side (Thomas, 2021). There were also concerns about the loss of the benefits to physical health through decreased physical activity and to psychosocial health from the inability to engage comfortably with others, socially, platonically, and sexually (Thomas et al., 2015).

Inability to Perform Activities of Daily Living

Generally, breast cancer survivors reported that BCRL had a negative impact on their daily lives (DiSipio et al., 2013; Hayes et al., 2012). Once lymphedema occurred, survivors often had diminished ability to perform daily tasks which required physical activity and mobility, such as basic household chores, exercise, physical engagement with friends and family, sexual engagement with a partner, and work tasks that required even minor manual labor (DiSipio et al., 2013; Hayes et al., 2012; Whatley et al., 2016). Women with BCRL were also aware of the need to avoid injury to the affected arm by primarily using the unaffected arm (Acebedo et al., 2019; Cal & Bahar, 2016). In addition, women who received surgery on their right breast reported more difficulty in performing activities of daily life, if this side was the dominant limb (Cal & Bahar, 2016). Being unable to perform even basic self-care or family/household responsibilities may have left survivors with a sense of guilt at being unable to satisfy their “role” as wife/mother and potentially being perceived as a burden (Cal & Bahar, 2016; Tsuchiya et al., 2015; Winch et al., 2015).

Symptom Experience

Lack of knowledge about lymphedema was one of the most frequent issues reported among study participants (Ostby et al., 2018). Often, survivors were uninformed about lymphedema and its symptoms (Acebedo et al., 2019; Cal & Bahar, 2016; Deborah, 2019; Maree & Beckmann, 2016; Ridner et al., 2012). Survivors reported unpleasant and/or unexpected symptoms in their affected arm, such as pain (Acebedo et al., 2019; Deborah, 2019; Loudon et al., 2017; Maree & Beckmann, 2016; Ridner et al., 2012; R. Thomas et al., 2015; Whatley et al., 2016; Winch et al., 2015); spasms (Acebedo et al., 2019); swelling (Acebedo et al., 2019; Cal & Bahar, 2016; Deborah, 2019; Maree & Beckmann, 2016; Ridner et al., 2012; Whatley et al., 2016); numbness (Acebedo et al., 2019; Maree & Beckmann, 2016); lack of strength (Acebedo et al., 2019); weakness (Deborah, 2019); and heaviness (Cal & Bahar, 2016; Loudon et al., 2017; Maree & Beckmann, 2016; Whatley et al., 2016). There were also unpredictable BCRL symptoms that affect survivors' level of functioning in their daily lives (Deborah, 2019; Rosedale & Fu, 2010).

With education and support, survivors were potentially able to accept and learn to live with the symptoms (Acebedo et al., 2019), as they learned about symptom management, and accept that they would have to confront and manage symptoms throughout their lives (Cal & Bahar, 2016; Deborah, 2019; Rosedale & Fu, 2010; Thomas et al., 2015; Tsuchiya et al., 2015). Additionally, the visible symptoms of BCRL may cause a private health condition to become public and contribute to embarrassment (Deborah, 2019). As Tsuchiya et al. (2015) pointed out, lymphedema symptoms reinforced a sense of inferiority and women sometimes withheld symptom complaints to their providers. Although these difficulties had an impact, survivors tended to inform their families later in the survivorship trajectory, as they did not want their families to be worried about their condition (Tsuchiya et al., 2015).

Psychological Issues

Body Image

Physical changes caused by BCRL may have negatively affected how participants perceive their bodies, including self-reports of altered self-image, decreased sexual appeal, shame, embarrassment, decreased self-esteem, lower self-confidence, increased self-consciousness, and inadequate attractiveness (Acebedo et al., 2019; Cal & Bahar, 2016; Deborah, 2019; Ridner et al., 2012; Río-González et al., 2018; Whatley et al., 2016; Winch et al., 2015). Additionally, the daily wearing of compression garments was a focus of self-consciousness about body image, as it marked women publicly as having lymphedema (Río-González et al., 2018; Winch et al., 2015), consequently sometimes drawing body image-defeating comments from strangers (Winch et al., 2015).

Emotional Issues

Emotional issues have been inherent with a diagnosis of breast cancer (DiSipio et al., 2013; Eaton et al., 2020). Likewise, survivors reported emotional issues from being diagnosed with lymphedema (Acebedo et al., 2019; Cal & Bahar, 2016; Eaton et al., 2020). Many women were fearful of the development of lymphedema for multiple reasons (Acebedo et al., 2019; Cal & Bahar, 2016). Initially, there was a simple, but understandable, fear of pursuing medical assistance due to the worry about possible cancer progression or recurrence (Rosedale & Fu, 2010). Psychologically, there was the fear of being turned away by health care providers due to a perceived sense of only being a bother to them for raising concerns about topics seemingly unrelated (such as socially-sensitive topics like difficulty or discomfort during intercourse) (Deborah, 2019; Rosedale & Fu, 2010). Without medical assistance and resources, the affected women may not know how to manage complications at home. This also led to other emotional issues, such as depression or anxiety (Whatley et al., 2016). Lacking guidance or understanding, their thoughts may have negatively focused on their fragile condition and mental health may have begun to deteriorate (Ridner et al., 2012).

Social Issues

Because of the psychological issues, lymphedema had a negative impact on survivors' social activities, as survivors reported that they could not maintain their prior social lifestyle (Cal & Bahar, 2016). Disruptions to basic daily or social activities due to lymphedema were reported as the cause of subsequent emotional issues. Negative self-image influenced the emotional state of survivors both with and without compression garments, especially for many of the survivors who had an observable volume difference between their two arms (Deborah, 2019; Whatley et al., 2016). For those with compression garments, there was the additional apprehension of being treated as injured/disabled in reaction to the garment (Winch et al., 2015). In terms of physical activity, women reported fear of making their symptoms worse, and so would withdraw from their usual activities, further leading to their sense of isolation and inadequacy (Whatley et al., 2016).

The additional stress and anxiety about the affected arm and subsequent social repercussions had a negative impact on sleep patterns (Acebedo et al., 2019) which only led to further stress and anxiety from exhaustion. Survivors often chose social isolation after developing lymphedema as, without understanding or guidance, this condition altered their social functioning (Deborah, 2019) to the point they would avoid social interactions out of fear, and, in turn, felt guilty due to a sense of failure to fulfill their prior social roles/duties (Tsuchiya et al., 2015; Whatley et al., 2016). Moreover, a recent pandemic outbreak and the ensuing social-distancing policies which contributed to the recently-changing health care system may have further affected the psychosocial needs of women with BCRL (Eaton et al., 2020). In light of a changing health care system, psychosocial research should examine how new policies apply to women with BCRL (Eaton et al., 2020).

BCRL Self-management

Self-management is the ability to regulate behaviors, thoughts, and emotions in a productive way. A wide range of educational and supportive options is necessary to help patients cope with chronic diseases and conditions like BRCL (Ostby et al., 2018). Complete decongestive therapy (CDT) is the 'gold standard' for lymphedema management (Armer et al., 2020; Yesil et al., 2017). CDT consists of two phases (active and maintenance) and includes a lifetime of surveillance and management (Armer et al., 2020; Yesil et al., 2017. Treatment of lymphedema includes specialized massage (manual lymphatic drainage), compression, exercise, and skincare, self-management activities that must be performed regularly, usually over the lifetime (Moseley et al., 2007; Yesil et al., 2017). The intensive decongestive Phase 1 is followed by the self-management Phase 2. BCRL self-management is very important in Phase 2, and failure to control symptoms may result in repeated episodes of cellulitis and progressive fibrotic skin changes (Ostby et al., 2018).

Interventions for BCRL Self-Management.

According to recent reports (e.g., Ostby & Armer, 2015), psychological and psychosocial factors contribute to poor adherence to BCRL risk-minimization and self-management regimens and behaviors. Healthcare providers were responsible for providing education to help individuals better understand their health. The ability to anticipate and provide adequate personal care relies on a thorough understanding of survivors' needs on a multidimensional level. A survivor's active involvement in understanding her health and individualized plan of care may enhance BCRL adherence with meaningful outcomes (Ostby & Armer, 2015).

To improve survivors' level of knowledge and their awareness of lymphedema care, the provision for systematic and comprehensive education needed to be addressed. A recent randomized control trial (RCT) aimed to evaluate the effect of lymphedema self-management in BCRL risk-reduction (Temur & Kapucu, 2019). In the experimental part of the program, a training booklet describing the exercise, massage, and BCRL risk-reduction methods was provided. The results demonstrated that the self-management intervention promoted QOL and decreased the symptom score (Temur & Kapucu, 2019). Researchers found that nurses were the most frequently-cited resource for information (Temur & Kapucu, 2019). In addition, nurses should be able to evaluate the at-risk survivor for lymphedema to educate them in risk-reduction actions, surveillance for symptoms, and refer them for early diagnosis and treatment. Risk reduction, early diagnosis and treatment, and informed self-management can contribute to a higher quality of life for the survivor (Gul & Erdim, 2009; McCaulley & Smith, 2014).

BCRL Quality of Life

Breast cancer diagnosis and treatment have been often associated with psychological distress and reduced QOL. The increasing number of breast cancer survivors increased public health attention and spending related to QOL (Herberger et al., 2017). A QOL theory developed from Abraham Maslow's human developmental perspective has provided an appropriate framework for considering the QOL impact of breast cancer and BCRL. The basic needs theory defined QOL as the level of satisfaction with the hierarchical needs of most members of the given society (Sirgy, 1986). According to Maslow's hierarchy of needs, an individual's behavior is determined by five categories of needs. A person's physiological needs, safety needs, love and belonging needs, esteem needs, and self-actualization needs fall under these categories (Sirgy, 1986). Quality of life in breast cancer survivors varies, depending on the stage of diagnosis, the modalities of treatment, and the months following completion of treatment. These periods were difficult times for survivors, both physically and emotionally (Paraskevi, 2012).

Maintaining the quality of life during and following breast cancer treatment often requires someone available to assist the survivor at home, particularly with household tasks or other activities that required arm mobility, and possibly provided personal care (e.g. activities of daily living and management of lymphedema) (Paraskevi, 2012). The fact that breast cancer survivors with lymphedema-specific impairments may have limitations in upper extremity mobility may contribute to diminished overall quality of life (Jørgensen et al., 2021). Meeting the survivor's basic needs is necessary to meet the hierarchical needs for QOL to be maintained. According to Maslow's theory, it may be challenging for breast cancer survivors with BCRL to independently reach the level of satisfaction of most members of society.

Therefore, it is critical for healthcare professionals to become familiar with the impact of a breast cancer diagnosis, its treatment, and its long-term effects on survivors. Nurses play a crucial role to identify and meet survivors' needs and share knowledge to promote quality of life. An intervention to enhance the quality of life has major importance for mitigating the impact of BCRL on QOL. BCRL self-management activities, such as manual lymphatic drainage, compression, exercise, and skincare, must be performed regularly, usually over the lifetime (Moseley et al., 2007). When treatment is inadequate, lymphedema can result in skin thickening, a sensation of heaviness, loss of normal sensation, impaired function, pain, discomfort, and risk of infection in the affected limb. By providing information about common post-treatment symptoms, potential complications, and individualized management, nurses can further assist survivors during and following breast cancer treatment (Armer et al., 2008).

Work and Survivorship

Work has been described in a variety of ways in the literature (Pritlove et al., 2019). The term may mean to perform work or fulfill duties regularly for wages or salary. The term can also refer only to structured activities outside the home, such as a paid job or an unpaid volunteer position. Work may also refer to activities performed within the home without remuneration. In this current study, participants reported both paid and unpaid work as it relates to the outcomes studied in this research project.

In the context of breast cancer survivorship, especially as related to BCRL, a literature review by Eaton et al. (2020) found that BCRL could significantly impact employment and limit return-to-work. The cascading nature of the economic burden of BCRL on long-term savings, work opportunities, and insufficiency of insurance to cover lymphedema needs could drive financial deficits.

Returning to Work

The issue of return to work (RTW) following breast cancer surgery is anticipated to become quite common in future years, given the rise in breast cancer incidence, the age at the time of cancer diagnosis, and the decline in cancer-related mortality. As a result, those influencing elements that may obstruct or facilitate RTW should be addressed. For breast cancer survivors, RTW is a critical milestone, and this is especially so for survivors who have BCRL.

Studies have shown the negative effect of BCRL on women's work and careers over and above the initial impact of breast cancer in the long term (Sun et al., 2017). Survivors with BCRL may encounter numerous obstacles, such as decreased physical function, discomfort, swelling, and decreased work performance, disproportionately affecting women of low socioeconomic standing (SES) (Deborah, 2019; Rosedale & Fu, 2010). Health care providers, the workplace, and insurance providers were all lacking in knowledge and collaboration with survivors with BCRL.

Return-to-Work Timeframe

According to research, the average RTW time among breast cancer survivors varied throughout countries, ranging from 11.4 months in the Netherlands to 7.4 months in Canada and merely three months in Sweden. After one year, the percentage of people who returned to work ranged from 54.3% in a cross-sectional study in France to 82% in a prospective study in the United States (Chaker et al., 2015). Data are not reported on breast cancer survivors' RTW in Thailand.

Previous studies have looked into the effects of cancer therapy on work, with the majority of them focusing on breast cancer. In a 2011 meta-analysis, 28 out of 64 trials reported data on employment or return-to-work rates following treatment. In total, 63.5% of patients (range 24-94%) were able to return to work, with the rate continuously increasing as time passed after cancer treatment. This ranged from 40% at six months after diagnosis to 62% at twelve months, 73% at eighteen months, and 89% at twenty-four months after cancer diagnosis (Mehnert, 2011). Moreover, survivors without BCRL were more likely to return-to-work, as compared to those with BCRL (Azarkish et al., 2015).

BCRL Return-to-Work

BCRL has the potential to have a substantial influence on employment and return-to-work opportunities (Fantoni et al., 2010; Vignes, 2020). BCRL was associated with a lower return-to-work rate and a longer time to return to work, according to findings from a study of medical chart data (Peugniez et al., 2011). Furthermore, the rate of RTW is influenced by physical, psychological, and organizational constraints (Peugniez et al., 2011). Individual variables, work environment, culture, and resources, on the other hand, were linked to reduced work engagement and ability, employment status, and work performance (Sun et al., 2017). Moreover, participants in a prior qualitative study by Sun et al. (2021) perceived BCRL and its treatment as affecting the return-to-work process in a variety of ways. They experienced BCRL impact manifested in diminished physical function, changes in their work-life routine, and/or psychological effects. Participants also described external variables (both positive and negative) that could help or hinder their return-to-work experience. These elements were woven into complex patterns to produce each unique experience (Sun et al., 2021).

Factors Related to Return-to-Work by Women with BCRL

Physical Impairment Influences Survivors with BCRL at Work

An essential feature of breast cancer that many survivors found difficult to deal with was the ability to RTW. Breast cancer and lymphedema, in particular, had a substantial negative impact on women's jobs and careers. Breast cancer survivors with BCRL and its associated symptoms, such as pain, heaviness, tightness, and decreased range of motion, reported that it limited their ability to function in daily life and negatively impacted their physical and mental health, as well as their social and recreational lives (Hayes et al., 2012).

For breast cancer survivors, being able to return to work was a crucial part of healing, yet difficulties and disparities still existed. The capacity of survivors to RTW might be impacted by treatment side effects that both cause and prolong functional disability. Survivors whose occupations demanded physical arm function might experience these effects more severely (Vidt et al., 2022). Lymphedema interfered with some breast cancer survivors' work involving heavy-lifting, gripping, holding, and fine motor dexterity (Collins-Bohler, 2012.; Fu, 2008).

Previous studies confirmed that the impaired physical function from lymphedema not only hindered the women in performing their work, but also brought a great deal of daily emotional distress (Boyages et al., 2016; Fu, 2014; Sun et al., 2017). Participants reported job changes as a result of stress and/or physical impairment, which had an impact on attendance and performance (Boyages et al., 2016). Supporting this, Gartner et al. (2010) found that lymphedema had an influence on women's daily activities at work (*N*=1884), with 36% of the sample reporting this effect. In particular, 47% of women reported light work above shoulder level was difficult; 27% reported everyday activity including shoulder rotation was difficult; and 59% of women reported heavy work was difficult. Furthermore, BCRL symptoms such as pain, tiredness, restricted range of motion, and weakness in the upper limbs, as well as physical limits, made performing occupational activities difficult or impossible (Peugniez et al., 2011; Zomkowski et al., 2018). Thus, research is clear that upper limb lymphedema can significantly impact work, sometimes upending careers (Vignes, 2020).

Work Demands and Work Environment Impacted by BCRL

Exiting the workforce or reducing hours due to BCRL may occur for a variety of reasons, including pain and restricted arm mobility affecting the ability to complete tasks, infections causing absences, restrictions on the wearing of compression sleeves or gloves in specific occupations, reduced mental health related to concern about job security due to inability to complete assigned responsibilities, depression, especially when one's job responsibilities are impacted, and feeling helpless (Fu et al., 2013). All experts concurred that lymphedema could limit a person's capacity to work and their employability. Restricted mobility or function of the damaged limb, together with time-consuming therapy modalities, discomfort, and psychological stress, were the main causes of limited employability and capacity to work. The most suitable career was teacher, while cook was the least suitable (Neubauer et al., 2017).

Individual Characteristics and BCRL RTW

Several personal characteristics or sociodemographic factors may influence the return-to-work decisions of breast cancer survivors. The type of mastectomy, axillary node dissections, and receiving chemotherapy were all factors linked to poorer work outcomes in a review of the literature (Hauglann et al., 2012; Johnsson et al., 2009; Thomas, 2021). It is important to think about the meaning of work and how the perception of illness impacts the decision to return to work. In many cases, returning to work could serve as a way to break out of an unhealthy role and get back into a sense of normalcy (Blinder et al., 2012).

Cultural Factors and BCRL RTW

Attitudes and social norms concerning the importance of survivors returning to work, as well as the resources that society may give for this process, were examples of cultural factors. Breast cancer survivors' decisions on whether or not to try to return to work may be influenced by societal attitudes (Sun et al., 2017). Societal attitudes may influence breast cancer survivors' decision about whether or not to even attempt to return to work. BCRL survivors may face negative experiences with societal expectations of survivors, as the lack of BCRL awareness by the public might make survivors with BCRL felt noticed and misunderstood (Sun et al., 2021)

Interventions for BCRL RTW

For optimal outcomes, women with BCRL are required to have a safe and secure RTW, with fewer negative effects; toward this end, the literature suggests early multidisciplinary interventions (Zomkowski et al., 2018)**.** The earlier breast cancer survivors understand new health conditions and needs, the better the relationship between the employees and employers will be (Testa et al., 2013). Therefore, educational programs on RTW are necessary to create a safe workplace; further, this has potential to help breast cancer survivors to improve relations with employees and employers (Désiron et al., 2016).

Currently, available literature have described the need for functional evaluations by health professionals, identifying and targeting survivors' goals, specific training on workability, and rehabilitating upper limb function and reducing complaints (Désiron et al., 2016). For breast cancer survivors, effective and methodologically rigorous rehabilitation intervention research is lacking. This research is necessary to develop and test effective rehabilitation strategies to help survivors return to work (Algeo et al., 2021).

Education for chronic illness self-management is necessary, specifically in the area of BCRL. For breast cancer survivors, nurses have played significant roles in teaching self-management of lymphedema (Temur & Kapucu, 2019), education essential to both facilitate health outcomes and ease the transition of return-to-work. Supporting clients to manage their health is necessary, but there is also a requirement for a general language with which to communicate about self-management and a general program of self-management actions for cancer care. Oncology nurses have built relationships with their clients and created mutually designed care plans that facilitated and empowered clients to care for themselves in the way they favor (McCorkle et al., 2011). Facilitating clients' self-management offers information exchange, including suggestions, instructions, and advocacy. Healthcare providers facilitate clients' self-management by delivering directional support, strengthening person autonomy, and offering guidance and management on better self-care. The interrelationship of BCRL self-management and principles of vocational rehabilitation, as an area of facilitating return-to -work after trauma or injury, has been a largely untapped area for practice and research. With the appropriate knowledge, this is an area well suited to the skills of oncology nurses.

Conclusion

The purpose of this chapter was to provide background information on the factors that influence a survivor's decision to return to work or make changes to their working environment, following a diagnosis of breast cancer and the development of lymphedema. Moreover, this chapter summarizes previous literature reporting BCRL challenges with physical, psychological, and social impact, self-management, quality of life, return-to-work, and interventions, revealing the gaps from previous studies. BCRL challenges with physical outcomes include physical impairment, inability to perform activities of daily living, and symptoms experienced. BCRL influences psychological perspectives, including body image, and emotional and social perspectives. The potential factors that influence a survivor's decision to return to work may include these physical, psychological, or social impairments, work demands and work environment, individual characteristics, and cultural factors. Gaps in the current research on associations of BCRL and RTW are identified. Currently, it is evidence that there is no study of RTW research among Thai breast cancer survivors with lymphedema. Chapter 3 will present a literature review manuscript as preliminary work. This review provides an update on interventions to improve quality of life and physical well-being, such as reducing physical impairment, improving range of motion, limiting pain, and improving grip strength among women with BCRL.

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CHAPTER THREE

PRELIMINARY WORK

INTERVENTIONS TO IMPROVE PHYSICAL WELL-BEING AND QUALITY OF LIFE AMONG BREAST CANCER SURVIVORS WITH LYMPHEDEMA: A LITERATURE REVIEW

Narkthong, N., Hulett., J. M., Anderson, E. A., Armer, J. M. (2023, in process). INTERVENTIONS TO IMPROVE PHYSICAL WELL-BEING AND QUALITY OF LIFE AMONG BREAST CANCER SURVIVORS WITH LYMPHEDEMA: A LITERATURE REVIEW.

Abstract

Purpose of the review: Breast cancer survivors live with the risk of developing breast cancer-related lymphedema (BCRL) as a side effect of treatment. It generally influences one-third of all breast cancer survivors and may significantly reduce both the physical and psychological well-being of affected women. This report reviews interventions used to improve physical well-being and quality of life (QOL), such as reducing physical impairment, improving range of motion, limiting pain, and improving grip strength among women with BCRL.

Method: CINAHL, PubMed, and MEDLINE (Ovid) databases were searched, yielding a total of 305 articles for screening. Twenty-six studies met the inclusion criteria which included: women with BCRL age(s) 18+ years; articles published from January 11, 2015, to November 30, 2022; experimental design; interventions to improve physical well-being and quality of life (QOL) among BCRL; and full text available in English. This review excluded studies of other causes of lymphedema (non-BCRL), and those not published in English. PRISMA checklist and PRISMA diagram were employed to illustrate the quality and the flow of this review.

Results: Twenty-eight clinical intervention studies were reviewed. Both non-invasive and invasive BCRL intervention programs require well-trained health professionals, including physicians, nurses, and lymphedema specialists. These interventions can be used to reduce BCRL symptoms, such as increased arm volume, pain, and numbness, to improve physical well-being and quality of life among breast cancer survivors.

Conclusions: Non-invasive interventions are recommended for early-stage BCRL, whereas invasive procedures may be recommended to treat advanced lymphedema which does not respond to non-invasive interventions.

Implications for Cancer Survivors. This review reports current interventions that can be used to manage symptoms and promote physical well-being and QOL among survivors with BCRL.

Keywords: Breast Cancer-related Lymphedema, Literature Review, Interventions, Quality of Life, Physical Well-being.

Introduction

Breast Cancer Today

Breast cancer is currently the most common cancer globally, accounting for 12.5% of all new annual cancer cases worldwide (Breast Cancer Organization, 2023). Globally, breast cancer rates have steadily increased. Approximately 3.1 million breast cancer survivors live in the United States, a number that is predicted to reach 4.5 million in 2023 (Rosenberg et al., 2015). Breast cancer survivors often suffer from lymphedema as a result of cancer treatment. It generally affects one-third of all breast cancer survivors and may significantly reduce both physical and psychological well-being, including quality of life (QOL), of affected women (Armer et al., 2020; Temur & Kapucu, 2019).

Survivors with BCRL

Survivors with BCRL experience physical and psychological changes which affect them on a daily basis (Armer et al., 2010; Radina & Armer, 2001). Current studies have illustrated that lymphedema leads to significant reductions in QOL, particularly in survivors suffering from lymphedema following cancer treatment (Taghian et al., 2014). BCRL is also associated with long-term impairments in the dimension of health-related QOL, especially affecting the physical and psychosocial domains (Jørgensen et al., 2021). Moreover, social relationships can be significantly influenced by physical and psychological impairments from BCRL (McWayne & Heiney, 2005). Following a 2020 literature review by Eaton et al (2020), it was found that BCRL is associated with poorer psychosocial well-being and lower QOL because of symptoms such as anxiety, depression, emotional distress, fatigue, self-care, relationship problems, impaired mobility, or difficulty participating in social activities.

A previously-published 2015 review by Finnane et al. (2015) of the evidence for effective lymphedema treatment illustrated the scientific evidence for identified lymphedema treatments; suggested clinical practice guidelines should be updated; and acknowledged the relative weakness of the scientific evidence. Lymphedema affects women not only physically, including limited arm mobility, pain, numbness in their affected arm, but also psychologically, including negative self-perceptions of their bodies and loss of self-esteem (Fu et al., 2015; Taghian et al., 2014). Various symptoms and complications are associated with lymphedema; thus, it is necessary to start interventions, programs, or treatment protocols immediately after the diagnosis, irrespective of the severity or stage of the disease (Yesil et al., 2017). This review aimed to examine the body of literature since 2015 for interventions utilized to improve physical function and physical well-being, including QOL, among breast cancer survivors to order to increase the necessary lymphedema knowledge of health care professionals caring for breast cancer survivors living with BCRL.

Interventions to Improve Physical Well-being and QOL

Research has shown that lymphedema has a negative influence on many dimensions of daily life, leading to physical impairments, lowered self-esteem, depression, fear, and body-image. Moreover, social relationships can be significantly influenced by these physical and psychological impairments (McWayne & Heiney, 2005). Interventions targeting physical well-being among breast cancer survivors with lymphedema are aimed at reducing physical impairment in the affected limb, improving range of motion, limiting pain, and improving grip strength (Ochalek et al., 2018; Pasyar et al., 2019; Yesil et al., 2017). A comprehensive review of the literature by Forner-Cordero et al. (2010) reveals satisfactory results of complete decongestive therapy (CDT) in reducing the volume of lymphedema (LE). However, it was reported that the rate of favorable results varied between 22 to 73% (Forner-Cordero et al., 2010). This report reviews interventions used to improve physical well-being and QOL, such as reducing physical impairment, improving range of motion, limiting pain, and improving grip strength among women with BCRL.

Methods

The literature review examined intervention studies aimed to improve physical well-being and QOL among survivors with BCRL. To accomplish the aim of this literature review, Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was utilized (Page et al., 2021).

Search Strategy

CINAHL, PubMed, and MEDLINE (Ovid) databases were searched using the following search terms: “breast cancer-related lymphedema”, “lymphoedema”, “lymphatic volume”, “lymphedema management”, “lymphatic drainage”, “lymphedema therapy” and “enhance the quality of life”, “breast cancer surgery”, “intervention”, “lymphedema exercise” and “physical well-being” and terms were combined using the linking operators. Databases were searched for the time period from January 1, 2015, to November 30, 2022. In addition, the terms were applied to Cochrane Library databases and Google Scholar searches. Reference lists from eligible studies were reviewed in an attempt to locate any further publications.

Study Selection and Data Extraction

Inclusion criteria focused on: secondary lymphedema post-breast cancer treatment; studies with adult females (aged 18+ years); published articles from January 1, 2015, to November 30, 2022; quantitative results of primary empirical studies; quantitative experimental studies using instruments that assessed the QOL and/or physical well-being among survivors with BCRL; interventions that improved the physical well-being, such as reducing physical impairment in the affected limb, improving range of motion, limiting pain, and improving grip strength among those with BCRL; interventions that aimed to improve and improved QOL in survivors with BCRL; and articles with full text available in English. This review excluded: studies with other causes of lymphedema (non-breast cancer-related, primary lymphedema), not published in English, gray literature, dissertations, case studies, and full articles not available /abstract only.

Each study was analyzed using the following variables such as, study design, number of participants, setting, intervention, outcomes of fluid volume, pain, arm circumference, physical well-being, quality of life, results, and limitations. The PRISMA 2020 protocol and flow chart were used in this review (Page et al., 2021). The PRISMA checklist was employed to evaluate quality and allowed the reviewer to assess the strengths and weaknesses of the studies. The PRISMA flow diagram demonstrates the flow of information through the different phases of the review; it presents the number of records identified, included, and excluded, and the reasons for exclusions (Figure 3.1).

Results

From a total of 305 retrieved records, there were 28 clinical intervention studies identified that met the inclusion criteria (Figure 1). Included studies were organized into the categories of non-invasive (*n* = 24) and invasive interventions (*n* = 4). *Non-invasive* interventions included: complete decongestive therapy [CDT] (*n* = 6); complementary and integrative health [CIH] approaches (*n* = 2); Physical Therapy Program [PT] vs Manual Lymphatic Drainage [MLD] (*n* = 1); Self-lymphatic drainage [SLD], Compression Bandaging [CB] and Reflexology Lymphatic Drainage [RLD] (*n* = 1); Photobiomodulation Therapy

[PBMT] (*n* = 2); Moxibustion (*n* = 2); Compression Garment (n = 3); Self-management (*n* = 1); and Exercise (*n* = 5). *Invasive* interventions included: surgical management (*n* = 2); liposuction (*n* = 1); lymphatico-venous anastomosis [LVA] (*n* = 1); and cervical stellate ganglion block [SGB]) (*n* = 1) to treat persistent lymphedema.

In terms of study sample characteristics, the types of breast cancer surgery in participants included a radical mastectomy, modified radical mastectomy (MRM), simple total mastectomy, and axillary lymph node dissection (ALND). Sample sizes ranged from 20 to 161 participants. Post-operative cancer treatment interventions varied from a month after completing breast cancer treatment to three years later. Participant ages ranged from 18 to 80 years (Bahtiyarca et al., 2019; Mazor et al., 2017; Sener et al., 2017; Whatley et al., 2016; Yesil et al., 2017; Yesil et al; 2021); 18 to 65 years (Temur & Kapucu, 2019; Wang et al., 2019); 50 to 70 years (Melam et al., 2016); and 30 to 80 years (Yao et al., 2015).

In terms of study setting, the studies were conducted in 13 different countries: China (*n* = 2) (Wang et al., 2019; Yao et al., 2015); Egypt (*n* = 1) (Tantawy et al., 2019); Germany (*n* = 1) (Storz et al., 2017); Iran (*n* =2) (Abbasi et al., 2018; Pasyar et al., 2019); Japan (*n* = 1) (J.-H. Park, 2017); Korea (*n* = 2) (Cho et al., 2016; M. W. Park et al., 2019); Netherlands (*n* = 1) (Winters et al., 2017); Poland (*n* = 2) (Ochalek et al., 2018, 2019); Sweden (*n = 1*) (Hoffner et al., 2017); Saudi Arabia (*n = 1*) (Melam et al., 2016); Turkey (*n* = 9) (Atalay et al., 2015; Bahtiyarca et al., 2019; Iacorossi et al., 2019; Sener et al., 2017; Tastaban et al., 2020; Temur & Kapucu, 2019; Yesil et al., 2017; Yesil et al., 2021); UK (*n* = 2) (Phillips et al., 2019; Whatley et al., 2016); and USA(*n* = 2) (Mazor et al., 2017; Zhang et al., 2017).

Most studies reviewing invasive interventions of lymphedema have been conducted in the Western world (UK, Sweden, and the Netherlands), whereas noninvasive interventions for lymphedema have been more frequently conducted in the Western world (USA, UK, Germany, and Poland), in Western Asia (Iran, Turkey, Egypt, and Saudi Arabia) and in Southern Asia (Korea, China, and Japan).

Non-invasive interventions

Nine non-invasive interventions were conservative interventions that did not require an incision into the body, the removal of tissue, operation, vital sign monitoring, anesthesia, or hospitalization. The noninvasive intervention timeframes varied from four weeks ($n = 17$), eight weeks ($n = 2$), six months ($n = 2$), to 12 months ($n = 1$). Outcomes were evaluated at baseline and a range of two weeks, six months, and 12 months after completing the program, most frequently at one month ($n = 8$) and two months ($n = 3$). The summaries of studies with the nine categories of non-invasive interventions included in this are included below.

Complete Decongestive Therapy (CDT)

Five studies, including one randomized controlled trial (RCT), evaluated CDT and its impact on physical well-being, while four studies compared CDT with other interventions, including relaxation plus CDT (R+CDT), CDT plus intermittent pneumatic compression and conventional therapy. Samples sizes ranged from 31 to 76 for these five studies.

Atalay et al. (2015) showed that the “gold standard” treatment of CDT provided by a trained lymphedema therapist five times a week for four weeks yielded a significant reduction in limb volume ($p < 0.05$), with a positive correlation ($r = 0.4$) between arm circumference and depression in a one-group pretest-posttest experimental design ($N = 58$). Further, after four weeks there was a decrease in circumference measurements in phase one from 38.8±3.3 cm and after the program to 34.0±2.9 cm; in phase two, the shoulder ROM improved.

In one group of pretest-posttest designs (*N* = 60), Yesil et al (2017) investigated the effects of CDT on the quality of life, depression, neuropathic pain, and fatigue among those with BCRL. There was a statistically significant reduction in the volume of the involved limbs after the treatment ($p < 0.001$). There was a significant improvement in the general health status and functional scores of the EORTC QLQ-C30 ($p < 0.001$, $p = 0.004$, respectively) (Yesil et al., 2017).

A recent study by Yesil et al. (2021) used a one-group pretest-posttest design to examine how CDT affected quality of life, upper extremity function, and kinesthetic sensation in their hands in individuals with BCRL. After the treatment, the mean volumes of the limbs before and after the treatment protocol were 3,920.1±897.9 mL and 3,297.6±773.1 mL, respectively, indicating a statistically significant reduction in the volume of the involved limbs after the treatment ($p < 0.001$). The EORTC QLQ-overall C30's health status and functional scales both showed a substantial improvement ($p = 0.012$ and $p = 0.001$, respectively), while the symptom score showed a significant decrease ($p = 0.001$). After the treatment, the patients' DASH scores, as well as their visual and kinesthetic sense ratings, considerably improved ($p = 0.016$, $p = 0.008$, and $p = 0.001$, respectively) (Yeşil et al., 2021).

Additionally, in a quasi-experimental study by Abbasi et al. (2018) (*N* = 31), there were significant differences between two groups of women who received CDT (*n* = 15) and who received Relaxation plus CDT (R+CDT) (*n* = 16). A greater volume of reduction in the edema volume was achieved through RCDT compared to CDT alone. Over the entire study period, the percentage of reduction in the volume of edema was slightly greater in the RCDT group than in the CDT group (64.3% vs. 62.4%). The reduction in the depression and anxiety scores between the two groups was significantly different ($p = 0.024$; $p = 0.011$, respectively) throughout the study. The mean fluid volume differed between groups significantly at baseline and in the 3rd and 9th weeks ($p < 0.008$) (Abbasi et al., 2018).

An RCT (*N* = 76) illustrated the role of intermittent pneumatic compression in the treatment of unilateral arm lymphedema (Tastaban et al., 2020). Seventy-six participants were randomly assigned into two groups; group one received CDT (*n* = 38) and group two received CDT plus intermittent pneumatic compression (*n* = 38). After the program, the percentage depletion of excess volume was non-significantly greater in the CDT-plus-intermittent-pneumatic-compression group (18.9% to 8.9%) than in the CDT-alone group (18.4% to 10.7%) and the clinical scores illustrated improvements in CDT-plus-intermittent-pneumatic-compression group (54.6 %) compared to the CDT-alone group (49.6 %). Visual Analog Scale (VAS) with a 0-10 Numerical Rating Scale was used to assess the clinical symptoms of pain (during activity, resting, and sleep), heaviness, and tightness in the afflicted arm. Both groups showed a decline in the percentage excess volumes (PEVs). Although the CDT-plus-intermittent-pneumatic-compression group's percentage decrease of extra volume was better than the CDT-alone group, there was no significant intergroup difference (Tastaban et al., 2020).

A quasi-experimental research study by Melam et al. (2016) (*N* = 60) examined the effect of conventional therapy (CT) (*n* = 30) and CDT (*n* = 30) on QOL and pain among survivors with BCRL. Conventional therapy (CT) group participants received manual lymphatic drainage, low elastic compression garment, gleno-humeral mobilization, and deep breathing exercises. A CDT group received manual lymphatic drainage, compression garment worn 23hrs daily, remedial exercises, and a home program. Both groups received treatment 5 times a week for 6 weeks. There was improvement in quality of life and pain after the program in both groups ($p < 0.01$). However, the CDT group had greater improvement than the CT group, as the estimated marginal means showed a higher reduction of pain (*M* = 4.8) in the CDT group than the CT group (*M* = 3.8) (Melam et al., 2016).

Physical Therapy Program (PT) and Manual Lymphatic Drainage (MLD)

An RCT (*N* = 41) compared outcomes between a PT program (*n* = 20) and a PT-MLD program (*n* = 21) on BCRL and QOL. A PT program was provided three times a week for four weeks for both groups; the PT-MLD group was trained to perform manual therapy for 30 minutes by a skilled physical therapist. After one month, the numeric rating scale (NRS) pain score and arm volume were significantly lower in the PT-MLD group than in the PT-alone group ($p < 0.05$) (Cho et al., 2016).

Manual Lymphatic Drainage (MLD), Self-lymphatic Drainage (SLD), and Compression Bandaging (CB)

An RCT reported by Bahtiyarca et al. (2019) aimed to investigate the effects of adding self-lymphatic drainage (SLD), rather than manual lymphatic drainage (MLD), to compression bandaging (CB) therapy in the first phase of complex decongestive therapy (CDT) on arm edema, quality of life, upper extremity function, and anxiety-depression in patients with breast cancer-related lymphedema (BCRL) (*N* = 24). MLD, one component of CDT performed initially by specially-trained lymphedema therapists, is a specialized massage technique that stimulates the lymphatic flow and helps transport the lymph from swollen to non-swollen areas. SLD is a self-administered form of MLD that aids in the movement of surplus fluid from a swollen (or at-risk) area to an area where the lymph nodes are functioning effectively (Bahtiyarca et al., 2019). SLD is a simpler form of self-MLD that is easier for the individual to use and takes less time (10-15 minutes) than MLD. Twenty-four participants were randomly assigned to evaluate the effects of combining SLD (*n* = 10), rather than MLD (*n* = 14), with the compression bandaging

(CB) program, in the first phase of CDT (Bahtiyarca et al., 2019). This study was conducted for eight weeks. There was a significant volume decrease in both groups at the end of the treatment from baseline ($p = 0.002$ and $p = 0.004$, respectively). The volume decrease of the affected arm was similar in both groups and no significant difference was observed between the two groups ($p=0.939$) (Bahtiyarca et al., 2019).

Reflexology Lymphatic Drainage (RLD)

In a one-group, pre-posttest research design, participants with stable unilateral BCRL following axillary lymph node dissection (ALND) ($N = 26$) received RLD treatments performed once a week for four consecutive weeks. A reflexology procedure typically entails employing thumb, finger, and hand techniques to apply pressure to particular locations on the feet (Whatley et al., 2016). A control group received only standard routine care in a lymphedema clinic. There was a significant difference across the three limb volume measures at the baseline, the first, and second follow-ups [F (1.34, 28.13) 43.50, $p < .001$]. The mean limb volumes (mL) were 2478.0, 2344.6, and 2346.8, respectively (Whatley et al., 2016).

Complementary and Integrative Health Approaches (CIH)

One of the most frequently studied CIH approaches historically used in studies to manage BCRL is yoga. Two studies are reviewed in the timeframe of this literature review.

A pilot RCT evaluated the effect of an 8-week yoga intervention on QOL and upper extremity volume in women with breast cancer-related lymphedema ($N = 40$) (Pasyar et al, 2019). Participants were assigned to the intervention group ($n = 20$) or the control group ($n = 20$) (Pasyar et al., 2019). The intervention group participated in a yoga exercise intervention for 8 weeks, including a twice-a-week instructor-led class and a once-a-week home practice. Four weeks after the intervention, a significant difference was observed between the groups concerning role functioning in QOL ($p = 0.03$). Eight weeks after the intervention, a significant difference was observed between groups concerning physical and emotional functioning in QOL ($p < 0.05$) (Pasyar et al., 2019).

Moreover, another one-group pretest-posttest research design ($N = 17$) illustrated the feasibility, safety, and estimated efficacy of yoga in post-operative care of women at high risk for BCRL. The women participated in an Ashtanga yoga intervention for 8 weeks. Sessions consisted of weekly instructor-led practice and weekly home practice. Particular attention was given to poses that emphasized upper body strength and flexibility, while avoiding significant time with the upper extremity (UE) in a dependent position. After the intervention, the mean volume in the at-risk UE was slightly reduced (-21.68 mL [95% CI -75.45, 32.09]; $p = 0.397$), indicating a small, non-statistically significant decrease. Average volume change in the unaffected limb was 5.92 mL (95% CI -29.87, 41.71; $p = 0.725$). ROM for shoulder flexion and external rotation significantly increased bilaterally ($p < 0.01$; $p < 0.05$, respectively). Shoulder abduction ROM significantly improved for the unaffected limb ($p = 0.001$). Following the intervention, strength improved on the affected side for shoulder abduction and grip strength, and bilaterally for elbow flexion ($p < 0.05$ for all) (Mazor et al., 2017).

Physical Activity and Exercise

Physical activity is defined as any movement that is carried out by the muscles that require energy. This covers every movement people do during the day, with the exception of sitting or lying down. In other words, it is any movement a person does. Exercise is, by definition, planned, structured, repetitive, and intentional movement. Various types of physical activity and exercise such as dragon boat racing and sports (Iacorossi et al., 2019), weight-lifting (Zhang et al., 2017) and Pilates (Sener et al., 2017) have been used as interventions in lymphedema management. Four RCTs (Park, 2017; Iacorossi et al., 2019; Zhang et al., 2017; Sener et al., 2017), and one observational study (Iacorossi et al., 2019) evaluated physical activity such as lymphedema exercise. Samples sizes ranged from 60 to 141 for these five studies.

The first physical activity study conducted by Park (2017), a 4-week RCT study with complex exercise, focused on shoulder ROM and pain for women with lymphedema ($N = 69$). An occupational therapist conducted interventions of complex exercise (CE) and MLD and pneumatic compression (PC) (MLD+PC) for each of two groups. The CE group included one hour daily, five times-a-week, for a total of four weeks of aerobic exercise and strength training. The MLD+PC group had 30 minutes of pneumatic compression and 30 minutes of manual lymph drainage five times a week for a month. After four weeks, the CE group had greater improvements in shoulder ROM and pain compared with the MLD+PC group ($p < 0.05$).

An observational two-group design study examined dragon boat-racing and its effect on lymphedema occurrence and quality of QOL ($N = 100$) (Iacorossi et al., 2019). Participants at risk for BCRL were divided into two groups. In Group A ($n = 50$) all the women were involved in the dragon boat sport twice a week for at least six months. Group B ($n = 50$) was made up of women who did other types of sports (other than dragon boat racing) with the same frequency and for at least six months and/or underwent alternative treatments such as compression therapy. The results revealed that lymphedema incidence in Group A was 4.0% (2 of 50), whereas in Group B it was 26.0% (13 of 50). Women who participated in dragon boat racing also reported a healthier lifestyle, lower body mass index, and a better QOL (set point: 61.8 [Group B] vs 80.0 [Group A]) (Iacorossi et al., 2019).

An RCT of 141 participants with BCRL aimed to compare changes in arm tissue composition and self-reported lymphedema symptoms after one-year of weight-lifting (*n* = 71) vs. the control (baseline physical activity) (*n* = 70) (Zhang et al., 2017). Participants in the weight-lifting group were provided with a 12-month community fitness center membership. For the first 13 weeks, participants were instructed on the safe completion of weight-lifting exercises in groups of 2–6 participants. Certified exercise professionals employed by the fitness centers led the twice-weekly 90-minute exercise sessions. Each session included stretching, cardiovascular warm-up, abdominal and lower back strengthening exercises, and weight-lifting exercises. Weight-lifting exercises for the upper-body included the dumbbell press, seated row, lateral or front raise, bicep curls, and triceps extension. Weight-lifting exercises for the lower-body included the leg press, back extension, leg extension, and leg curl. For each exercise session, three sets of each weight-lifting exercise were performed, 10 repetitions per set. After 13-weeks, participants continued with unsupervised weightlifting for 39 weeks. Participants in the control group were asked to maintain their baseline level of physical activity. The study revealed that after 12 months of weightlifting, composition of the affected arm was improved: lean mass (71.2g; *p* = 0.01) and bone mineral density (BMD) (14.0mg/cm2; *p* = 0.02) increased, while arm fat percentage decreased (−1.5%; *p* = 0.003). The composition of the unaffected arm was only improved in lean mass (65.2g; *p* = 0.04). Increases in lean mass were associated with less severe BCRL symptoms (Zhang et al., 2017).

Another RCT compared the effects of clinical Pilates exercises with those of the standard lymphedema exercises on BCRL (*N* = 60) (Sener et al., 2017). The participants were randomized into two groups: the clinical Pilates exercise group (*n* = 30) and the control group (*n* = 30). In the clinical Pilates exercise group, the patients were trained on Pilates exercises and postures.

Exercises were performed in groups of five to eight people three times a week, for eight weeks. Although there were significant improvements in all areas in the clinical Pilates exercise group ($p < 0.05$) for pain in the lymphedematous arm, severity of lymphedema, grip strength, shoulder range of motion, and disabilities of the arm, shoulder, and hand (DASH), quality of life with breast cancer (QLQ-BR23), and social appearance anxiety (SAA), the control group showed no improvements in grip strength shoulder flexion, and external rotation angles ($p > 0.05$) (Sener et al., 2017).

A recent RCT compared the benefits of resistance exercise training and virtual reality (VR) training on the severity of lymphedema symptoms, physical functioning, and QOL in women with BCRL ($N = 60$) (Basha et al., 2022). Two groups of women with unilateral BCRL were randomly assigned: the Xbox Kinect group ($n = 30$) received VR games based on the Kinect, and the resistance exercise group ($n = 30$) received resistance training. Additionally, CDT was given to both groups. For eight weeks, the intervention was carried out in five sessions each week. Excessive limb volume, the pain Visual Analogue Scale (VAS,) the Disability of the Arm, Shoulder (DASH) questionnaire, shoulder range of motion (ROM), shoulder muscles strength, hand grip strength, and the 36-Item Short Form Health Survey Questionnaire Form were among the outcome measures (SF-36). Results were assessed both before and after the intervention (week 8). In favor of the Xbox Kinect group, statistically significant differences were found in the VAS (pain intensity), DASH, shoulder ROM ($p = 0.001$), body pain ($p = 0.002$), general health ($p = 0.001$), and vitality ($p = 0.006$). However, there were statistically significant changes in favor of the resistance exercise group for shoulder flexion strength ($p = 0.002$), external rotation strength ($p = 0.004$), abduction strength, and handgrip strength ($p = 0.001$) (Basha et al., 2022).

Photobiomodulation Therapy (PBMT)

In 2014, the North American Association for Laser Therapy (NAALT) and the World Association for Laser Therapy (WALT) defined PBMT as the use of light in therapy to trigger biochemical reactions without generating heat or cytotoxicity (Storz et al., 2017). The use of photo biomodulation therapy, previously referred to as low-level laser therapy (LLLT), has gained popularity in the supportive care of patients with breast and ovarian cancer (Robijns et al., 2017). An RCT (N = 40) aimed to examine the effects of PBMT in the treatment of BCRL. Forty participants were randomized to the active laser group (n = 20) and the placebo laser group (n = 20) (Storz et al., 2017). Even though the placebo laser device has a functional but inactive laser, the weight, sound emissions, and visual appearance of both devices are similar to ensure tightly regulated double-blinded settings. Participants received irradiation with the cluster laser equipment. Irradiation was done in non-contact mode twice a week for four weeks. Participants were encouraged to keep up daily skincare and exercise their limbs. Following treatment, a 50% reduction in median pain score evaluated by ‘Face Pain Scale Revised’ was noted, along with an increase in mean QOL. After eight sessions of PBMT, the mean grip strength was consistently higher compared to pre-treatment; however, no statistically significant differences were found between the groups ($p > 0.05$) over time (Storz et al., 2017).

Moxibustion

Moxibustion is a kind of external treatment; it is based on the theory of traditional Chinese medicine (TCM), and it usually bakes acupoints with burning moxa wool (Wang et al., 2019). The spongy herb enhances the healing process with acupuncture and is small in appearance. Moxibustion is thought to boost blood circulation, relieve swelling, and relieve pain (Wang et al., 2019). Two RCT studies conducted in China examined the effect of moxibustion on BCRL. The first RCT study (*N* = 48) compared the effect of moxibustion on BCRL with another treatment group. Participants were assigned to the moxibustion group to receive moxibustion for 30 minutes every two days (*n* = 24); and an equal number were assigned pneumatic circulation every two days and a compression garment (*n* = 24). All participants were treated for four weeks. After the program, the moxibustion group had significantly greater differences in reduced limb circumference (1.13 cm) than the control group (0.61 cm) $p < 0.01$. Pain scores in the moxibustion group (4.87 ± 0.87) were lower than the control group (5.41 ± 0.80), $p < 0.5$. (Wang et al., 2019).

Another RCT (*N* = 30) study compared the effectiveness of combined acupuncture and moxibustion ("warm acupuncture") (*n* =15) with that of diosmin (a drug used for treating various disorders of blood vessels) (*n* =15) among survivors with BCRL (Yao et al., 2015). Measured by the index of effectiveness, limb circumference improved by 51.46% in the experimental group and by 26.27% in the control group ($p < 0.00001$). Moreover, warm acupuncture was found to be a safe method for women with BCRL, without adverse effects (Yao et al., 2015).

Compression Garment (CG)

Three RCT studies examined the effectiveness of compression garments (CG) on managing or reducing risk of BCRL (Ochalek et al., 2018; Ochalek et al., 2019; Tantawy et al., 2019). Samples sizes ranged from 41 to 66 for these three RCT studies.

Two RCTs were designed to evaluate the effectiveness of CG on limb volume and QOL after the postoperative period to one year (*N* = 45) and two years (*N* = 41) later (Ochalek et al., 2018; Ochalek et al., 2019).

CG was used to decrease the incidence of early postoperative lymphedema in the one-year study (N=45) (Ochalek et al., 2018). In the one-year study, both groups underwent a standardized exercise program. The experimental CG participants ($n = 23$) received circular-knit sleeves in compression Class 1 garments to wear every day after the post-operative period for a year; the control group was not given compression garments (NCG) ($n = 22$). After one year, the mean arm volume (mL) in the CG was lower (873.3 [1749.9 to 2130.6] than the NCG (2235.9 [2005.1 to 2335.2]) ($p < 0.000$) (Ochalek et al., 2018). The study continued to evaluate the effectiveness of compression garments on lymphedema for two years postoperatively (N=41) (Ochalek et al., 2019). The results revealed that there were statistically significant improvements in various QOL parameters (functioning, fatigue, pain, insomnia, future perspectives) in the CG group ($n = 20$) compared to the NCG ($n = 21$). At the end of observation, the CG (1959.5 mL [1751.6 to 2070.6]) showed significantly lower mean affected arm volume compared with NCG (2245.1 mL [1364.4 to 4631.6]) ($p = 0.023$).

Another RCT ($N = 66$) (Tantawy et al., 2019) compared the effects of Kinesio taping (KT) ($n = 33$) and the application of the pressure garment (PG, $n = 33$) on secondary lymphedema of the UE. KT was developed by Dr Kenzo Kase in 1973 (Tantawy et al., 2019). Tape that is thinner and more elastic by 120% to 140% compared with conventional tapes is applied to the skin. Taping serves a critical purpose in providing support during movement and preventing sports-related injuries. The sum of limb circumferences (177.5 ± 15.4 cm, 153.5 ± 9.24 cm), Shoulder Pain and Disability Index (SPADI) (75.8 ± 10.52, 48.4 ± 8.7), handgrip strength (4.27 ± 18.91, 27.7 ± 5.4), and QOL (64.4 ± 17.3, 73.28 ± 8.5) significantly improved after treatment in the KT group ($p < 0.05$). While the PG group showed no significant improvement in SPADI, handgrip strength, physical, role, pain, or fatigue scores ($p > 0.05$), the sum of limb circumferences significantly decreased ($p <0.05$). Significant differences in the sum of limb circumferences were observed between the KT (153.5 cm ± 9.24) and PG groups (163.4 cm ± 14.6) at the end of the intervention ($p < 0.05$).

Self-Management

In an RCT study conducted with 61 women with unilateral BCRL and a body mass index (BMI) ≤ 30, researchers aimed to evaluate the effect of lymphedema self-management in BCRL risk-reduction (Temur & Kapucu, 2019). The research team provided a training program for self-management activities to be performed three times a day (every day) for six months and gave participants a training booklet describing "exercise, massage, and prevention methods" in the experimental group (n =30) as part of the program (Temur & Kapucu, 2019). The difference between the intervention group and control group (n = 31) for the development of lymphedema was found to be statistically significant ($\chi 2$ = 25, 943; p = 0.000). The QOL reported by the intervention group was higher ($\chi 2$ = 43, 062) than that of the control group ($\chi 2$ = 38, 552).

Invasive interventions

Three invasive interventions in this review included interventions that required components of incision into the body, the removal of tissue, surgical procedure, vital sign monitoring, anesthesia, and/or hospitalization. These include liposuction (n = 1), Lymphatico-Venous Anastomosis (LVA) ($n = 2$), and Cervical Stellate Ganglion Block (CSGB) ($n = 1$).

Liposuction

Liposuction is a surgical procedure in which a 15-mm-long incision is made, and the hypertrophied fat is vacuum-aspirated as completely as possible from the body (Hoffner et al., 2017). A case-control study was conducted in which QOL measures were completed prior to liposuction and post-surgery (N = 60) at one-, three-, six-, and 12-months (Hoffner et al., 2017). The results illustrated that liposuction was associated with increased physical functioning (p =

0.001). The physical component score was higher at three months and thereafter, while the mental component score was improved at three and 12 months.

Lymphatico-Venous Anastomosis (LVA)

LVA is a procedure to restore lymphatic flow by anastomosing lymphatic channels to subcutaneous veins of 0.8 mm in diameter to bypass lymphatic damaged areas with minimally invasive surgery (Phillips et al., 2019). There were two one-group, pre-test and post-test research designs examining the efficacy of LVA in survivors with BCRL (Phillips et al., 2019; Winters et al., 2017) (*N* = 37; *N* = 29, respectively).

Phillips et al (2019) found a significant reduction in median excess limb volume post-operatively (6.6%-13.3%, $p < 0.005$), with volumetric improvement seen in 78% of patients (Phillips et al., 2019). Eighty-six percent of patients reported improved QOL postoperatively, with median Lymphedema Quality of Life Study (LYMQOL) scores increasing from 90 to 104 points ($p < 0.005$) (Phillips et al., 2019).

In the LVA study of by Winter et al (2017), the function of lymph vessels was tested pre-operatively using indocyanine green (ICG). Shunt patency was confirmed through ICG after surgery, which created 1–3 anastomoses. Arm volumes were measured before surgery and at 6- and 12-month follow-up. QOL was measured before surgery and at 6-month follow-up. Arm volume differences were measured between the affected and healthy arms. This study reported that the pre-operative mean difference in arm volumes was 701 ± 435 ml (36.9%). This was reduced to 496 ± 302 ml (24.7%) at 6-month follow-up ($p = 0.00$). At the 12-month follow-up, the mean difference in arm volume was 467 ± 303 ml (23.5%) ($p = 0.02$) (Winters et al., 2017).

Cervical Stellate Ganglion Block (SGB)

SGB is a therapeutic procedure in which a medication mixture is injected around the cervical sympathetic trunk. SGB has been utilized to treat a variety of medical issues, including breast cancer survivors' hot flashes, post-herpetic neuralgia, and complicated regional pain syndrome. An RCT conducted by Park et al. (2019) aimed to compare the effectiveness of cervical stellate ganglion block (SGB) ($n = 19$) and CDT ($n = 19$) in the treatment of BCRL ($N = 38$). Participants assigned in the CDT group underwent 10 sessions of CDT for 2 weeks, whereas the SGB group received 3 consecutive SGBs every two weeks. The baseline side-to-side circumference differences were 3.09 ± 1.97 cm at the upper arm and 3.88 ± 2.40 cm at the forearm. There were side-to-side circumference differences at the upper arm and forearm of 2.57 x 1.82 cm and 2.94 x 2.15 cm, respectively, after treatment ($p < 0.05$). The side-to-side differences of bioimpedance (i.e., calculated extracellular water (ECW)) was 0.204 ± 0.163 mL at baseline and 0.163 ± 0.129 mL at 2 weeks after treatment, showing a significant reduction ($p < 0.05$). There was no statistically significant difference between groups (Park et al., 2019).

Conclusion

This literature review provides updated information on interventions that may offer more intervention options for breast cancer survivors with lymphedema. Furthermore, the findings of this study can be used by nurses, and other healthcare professionals to better serve patients' needs and exchange knowledge. Nurses play a crucial role in serving patients’ needs and sharing knowledge (Armer et al., 2011). They can assist breast cancer survivors to deal with unpleasant complications during and after surgery by providing information about the common symptoms, complications, and interventions that can arise.

There is presently no cure for lymphedema. BCRL can be managed with risk-reduction behaviors, surveillance activities, early diagnosis, and care of the affected arm. The intention of this review was to update patients and health professionals on lymphedema interventions and health outcomes. Twenty-eight studies were reviewed, and the findings were summarized here.

Early-stage lymphedema (Stages 1 and 2) can be treated by non-invasive interventions (Temur & Kapucu, 2019; Yesil et al., 2017). Non-invasive interventions such as complete decongestive therapy (CDT), which includes the use of manual lymph drainage (MLD), daily compression bandaging and/or garments, skincare, and exercise, are a standard protocol for the management of lymphedema (Yesil et al., 2017).

The results of two studies comparing the effectiveness between CDT and CDT plus other interventions (relaxation and intermittent pneumatic compression, respectively) revealed that both groups had significantly improved physical well-being (Abbasi et al., 2018; Tastaban et al., 2020). However, thorough follow-up examinations, longitudinal follow-up, and cost evaluation are required in further research. During the maintenance stage, the long-term efficacy could not be proven, indicating that more research is needed. This further research would continue identifying the sensitive and specific measurements required to assess the outcomes, as well as show clinical conditions in which intermittent pneumatic compression would be permitted (Tastaban, 2020). This review identified a study evaluating the effect of lymphedema self-management on the reduced risk of BCRL and support of QOL among survivors with a BMI less than 30 (Temur & Kapucu, 2019). However, data are needed to examine the effectiveness of this program among women with a BMI greater than 30.

Once lymphedema has progressed to an advanced stage (Stages 3 and 4), surgical intervention may be recommended. Invasive interventions such as liposuction and LVA were provided for participants who suffered from lymphedema which was nonresponsive to non-invasive procedures and who were referred by their physician (Phillips et al., 2019; Winters et al., 2017). Even though LVA may be effective to improve physical well-being by reducing survivors' arm volume, this intervention was limited by its indication of when to perform, availability of expert resources such as experienced plastic surgeons, and insurance coverage. Moreover, this procedure was used to treat only more severe secondary lymphedema patients where traditional CDT had failed. Invasive lymphedema treatments remain expensive, generally require hospitalization, have a risk for surgical complications such as infection, and require a commitment to the post-op regimen and long-term follow-up, so it is critical to identify and begin non-invasive interventions early in lymphedema's emergence and progression.

It is critical to assess the therapies' strengths and limitations. Well-trained lymphedema therapists and other health professional specialists were necessary for non-invasive therapies such as CDT, MLD, reflexology, and traditional Chinese medicine procedures. Additionally, programs like yoga required yoga instructors who received special training in working with cancer survivors. Invasive procedures like LVA, on the other hand, necessitated the use of seasoned specialized surgeons, as well as the other specialized team members.

Self-management training is a program for reducing the risk for early-stage lymphedema and improving the quality of life in BCRL that nurses and other healthcare providers may implement. Nurses play a critical role in meeting the needs of patients and sharing information (Armer et al., 2011). Nurses can help patients reduce risk and improve management of lymphedema by providing information about risk-reducing practices, common symptoms, potential problems, and evidence-based therapies after breast cancer treatment. As a result, it is important for nurses to be attentive and aware of accurate and accessible resources to help lymphedema patients.

Limitations

The interventions summarized in this review have some limitations. The studies were conducted in multiple international settings (USA, Turkey, Saudi Arabia, UK, Iran, Korea, China, Japan, Germany, Sweden, Netherlands, Poland, and Egypt). These settings varied with regard to the operational definitions of lymphedema, used different intervention regimens, and generally lacked a power analysis. Additionally, inclusion criteria varied across studies with respect to specific, age-related interventions, as this review included a wide range of ages, from 18 to 85 years. Survivors with higher BMI, whom the literature suggests are at higher risk for BCRL development and who are commonly found among breast cancer survivors, have been excluded from some studies. These limitations possibly introduced threats to the internal validity of the studies. Collecting data from multiple settings may have affected the results in terms of the difficulty to control extraneous variables, such as operative technique and long-term follow-up. Also, a variation in operational definition potentially resulted in measurement bias, while different inclusion criteria may cause selection bias. In conclusion, the difference in detail of regimens may affect the results. These limitations should be taken into consideration in future larger, well-designed studies with precise operational definitions, more participants, and longer follow-up.

Implications for Cancer Survivors

Lymphedema following breast cancer treatment is a serious issue that nurses and other healthcare professionals must address. The findings of this review demonstrated that both non-invasive and invasive therapies may have value in helping breast cancer survivors with and at risk for lymphedema enhance their physical well-being. Previous research has shown that non-invasive and invasive therapies have the potential to reduce limb volume, particularly in BCRL, and enhance QOL. Non-invasive therapies can be utilized to treat lymphedema in its early stages; however, advanced-stage lymphedema may necessitate surgical intervention. Additionally, fewer studies have looked at aspects beyond limb volume, including physical well-being, depression, exhaustion, neuropathic pain, and return-to-work among survivors with BCRL. The phenomenon of BCRL is still under-studied in many countries where the environments of practice, availability of resources, and nursing roles can be quite different from those of other countries. Moreover, studies are needed to explore BCRL self-management, return-to-work, and QOL among breast cancer survivors with BCRL in many parts of the world, in order to design appropriate interventions to support physical well-being and QOL in these under-studied populations.

Lymphedema is an important complication after breast cancer surgery that nurses and healthcare providers need to address. Findings from this review show that the impact of both non-invasive and invasive interventions can improve physical well-being among breast cancer survivors with lymphedema. Previous studies demonstrated satisfying results of non-invasive and invasive interventions in reducing the volume of lymphedema, especially among BCRL. However, few studies have addressed the issues associated with lymphedema among younger women, such as physical well-being, depression, fatigue, and neuropathic pain. Therefore, it is important to consider age-related symptoms unique to younger and older women with lymphedema, as well as specific, age-related interventions to decrease the adverse physical experiences among breast cancer survivors with lymphedema. Hence, an interdisciplinary approach to address the issues of breast cancer-related lymphedema seems pragmatic.

In this chapter, we present preliminary research from a manuscript in progress that examines studies of BCRL interventions that have improved quality of life and physical health. In the next chapter, we describe the grounded theory research methods used to study Thai breast cancer survivors' perspectives on their employment and QOL as a result of BCRL, as well as the culturally influenced context facilitators and barriers that they encountered after returning to work.

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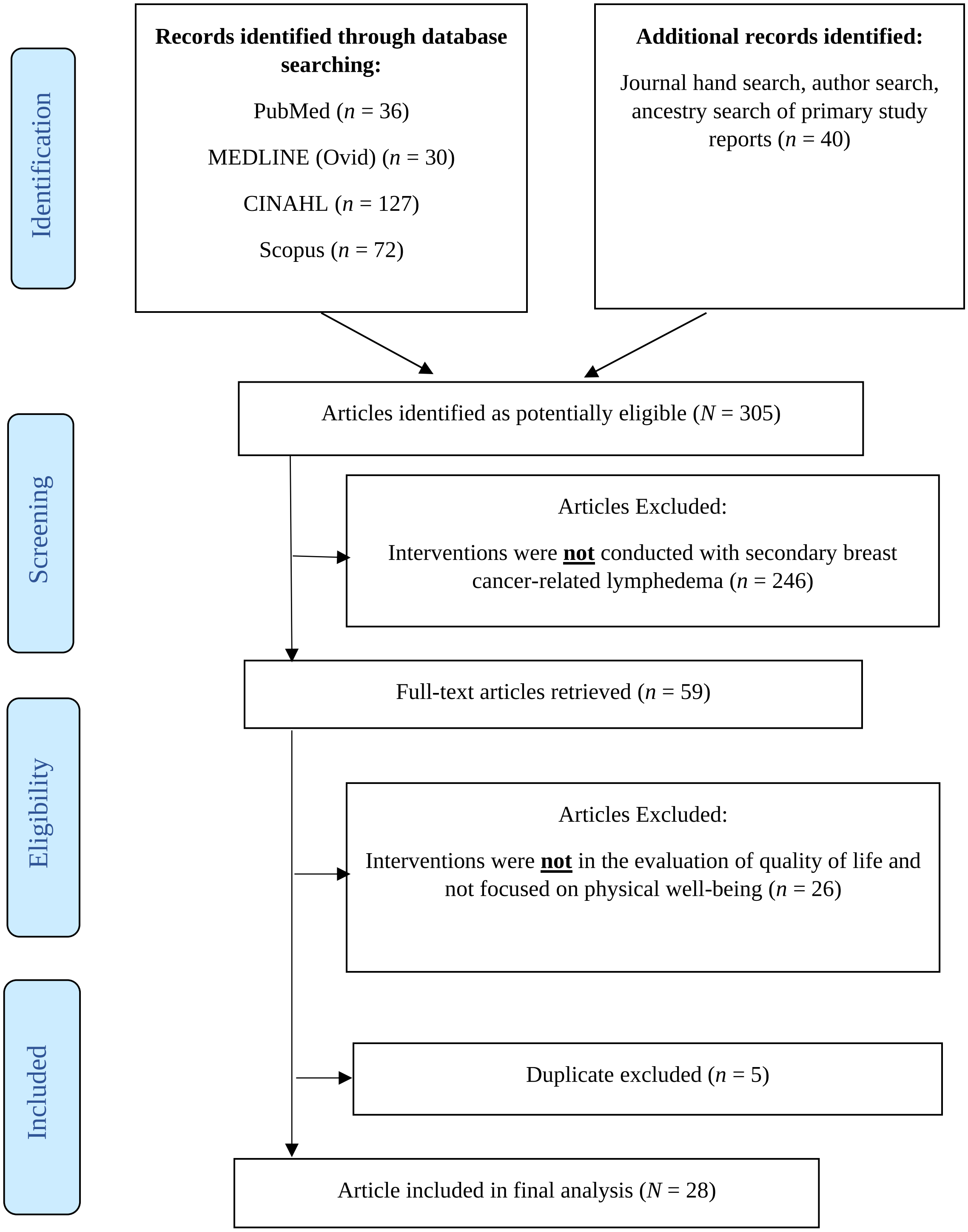
Figure 3.1

Literature Flow Diagram



CHAPTER FOUR

METHODS

Introduction

Chapter 4 describes the research study methods used to explore breast cancer-related lymphedema (BCRL) self-management and return-to-work among Thai breast cancer survivors with BCRL. A grounded theory approach was used to explore the experience of return-to-work of Thai women with BCRL by using semi-structured interviews with individual participants in the community setting.

Purpose

The main goal of this research was to examine Thai breast cancer survivors' perspectives on how BCRL affects their employment and related quality of life (QOL), as well as the culturally-influenced contextual facilitators and barriers that they faced as they returned to work in Thailand. Work engagement, work choice, workplace, function and role changes, and psychosocial consequences were all identified as possible influences of adaptation by breast cancer survivors with BCRL as they returned to or changed their work. Individual and community cultural attitudes should be considered in the study of return-to-work, according to the literature (Sun et al., 2021; Sun et al., 2017). The reviewed literature did not generate studies of return-to-work among Thai survivors with BCRL. Therefore, this study was to address this gap by: (1) investigating survivors’ perspectives regarding how BCRL influenced their QOL and return to work; and (2) examining the contextual facilitators and barriers as survivors returned to work in Thailand.

Specific Aim and Research Questions

Accordingly, the specific aim of the study was to explore the impact of BCRL on work and QOL for Thai survivors. Awareness of cultural influences on health behavior and work-related choices was incorporated into the study design. These explanations included aspects of culture, gender roles, work ethics and expectations, social structures and systems, and cultural narratives of cancer. This qualitative research was generated after noting the gaps in the existing literature, and so led to the exploration of survivors' individual experiences with BCRL when they returned to work. In this study, a grounded theory approach was used to explore the return-to-work experience of Thai women with BCRL by using semi-structured interviews with each participant. Grounded theory is a research method concerned with the generation of theory (Glasser & Strauss, 1967), a method that is grounded in data that have been systematically collected and analyzed (Strauss & Corbin, 1994).

The research questions (RQ) supported the study's specific aim by exploring the concepts of change, impact, and interchange between and among work, QOL, BCRL, and its self-management among Thai survivors:

RQ 1a): What are the issues and concerns for survivors with BCRL in Thailand when they return to work?

RQ 1b): What are barriers and facilitators among survivors with BCRL in Thailand when they return to work?

RQ 2a): How does BCRL impact work?

RQ 2b): How does BCRL impact work-related QOL?

RQ 3a): How does BCRL self-management impact work?

RQ 3b): How does work impact BCRL self-management?

RQ 4): How does the culture in Thailand impact survivors with BCRL when they return to work?

Study Design and Method Overview

Grounded Theory

Social scientists have used grounded theory broadly in qualitative research for many years. An inductively-derived theory was developed by employing systematic methodologies to examine the selected phenomenon of return-to-work with BCRL using a grounded theory approach (Strauss & Corbin, 1990). In examining women's health phenomena, a grounded theory approach is useful because it challenges the reductionist approach and emphasizes understanding women's experiences within the context of social relationships (Health Care for Women International, 2001). Using a reductionist approach, the researcher can extract from a wide variety of models, theories, and explanations what is essential for understanding information and its dynamics. A fundamental part of grounded theory is the tradition of symbolic interactionist interpretation (Glaser & Strauss, 1967) in which individuals react to their environment according to the subjective meanings they assign, meanings created and modified by social interaction involving symbolic communication between them (Del Casino & Thien, 2009). Grounded theory's purpose is to build theories regarding dominating social processes by offering theoretically thorough explanations of phenomena (Sherman et al., 2012). “In grounded theory, systematic analysis of the data is a rigorous technique that offers qualitative researchers a set of clear guidelines from which to build explanatory frameworks that specify relationships among concepts” (Charmaz, 2006, p. 510). Grounded theory attempts to discover or create a theory from data that have been collected in a systematic and comparative approach. The key techniques that inform and guide analysis and aid in theorizing include asking questions and making comparisons (Sherman et al., 2012). These precise grounded theory techniques were applied in this study for the generation of theory about return-to-work by breast cancer survivors with BCRL in Thailand.

The inductive process of grounded theory data analysis begins soon after the first piece of data is gathered and continues until all the data have been collected (Corbin & Strauss, 1990). As an inductive approach, grounded theory aims to generate new theory from data (Glaser, 1978; Glaser & Strauss, 1967). Research questions typically focus on the area of a study in an inductive approach. Inductive approaches are frequently focused on discovering new phenomena or looking at already-explored phenomena from a different perspective, as compared to deductive approaches which are usually focused on causality. The need to learn more about the dimensions and links in women's experiences with respect to what was entailed and what breast cancer participants faced when returning to work with a chronic complication such as BCRL was the primary motivation for employing this method. The method looks for which claims are true for a specific individual in a specific situation (e.g., return to work with BCRL), and statements are based on the person's perceptions and meanings (Glaser & Strauss, 1967). Thus, inductive approaches were appropriately applied in this study.

Grounded theory was utilized for this study because it allowed the researcher to analyze a wide range of human experiences in the context of their social environment (Strauss, 1993), in this case, return-to-work for survivors with BCRL. The purpose of grounded theory was to find connections between social events (such as returning to work) and examine how people's perceptions of situations affect outcomes. According to Henwood and Pidgeon (1995), the theory is used to analyze and make meaning of qualitative material that is initially unstructured. Grounded theory corresponds to the concept of theoretical building in experiences. It is an open-ended, flexible strategy that allows the researcher to investigate facts and ideas as they arise (Henwood & Pidgeon, 1995).

Sample

Setting

Thailand, the study's setting, is a Southeast Asian country with a population of roughly 64 million people located in the Indochina Peninsula. Thailand is divided into four main regions: Northern, Northeastern, Central, and Southern Thailand. Participants were selected from the community and private breast cancer groups on Facebook, rather than from clinics or hospitals, and resided in the four regions. All participants were recruited through announcements in breast cancer support groups, flyers, emails, social media, and in-person invitations. A community recruiting strategy has several advantages, including increased community relevance to the research issue, study strength within a cultural and local context, effective dissemination of findings to benefit public health and policy, and increased research trust (Narcisso et al., 2013).

Sampling

Purposeful sampling and snowball sampling were employed in the study. The idea behind purposeful sampling is that a researcher can use their knowledge of the population to select cases for inclusion in the sample (Polit & Hungler, 2001). When the research population focused on specific diagnoses, such as breast cancer survivors with lymphedema, purposeful sampling is employed. Most qualitative research aims to discover meaning and reveal multiple realities. Therefore, purposeful sampling was considered appropriate, as it allowed the selection of survivors with BCRL who indicated that they could provide their experiences about their return to work.

Sample Inclusion/Exclusion Criteria

Participants meeting the inclusion criteria were recruited: (1) breast cancer survivors aged 18 or older; (2) who were more than 12 months post-surgery and -radiation treatment; (3) subsequently diagnosed with treatment-related lymphedema; (4) employed or self-employed at the time of developing lymphedema; (5) fluent in both oral and written Thai language; and (6) able to consent to participate in the study.

Exclusion criteria for this study included the following: (1) diagnosis of lymphedema prior to breast cancer diagnosis; (2) in metastatic and advanced-stage cancer; or (3) extremity swelling caused by a primary tumor or tumor recurrence or metastases.

The incidence of male breast cancer in Thailand is low (males: 0.16 per 100,000 man-years versus females:18.0 per 100,000 woman-years) (Ly et al., 2013). Since the experience of breast cancer in males may differ from that of females (Ly et al., 2013), only female breast cancer survivors were recruited for this study. However, male survivors may be recruited and studied in a future study. Thus, in this study, and in keeping with standards for qualitative research, 13 Thai survivors with BCRL who returned to work were recruited for the study, with recruitment continuing until theoretical saturation was reached.

Data Collection

Recruitment and data collection commenced after the principal investigator obtained Institutional Review Board approval for research with human subjects from the University of Missouri. After potential participants were informed about the study, screened for eligibility, and consent (Appendix A) was obtained, data were collected through recorded semi-structured Zoom interviews and audio calls using the LINE application, a freeware app for instant communications on electronic devices such as smartphones, tablet computers, and personal computers. The researcher scheduled and conducted Zoom and audio call interviews at days and times convenient for the participants. Interviews lasted from 60-80 minutes. Even when the interviews were conducted by Zoom, the PI recorded only the voice from each interview on digital recorders; participants were allowed to turn their cameras on or off during the interview, based on their preferences.

There were three main steps of the screening, consent, and interview protocol. In part one, the PI introduced herself, provided information on the title and purpose of this study, screened for eligibility, affirmed consent to participate; and stated the date of the scheduled interview. In part two, the PI conducted a gentle introduction to the interview with questions about the kind of work participants had done and then continued the interview with sociodemographic data such as, birthdate, religion, marital status, education, occupation, income range, level of physical activity, previous medical history, including co-morbidities, and symptoms of BCRL (Appendix B). In part three, the PI carried out the interview using the semi-structured interview guide (Appendix C) to meet the study aim and answer the research questions. In the interview guide, questions referred to BCRL, related return-to-work experiences, and issues related to a change in employability to explore the impact of BCRL and its self-management on participants' work, career, and QOL. “How does lymphedema restrict your ability to work?”; “How do you think the changes caused by lymphedema affect your ability to meet work demands?”; and “How does lymphedema affect your work time?” are examples of questions that were asked. Data were collected through personal, semi-structured interviews as a conversation, using the techniques described by Glaser and Strauss (1967). Recruitment was continued and data were collected until theoretical saturation was reached, meaning there were no more (new) data that the PI might use to develop the category's features.

When the PI saw comparable situations repeated again, she was convinced that a category was saturated. When one category had been saturated, the PI moved on to new participants in search of data on other categories, in an attempt to saturate these categories, as well (Glaser & Strauss, 1967).

Glaser (1978) recommended the researcher write up the field notes immediately after the interview as an aid in coding and analyzing the data. The PI followed this approach and wrote up the field notes in the Thai language immediately after the interview. Since the interviews were conducted and recorded in the Thai language, transcription, translation, and back-translation were completed within three weeks after the interview. The PI performed the transcription. The PI worked with a professional nurse translator who is a linguist for translation and back-translation. The PI translated the transcription to the English language and asked the professional nurse linguist to perform a literal back-translation of this content to the Thai language. The PI compared the back-translation to the original text to make sure the back-translation was accurate and complete.

Data and Safety Monitoring Plan (DSMP)

The DSMP outlined below for this project was followed according to the protocol approved by the University of Missouri Institutional Review Board (IRB). The PI and her supervisor took responsibility for continuous monitoring of the research study, including maintaining the integrity and quality of the data and identification of unexpected and adverse events.

The PI employed Microsoft Excel software to build a potential participant database for contacting participants and tracking due dates for data collection reminders and appointments. This database was administered by the PI and stored in the password-protected MU Teams "cloud-based" platform. The Excel file linking name and contact information for participants was stored behind the password-protection of the folder and accessible only to the PI and her advisor. All voice records were transferred to IRB-approved secure cloud storage. Moreover, to ensure confidentiality, the PI herself transcribed all voice recordings. To further ensure privacy, participants were asked to choose a pseudonym. Only the pseudonym was used on the audio-recordings and transcripts.

Anti-virus software is run on all University computers continuously to detect incoming viruses. Updates of virus-scanning software are obtained weekly via an Internet connection. Firewall protection is in place to protect against file theft while accessing the Internet. These procedures have been reviewed by MU Information Technology Security using HIPAA standards and are highly effective in protecting against hacking, as well as coincidental data disclosure.

Data Analysis

From the beginning of data collection to the final analysis, data were regularly evaluated for meaning, common patterns, and emergent concepts. Patterns that appeared during the interview process were recorded in the interview guide and field notes. To determine descriptive categories, each word and sentence in the text was examined. Significant phenomena were labeled, and the code was recorded in the margin next to the relevant information.

In the process of coding, the researcher employed microanalysis of data (Corbin & Strauss, 1990) by breaking down the data line-by-line. Open and axial coding is a part of microanalysis, both of which include interpretation of the data by the researcher. In grounded theory, open coding is frequently used as the initial coding way to analyze qualitative data. Coding into concepts can be done by grouping codes based upon characteristics and outcomes that are similar, as well as comparing them. After completing the initial coding chart and using paper and pen, the researcher moved on to the next step of building a new coding chart. A new chart was built by naming the concepts that were noticeable first and adding codes to them. Once all codes had been placed within a concept, the researcher began comparing initial codes to concept names again. After the second chart was created, the researcher reviewed it with the supervisor (Corbin & Strauss, 1990). A descriptive code was developed that labeled the meaning of an issue and idea by describing all possible aspects of the issues and ideas in the data. When a selective coding approach was used, a core category was identified and then linked to others (Charmaz, 2000).

Axial coding is the process of connecting categories to subcategories around their properties and dimensions (Corbin & Strauss, 1998). Putting the pieces back together is a metaphor for the process, as data have been divided into many meaning units during the first phase of open coding. It is important to understand that axial and open coding occur concurrently, not serially. The phenomenon under investigation, in this case, return-to-work by Thai survivors with BCRL, was explained or represented by categories. Subcategories provide explanations for defining questions like *who, where, why,* and *how* (Corbin & Strauss, 1998). By using the metaphor described above, the properties and dimensions of the categories make up the interlocking puzzle pieces. Merriam (2009) described the process as clustering the data units that seemed to go together and then naming the cluster that became the category.

The last step was naming the abstract categories and considering subcategories, properties, and dimensions (Corbin & Strauss, 1990). To complete this step, the research questions were investigated as a frame of reference for the coding process (Corbin & Strauss, 1998). In order to make analytical decisions regarding which codes best described portions of collected data, the researcher compared the data across broader ranges of data grouped by initial coding. In accordance with a constant comparative method, this process was iterative, with the reduction of data occurring as more inclusive categories emerged that conceptualized and theoretically represented the data. To code the data, specific instructions included defining the actions that underpin the properties, searching for tacit assumptions, explaining implicit meanings and actions, identifying the significance of conceptual categories that emerged in the data, comparing data with data to identify relationships among concepts, and identifying gaps in the data (Charmaz, 2008). Through focused coding, the 36 initial codes were reduced to 19 distinct categories of the experience of Thai women with BCRL returning to work.

In the process of theoretical analysis and memo-writing, the researcher developed categories based on the data that emerged. To ensure a logical foundation for organizing the analysis and creating and refining links between the data, the memo-sorting process was iterative, consistent with a constant comparative analysis method. According to Stern (2007), sorting's primary goal is to create labels that serve as rubrics for all known categories. The researcher sorted memos by category title and then compared categories carefully. Memos were organized and reorganized during this process. The researcher investigated how the categorization of the categories reflected the experiences that the study participants had revealed (Charmaz, 2006). The researcher determined whether memos had been filed correctly or if they had been misfiled and should have been assigned to a different category using a comparison method (Stern, 2007) Analytical sorting was used because new inquiries required additional data gathering, analysis, or memo drafting. In order to build an outline for incorporating and reporting the grounded theory found in the research study, the researcher used the sorting technique to create a coherent picture of the data collected from study participants on their experiences of returning to work (Charmaz, 2006).

Quality Standards

Rigor in qualitative research is defined as trustworthiness; it is establishing trust and confidence in the conclusions of a study (Thomas & Magilvy, 2011; Letts et al., 2007). In their model of qualitative research *trustworthiness*, Lincoln and Guba (1985) were the first to emphasize *rigor* (Thomas & Magilvy, 2011). The four components of trustworthiness are *credibility, confirmability, dependability*, and *transferability*. These principles are further illuminated here.

Credibility

Credibility refers to the use of reliable explanations or viewpoints on human events so that people can recognize their own experiences in explanations or after hearing about them from others (Sandelowski, 1986). To gain *credibility*, the researcher had the participant guide the research process, collating the generated theoretical composition with the interpretation of the participant's phenomenon, and using the literal words of the participant herself in the theory.

Triangulation is a method that uses several methods to explain and understand a phenomenon, so it can provide more valid interpretations (Patton, 1999). Data triangulation refers to the utilization of a wide range of data, such as time, place, and people (Denzin, 2009). The researcher used *triangulation* to establish *credibility*, as well as member checks. Data triangulation was used in this study through the inclusion of sociodemographic and interview data, field notes, and journaling, in the context of cultural observations, national cancer databases, and reviewed literature. Findings may be verified, and any weaknesses in the data can be compensated for by the strengths of other data, improving the conclusions' validity and reliability. The method has been applied in a variety of settings to enhance findings’ conclusions and reduce the possibility of erroneous interpretations (Denzin, 2009).

Member checks refer to data or results which are returned to participants to check for accuracy and resonance with their experiences; this process was applied in this study to further support *credibility*. After the interview, as analysis took place, participants were followed up to verify data interpretation. Moreover, discrepancies in translation and back-translation were reviewed and reconciled by the researcher and linguist while referring to the audiotape.

Confirmability

Confirmability is the extent to which the findings may be verified or supported by other sources. Confirmability was addressed by verifying that the findings were shaped by participants more so than they were shaped by a qualitative researcher. The researcher's supervisor reviewed all the coded data. Furthermore, the researcher had frequent meetings via zoom and email communication with the supervisor during the data analysis to examine notes, memos, transcripts, and the analytic process, as well as any concerns that arose. Peer review, such as requesting her supervisor to audit the decision points throughout the process and discussing ideas and data interpretation with her supervisor, assisted to reduce bias in the study (Letts et al., 2007).

Moreover, the researcher provided an *audit trail* and *reflexivity*. An *audit trail* describes the steps taken from the start of a research project to the presentation and reporting of findings. An investigation record documented what was done during the investigation (Lincoln & Guba, 1985). *Reflexibility* involves critical reflection about self (biases, preferences, preconceptions), the research relationship (relationship to the respondent), and how the relationship affected participants' answers to the questions (Korstjens & Moser, 2018). The researcher recorded field notes, carried out journaling immediately following each interview, and reflected on these and the updated audit trail, as data were collected and analyzed.

Dependability

The consistency of the data and the findings are referred to as *dependability.* The *audit trail* is a record of the decisions taken during the research process (Letts et al., 2007). The researcher provided a detailed explanation of the research process, including data collection methods, analysis, and interpretation, frequently with evidence of an audit trail or peer review. The researcher completed a code-recode procedure to improve *dependability* in this study. After coding a section of data, the researcher waited at least two weeks and then returned and recoded the same data and evaluated the results.

Transferability

When the findings of this study are *transferable* in the sense that they may fit into various contexts as defined by readers, or when readers find the report's significance relevant to their own experiences, this is referred to as *transferability* (Crooks, 2001). Transferability was enhanced by doing a thorough job of describing the research context and the assumptions that were central to the research. For example, breast cancer survivors with BCRL and partners, providers or co-workers of this population may find the results of this study similar to their experiences, even if they are from different settings or even have different cancers leading to upper extremity UE and lower extremity (LE) lymphedema. Moreover, for checking *rigor* in this investigation, the researcher also included Glaser's (1978) criteria: *fit, workability, relevance,* and *modifiability*. These principles are reviewed next.

Fittingness

Fittingness is defined as when study findings are valuable and useful to readers from their own experiences; also, when the findings are reflective of the events in life under investigation, this is referred to as *fittingness* (Sandelowski, 1986). *Fittingness* can also be achieved by explaining how the literature relates to each of the theory's categories, as well as determining the study's scope in terms of sample size, setting, and level of theory created (Chiovitti & Piran, 2003). For instance, the researcher used *fitting* concepts during the process of data analysis. For example, with the researcher's supervisor overseeing all the processes of data analysis, the researcher assessed the *fit* of one concept to another. By identifying the dominant concept, the researcher established the basis on which the second concept could be categorized. Dominant and secondary concepts were examined as recognized components or characteristics by the researcher, and once a common component was identified, it indicated where the two concepts merge (Morse & Singleton, 2001).

Workability

Theories are supposed to offer forecasts, explanations, and interpretations of what happened in the area of inquiry (Lomborg & Kirkevold, 2003). When the researcher had checked the *work* of the theory to explain relevant behavior in the substantive domain of the study, *workability* was assessed (Charmaz & Thornberg, 2021). The researcher utilized the findings of this study to develop a theory to explain and understand the behavior of breast cancer survivors with lymphedema, as well as forecast future behavior when they return to work.

Relevance

Relevance refers to the effectiveness of theories in the field they were intended to describe, with an emphasis on the basic problems and processes that occurred in that field (Lomborg & Kirkevold, 2003). This study had *relevance*, as the researcher detected how the findings of the study relate to the population in the substantive field, by comparing the findings with Thai survivors with BCRL returning to work with those of other cultural groups.

Modifiability

According to Glaser (1978), the *modifiability* of a grounded theory can change as new data emerge, resulting in qualification or extension of the theory. *Modifiability* is met when a theory can be modified as new data are received. A substantive grounded theory can only be considered "closed in part" because new ideas and evidence can change the theory. As a result, *modifiability* is a never-ending process, and grounded theory has potential for improvement (Giske & Artinian, 2007). The return-to-work findings with Thai breast cancer survivors with BCRL in this study can be modified with new data; as a result, the findings of this study (and future studies) have the potential to improve the theory.

Ethical and Human Subjects Considerations

Ethical considerations must be included in any part of a study. This study employed the three principles of *respect for persons, beneficence, and justice* which are based on the Belmont Report (Department of Health, Education, and Welfare, & National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 2014).

In most cases of research involving human subjects, *respect for persons* demands that subjects enter into the research voluntarily and with adequate information. *Informed consent* was employed in this study to demonstrate respect for persons. This study was conducted after obtaining approval from the University of Missouri Institutional Review Board. The participants conveyed their agreement to participate in the study with verbal consent. The researcher provided contact information, including a telephone number and email address, for future reference.

Beneficence in this study was achieved as the persons were treated in an ethical manner, not only by respecting their decisions, but also by protecting them from harm. Moreover, the researcher drew on her previous experience from the pilot study and as a nurse to minimize possible harm in this qualitative study.

To reach *justice*, Thai breast cancer survivors in any part of Thailand were recruited in this study through broad community-based and social media recruitment strategies, as mentioned earlier in the sample selection. All participant information was maintained confidentially.

University of Missouri Institutional Review Board (IRB) approval is required to maintain participant rights within the research. Only after gaining IRB approval, the researcher recruited and consented participants and gathered data. Prior to consenting, participants had the opportunity to ask questions and raise any concerns they may have had about the research. They were notified of the protections in place to protect data confidentiality, as well as their ability to terminate the interview at any time (Appendix A).

Informed consent included contact phone numbers and email addresses for the IRB and the researcher (Natsayakarn Narkthong). The PI took responsibility for the *informed consent* process. The consent was obtained verbally via Zoom or Lines on the day of the interview appointment following an informational script. The script included the following: the purpose of the study, estimated time for completing study instruments and interview, duration of participation, number of anticipated participants for enrollment, researcher contact name/number/email for questions, and participants’ rights. This consent was read to each participant. The language of the consent was Thai and the consent approved by the IRB was previously translated and back-translated by the nurse linguist and researcher to assure the accuracy of meaning.

This qualitative study met the criteria for no more than minimal risk of harm to the participants and included no procedures for which written consent is normally required outside of a research context. Therefore, with this IRB application, the researcher requested a *waiver of written consent*, as a signed informed consent document would be the only record linking the participants’ identity to the research. Using a waiver of written consent reduced the risk of potential harm in the event of a confidentiality or data breach. Instead, the researcher documented that participant consent was obtained using a form created for this specific purpose.

Participant interviews were scheduled only after participants consented to participate. Project approval was obtained from University of Missouri Institutional Review Board prior to the beginning of the information and consent process in order to assure the protection of participants’ rights within this study. Due to the nature of qualitative research, including interviews and observation, participants may experience potential minimal risks associated with interactions, such as misinterpretation and differences in viewpoints and values (Vivar, 2005). To limit this risk, the researcher drew on her previous experience from the pilot study and her nursing experience, as well as her abilities such as good listening skills, strong interpersonal instincts, the capacity to understand and describe both big and small thoughts, and the ability to communicate the interview and study findings (Minichiello & Kottler, 2022).

Conclusion

This chapter described the rationale for using grounded theory research to explore survivors' individual experiences with BCRL, BCRL self-management, and facilitators and barriers when they return to work. Specific aim and research questions, study design and methodology overview, sample selection including setting, sampling, and sample inclusion/exclusion criteria, data collection, data and safety monitoring plan, data analysis, quality standards, ethical principles, and human subjects consideration in qualitative research have been identified and discussed. The next chapter provides the findings based on the preliminary work: The Experiences of Thai Women at Work with Breast Cancer-Related Lymphedema (BCRL): A Pilot Study.

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CHAPTER FIVE

THE EXPERINCES OF THAI WOMEN AT WORK WITH BREAST CANCER-RELATED LYMPHEDEMA

A PILOT STUDY

Abstract (350 words max)

Title: A Pilot Study: The Experiences of Thai Women at Work with Breast Cancer-related Lymphedema (BCRL)

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Purpose: This qualitative pilot study aimed to examine the work-related experiences of individual Thai women with breast cancer-related lymphedema (BCRL). Findings will inform survivorship care-planning related to survivors' return-to-work by health care providers.

Background and Significance: Breast cancer is the most common cancer among Thai women. Breast cancer survivors are at a lifetime risk for lymphedema, a protein-rich fluid accumulation in the affected areas. Lymphedema may be associated with functional, psychosocial, and physical sequalae impacting quality of life during years of survivorship.

Methods: A grounded theory approach was selected to uncover a process inherent to a substantive field of inquiry by formulating an explanation that explains the phenomenon. Following informed consent procedures, two Thai breast cancer survivors with BCRL (ages 37-38) were recruited. These participants were more than 12 months post-cancer treatment, diagnosed with lymphedema, and employed or self-employed at the time of developing lymphedema. Data collection was comprised of semi-structured interviews conducted by Zoom, with assessments of work demographics, lymphedema-related changes, interpersonal changes at work, environmental characteristics, and final reflections on thoughts regarding the future and enduring aspects of BCRL.

Results: Three themes emerged from the data. The first theme was "issues and concerns." Illustrating concepts included: career requirements, workplace conditions, transferability of work skills, societal expectations of survivors, and work alternatives. The second theme was "BCRL experiences of work facilitators." Illustrating concepts included: (1) internal facilitators: existential issues, self-esteem, gratitude, and resilience; and (2) external facilitators: resources, time, and BCRL knowledge. The third theme was "BCRL experiences of work-related barriers." Illustrating concepts included: (1) internal barriers: physical limitations, and unpleasant feelings at work; and (2) external barriers: limited resources. The BCRL impact was cyclical and enduring in nature.

Discussion and Implications: These research findings can help those in the BCRL community (patients, family members, and clinicians) better understand the impact of this condition on work-related experiences. In order to optimize work adaptation and quality of life for Thai breast cancer survivors with BCRL, further research is important.

Introduction

As of 2020, breast cancer had been diagnosed in 7.8 million women within the prior 5 years, making it the most common cancer in the world (World Health Organization, 2021). Breast cancer causes more disability-adjusted life years (DALYs) in women than any other type of cancer (World Health Organization, 2021). In 2023, an estimated 297,790 women will be diagnosed with breast cancer in the U.S, making it the most common cancer in American women (American Cancer Society, 2022). Breast cancer affects women of all ages in every country in the world, with rates rising as women get older. According to the World Health Organization, in 2020, there were 22,158 new cases of breast cancer in Thailand and 76,440 cases at five-year prevalence (World Health Organization, 2021). Lymphedema is one of the most troublesome complications that can result from breast cancer treatment. Although current changes in breast cancer treatment (such as more conservative breast cancer surgery and minimally invasive surgical techniques associated with early diagnosis) have decreased the risk of breast cancer-related lymphedema (BCRL), BCRL remains a major issue for women with breast cancer. At 60 months after treatment, LE incidence varied from 43% to 94%, with 2 cm circumferential change at any measured anatomic region being related with the highest probability for lymphedema onset and signs and symptoms being the lowest (Armer & Stewart, 2015).

There are numerous ways BCRL can affect a woman’s day-to-day living, from physical discomfort to psychological issues like low self-esteem or depression (Deborah, 2019; Whatley et al., 2016). A survivor's combination of physical and psychological impairments could negatively affect their social lives, leading to isolation due to guilt or shame (Acebedo et al., 2019; Cal & Bahar, 2016; Deborah, 2019). Studies have illustrated that lymphedema leads to significant depletion of quality of life, specifically in patients suffering from lymphedema after breast cancer treatment (Taghian et al., 2014). The combination of physical and psychological impairments ultimately has an impact on the patient's social life, as it may result in isolation out of fear or shame (McWayne & Heiney, 2005), whether perceived or self-induced. As cancer survivors, they are already particularly vulnerable to this, as they can face many challenges in returning to their normal lives and work after primary treatment.

Both BCRL and its treatment have direct and indirect effects on work, with environmental and personal factors further shaping the return-to-work experience (Sun et al., 2021). Even though there are recognized potential connections between lymphedema and negative work outcomes, there is almost no published research that investigates the precise reasons for the association (Sun et al., 2021) and there have been scanty qualitative studies that have reviewed lymphedema patients' lives through their individual experiences, perspectives, challenges, and barriers (Cal & Bahar, 2016).

Without knowing how lymphedema influences work experience, healthcare providers cannot provide effective rehabilitation services to breast cancer survivors who need help with restoring and retaining occupational life. Previous studies of lymphedema have been conducted in the USA and other countries within the Western world. However, the phenomenon is understudied in non-Western countries, where the environments of practice, availability of resources, and nursing roles (especially nursing interventions) can be quite different from those of the West. This qualitative research is generated after noting the gap in previous studies, and so leads to this exploration of Thai patients' individual experiences with BCRL when they return to work. In this pilot study, a grounded theory approach is used to explore the return-to-work experience of Thai women with BCRL by using semi-structured interviews with each participant. This qualitative research is guided by the following research questions: 1) What are the primary issues and concerns for patients with breast cancer-related lymphedema when they return to work in Thailand? 2) What are the barriers and facilitators among patients with breast cancer-related lymphedema when they return to work in Thailand? This initial pilot study was a key step in planning and modifying the main study as part of the full research process (In, 2017).

Method

Design

This study applied grounded theory methodology because this approach allows the researcher to examine a wide range of human experiences in light of their social environment (Strauss, 1993). Using grounded theory, the researcher can examine how peoples' perceptions of situations affect outcomes and search for connections between social events (Foley & Timonen, 2015). This approach is used to make sense of qualitative data that is initially unstructured, according to Henwood and Pidgeon (1995). In other words, it represents theoretical grounding based on experience. A researcher can explore facts and ideas based on an open-ended, flexible approach.

Setting

Participants were chosen from the community, rather than from clinics or hospitals. A community recruiting strategy has several advantages, including increased community relevance to the research issue, study strength within a cultural and local context, effective dissemination of findings to benefit public health and policy, and increased research trust (Narcisso et al., 2013). Participants were recruited through announcements in breast cancer support groups and snowball sampling in Thailand.

Sampling and Participants

Purposeful sampling was employed in the study. Purposeful sampling was founded on the idea that a researcher's knowledge of the population can be used to select cases for inclusion in the sample (Polit & Hungler, 2001). When the focus of the research population pertains to a certain diagnosis, purposeful sampling is employed in the gathering of descriptive data and is viewed as a good way to investigate the participant's (patient’s) perception, also known as the lived experience of a particular phenomenon (Palinkas et al., 2015).

In this pilot study, two Thai women were recruited for participation in the study. Participants met eligibility criteria, as they: (1) were > 18 years of age; (2) were more than 12 months post-surgery and radiation treatment; (3) were subsequently diagnosed with lymphedema; (4) were employed or self-employed at the time of developing lymphedema; (5) were fluent in both verbal and written Thai language; and (6) volunteered to participate in the study.

Exclusion criteria included the following criteria: (1) were < 18 years of age; (2) were diagnosed with metastatic and advanced-stage cancer; or (3) had causes of extremity swelling such as tumor recurrence or metastases.

Data Collection

Data collection began after the principal investigator (first author) obtained Institutional Review Board (IRB) approval from the University of Missouri. After consent was obtained, data were collected through semi-structured interviews conducted by Zoom. The first author conducted the interviews at a time convenient for the participants, with interviews lasting for 45-60 minutes. There were three main parts of the interview protocol. Part one: the interviewer introduced herself and provided information about the purpose and title of the study, and nature of the interview. Part two: Sociodemographic and medical history data of the participant, including age, marital status, occupation, income, education, smoking habit, and level of activity, and previous medical records including breast cancer surgery date and type, number of chemotherapy cycles (if any), radiotherapy sessions (if any), use of tamoxifen or hormonal therapy (if any), and pain were recorded by the interviewer. Part three: the interviewer provided IRB-approved guiding questions to reach the aim of this study.

Data were collected by the personal, semi-structured interview as a conversation using the technique described by Glaser and Strauss (1967). All questions referred to breast cancer-related lymphedema and related return-to-work experiences to explore the impact of breast cancer-related lymphedema on women's work and career.

All interviews were based on a semi-structured interview guide to give structure to the conversation. Questions focused on work demographics, lymphedema-related changes, interpersonal changes at work, environmental characteristics, and final reflections on the thoughts regarding the future and enduring nature of breast cancer-related lymphedema. Glaser (1978) recommends writing up the field notes shortly after the interview as it allows the researcher to code and analyze the data immediately. The researcher followed this approach and wrote up the field notes immediately after the interview. Since the interviews were conducted in the Thai language by the first author, who speaks Thai as her native language, back-translation was utilized before starting the analytic process.

Data and Safety Monitoring Plan (DSMP)

The DSMP outlined below for this project was adhered to for the protocol approved by the University of Missouri Institutional Review Board (IRB). The research team took responsibility for continuous monitoring of the research study, including maintaining the integrity and quality of the data and identification of unexpected and adverse events. Moreover, to ensure confidentiality, all audiotapes were transcribed by the researcher and, to ensure privacy, participants were asked to choose a pseudonym.

Data Analysis

Grounded theory data analysis is an inductive process that begins soon after the first piece of data is gathered and continues until all data have been collected (Corbin & Strauss, 1990). The major steps of grounded theory, as established by Strauss and Corbin (1990), were used to analyze the data. From the beginning of data collection to the final draft, data were regularly evaluated for meaning, common patterns, and emergent concepts. Patterns that appeared during the interview process were recorded in the interview guide. To determine descriptive categories, each word and sentence in the text was examined. Significant phenomena were labeled, and the code was recorded in the margin next to the relevant information.

In the process of coding, the researcher employed microanalysis of data (Corbin & Strauss, 1990) by breaking down the data line by line. The initial open coding process took approximately 30 hours and resulted in approximately 340 codes. Moving from codes to concepts required clustering the codes together based upon similarities in characteristics and events, as well as comparing for differences. The researcher completed the next step of the process using pen and paper and the initial coding chart. The researcher named obvious concepts first and then placed codes within these concepts in a new chart. Then, the researcher continued the process of correlating initial codes to the concept names until the researcher had all the codes placed within one of the 14 identified concepts. The researcher then reviewed the second chart created.

The last step was the most complicated step: naming the abstract categories and considering subcategories, properties, and dimensions. Since this was the most challenging step, two research questions were employed as a frame of reference for the coding process and analysis: (1) What are issues and concerns for patients with breast cancer-related lymphedema when they return to work in Thailand? (2) What are barriers and facilitators among patients with breast cancer-related lymphedema when they return to work in Thailand? Three categories emerged from the microanalysis of the interview data. These included issues and concerns; lymphedema-related experiences of facilitators at work, and lymphedema-related experiences of barriers at work.

Throughout the study process, field notes were kept documenting the researcher's thoughts, insights, and observations concerning the data. Additionally, memo-ing commenced during the data analysis, after the initial interview and continued throughout the data collection and analysis phases. The researcher observed the women's attitudes, body language, facial expressions, and verbal communication styles in addition to recording the interviews. These observations were recorded as part of the procedure and could then be compared to the original data that had been processed. All field notes were coded and categorized, and their results were compared with other new information gathered.

Results

Two eligible Thai breast cancer survivors with BCRL (ages 37-38) were recruited in this study. The first participant (PT 1) formerly worked as an Intensive Care Unit (ICU) nurse and, after being diagnosed with BCRL, changed her job to be an Outpatient Department (OPD) nurse. The second participant (PT 2) worked as a lawyer and was able to continue to do so, with some adjustments, after being diagnosed with BCRL. Both participants reported that they continued to maintain sufficient income and were married at the time of their interview. They underwent modified radical mastectomy more than two years prior to the interview. The participants also completed their cancer treatment (chemotherapy and radiation) more than two years prior to the interview. PT 1 had been diagnosed with BCRL for 5 years, whereas PT 2 had been diagnosed with BCRL for 1 year.

During analysis and review, there were three primary categories that emerged from the data. The first category was “work-related issues and concerns.” This category was illustrated by concepts such as career requirements, workplace and its condition, transferability of work skills, societal expectations of survivors, and options or choices regarding work opportunities. For example, Participant 1 reported how her experience and the effects of BCRL were issues because of how they impacted her ability to perform within her workplace, resulting in the concern about possibly needing to change her job. “When I was diagnosed with breast cancer, it was hard for me to reach the requirement of an ICU job. I knew that I had to ask for some help from my co-workers and sometimes it was quite hard to wait for someone to give me a hand, as the critical patients do require immediate care.”

The second concept was “BCRL-related experiences of facilitators at work.” This category was demonstrated by concepts such as internal and external facilitators.

Internal facilitators refer to the experiences that relate to, belong to, or exist/develop within the participant’s mind, including existential issues, self-esteem, gratitude, and resilience. Participants 1 and 2 illustrated their existential issues as they found a sense of purpose and pride in their occupation. Participant 1 reported, “My work is fascinating, I enjoy working, I love to be a nurse, but it is tiresome at the same time. But I enjoy performing independent nursing roles because you can make a plan, you can design it, provide it (to) become something patients appreciate and esteem, so I enjoy performing it." Participant 2 revealed, "I enjoy being at work, enjoy being with the clients, encouraging them, supporting them, and am able to go about by my normal duties at the place. I am ok, I enjoy doing it."

External facilitators refer to experiences of relating to, or being connected with, social, environmental, or any other factors or influences outside of the individual's own thoughts/perceptions/feelings. These included resources, time, physical support, adaptations/adjustments to their work environment, or access to BCRL knowledge that helped them achieve the demands of their work position. Participant 1 reported, "Thus, I decided to consult with the head of ICU and the doctor, as well; then I got a new job and I work as an OPD nurse." Participant 2 informed, "I am not able to use my affected arm effectively and, with that, I have the support of my colleagues to help me lifting things or carrying stuff; also, they are supportive. They don't put any extra physical work on me."

The third category is "BCRL experiences of barriers at work." This category was developed by identified internal and external barriers.

Internal barriers included the impact of physical limitations on mental and emotional wellness and unpleasant feelings (shame/self-esteem/guilt) at work. External barriers included lack of resources to assist or accommodate for any physical limitations. Participant 1 shared her experience of physical limitations and the associated unpleasant feelings she experienced: "I tell them (colleagues) about my limitation. I have to beg them or exchange some nursing procedure. I tell them, please can you help me do this? and they do it. (Pause; sigh). So, it's uncomfortable and I felt useless sometimes." Moreover, Participant 1 reported there was a lack of resources when she needed to have help: “I knew that I had to ask (for) some help from my co-workers and sometimes it was quite hard to wait for someone to give me a hand, as the critical patients do require immediate care. Sometimes. I do hesitate to ask my co-workers, as well, as they need to do their job, too.”

Issues and Concerns

Breast cancer survivors with BCRL returning to work are often impacted by the constant consideration of present or potential future issues from BCRL, leading to concerns on their ability to perform or maintain their position and nervous worrying about the future of their career.

Career/Work Requirements

In their interviews, the participants presented many references to work-related issues and concerns with BCRL and how it had affected their work lives. From this, the subcategory of career/work requirements was one of the first to emerge. The dimensions of this subcategory range from achievement to nonachievement of job position requirements.

Participant 1 reported that BCRL made it more difficult for her to meet the requirements of her previous job as an ICU nurse. Participant 1 then compared her previous experience and job duties as an ICU nurse to her current experiences and job duties as an Outpatient Department (OPD) nurse.

In contrast, Participant 2 was able to continue her job as a lawyer, as her job duties were not constrained by her ability to use her affected arm. She would experience unpleasant symptoms while working, but she was still able to meet her work requirements.

This theme is supported by these responses:

"As far as the doctor, my head of ICU, my co-worker and I—we are concerned about patient safety, as well." "At first, the current boss and my current co-workers [in the new position as OPD] are worried about my condition, as they think I may not have sufficient competence to perform the OPD job, either, due to my health problems." (PT1) "At my current workplace (OPD), they still admire what I do, they are satisfied with it." (PT1)

"I am able to go about my duties as normal." "So, as long as I am able to bandage my arm, I don't have any pains. I am able to deal with all the work demands." (PT 2)

Workplace and Its Condition

The next subcategory was workplace and its condition. This emerged from the participants' experience of their workplace and the contextual factors of the workplace. The dimensions of this subcategory involved time, as related to the participants' workplace after diagnosis with BCRL to the present. Only Participant 1 had an issue with the workplace and its condition, as BCRL had decreased her performance, as noted by these responses:

"When I was diagnosed with breast cancer, it was hard for me to reach the requirement of an ICU job. I knew that I had to ask for some help from my co-workers and sometimes it was quite hard to wait for someone to give me a hand, as the critical patients do require immediate care." (PT 1)

"Like I said, it has slowed down work for me, because (I) am not able to perform as I should formerly, I was the fast and active type. I don't do things slowly, but now I am a bit relaxed. It takes more time for me to finish one thing than before." (PT 1)

Transferability of Work Skills

The third subcategory was transferability of work skills. This emerged from the participants' experience, knowledge, and skills. These are the work-related abilities of the participant that are integral in keeping their job and/or can assist them in finding a new job. The dimensions of this subcategory involve being able and being unable to transfer work skills from a previous job to a new job. Both participants' careers provided them with work skills and abilities that could be transferred to or assist in obtaining new jobs, as supported by the information they reported about their respective careers.

"I perform some nursing procedures at an out-patient department, such as wound-dressing, vaccination, injection, and intravenous procedures. It's in a university hospital. We mainly provide information and some nursing procedures for outpatients." (PT 1)

"I have worked as a registered nurse for 12 years. I had worked at the Pediatric Intensive Care Unit (PICU) for ten years. I have changed my workplace a couple of years ago. Currently, I have worked for an out-patient department for two years." (PT 1)

"I am a lawyer, a licensed professional who advises and represents others in legal matters, and I practice my career at the workplace." (Line 8-9) "I have worked as a lawyer since 2007, actively, yes." (PT 2)

Participant 2 was able to continue in her current job and field. Only Participant 1 reported that she did ultimately have to rely on the ability to transfer work skills from her previous job as an ICU nurse to her current job as an OPD nurse, as both jobs require her nursing experience and knowledge, and so was able to maintain her career.

Societal Expectations of Survivors

The fourth subcategory was societal expectations of survivors. This occurred when the participants talked about the negative or discriminatory societal or cultural attitudes that others have regarding people with an illness wishing to maintain their current job duties and employment. The participants expressed concern about the general public's lack of awareness about BCRL (and more specifically included persons in the places of their employment). Due to this lack of understanding among the broader public, BCRL survivors felt cut off and misunderstood. The dimensions of this subcategory involved neutral attitudes to negative attitudes from people in their culture. Both participants suffered with social discrimination, as supported by the responses.

“Physically, (I) am alright and I don’t like it because (I) am not obese; I didn’t even gain weight. It may be a sickness, the way people see you and look at you as if you are a very sick person who should sit in the house, not going out, or even still working.” (PT 1)

“For breast cancer, they know about it, but for lymphedema, people don’t know about it. If they see the change in size of your hand and if you bandage it, they think it is rheumatism. They don’t know much about lymphedema. Some of them told me that I should not keep my work, as I am a sick person.” (PT 2)

Options or Choices of Work

The last subcategory is options or choices of work. This emerged in reactions to when the participants were told of their now-limited opportunities when pursuing new jobs. Only Participant 1 experienced limitation on her options or choices in applying for a new job due to

BCRL. When she was required to find a new job that would require less use of her affected arm, she had to defend her position as a fit nurse.

"The current boss is worried about my condition, as I may not have sufficient competence to perform OPD job due to my health problem. I do understand that and tell her I will do my best." (PT 1).

BCRL Experiences of Facilitators at Work

BCRL experiences of facilitators at work emerged when the participants reported someone or something that brought about a positive outcome (such as accomplishments at work or attaining job requirements). BCRL experiences of facilitators at work were divided into two groups: internal facilitators and external facilitators.

BCRL Experiences of Internal Facilitators at work

Internal facilitators are those aspects that happened within the participants' minds that encouraged or motivated them to overcome external difficulties or limitations they may have encountered, either societal or physical, within their career. These facilitators were integral in how the participants found internal fortitude and sense of purpose that led to finding positive reasons and methods for accepting, adjusting and coping, where necessary, within their work lives. This in turn enabled them to complete career requirements and sustain a sense of purpose and accomplishment.

The Existential Issues

The existential issues are the first subcategory of internal facilitators. The dimensions ranged from neutral to positive as the participants expressed the challenges of their existence and living with BCRL and centered on the experience of thinking, feeling, and acting. These further included central motivating aims of life, purpose connected to vocational meaningfulness, and satisfying work. Participants emphasized their life purpose with their family and work in the interview, as evident in the following responses.

"My work is fascinating, I enjoy working, I love to be a nurse, but it is tiresome at the same time. But I enjoy performing independent nursing roles because you can make a plan, you can design it, provide it (to) become something patients appreciate and esteem, so I enjoy performing it." (PT 1)

"My career is important to me because that is what aids you to take care of yourself and your family, I have two kids. So, I am able to support my kids and my family." (PT 1)

"I enjoy being at work, enjoy being with the clients, encouraging them, supporting them, and am able to go about by my normal duties at the place. I am ok, I enjoy doing it." (PT 2)

Self-Esteem

The second subcategory of internal facilitators was self-esteem. The dimensions range from neutral to positive, as the participants described how they felt about themselves after being diagnosed with BCRL. Both participants reported overall opinions of self, but those opinions acted as internal facilitators when they regarded the pride they felt when thinking of their abilities, acceptance, and adaptability in overcoming limitations and perceptions of BCRL, as evidenced by the following remarks.

“I used to wear long sleeves to hide my affected arm, but now I don’t care, and I just wear whatever makes me feel comfortable, even sleeveless clothes. I mean, I don’t have to hide my affected arm anymore.” (PT 1)

“People keep asking me about the bandage and what it is used for; some think it’s rheumatism. I always tell them that it is to reduce pain. they keep asking questions, but I make sure the bandage is on my arm and I haven’t had any pain.” (PT 2)

Gratitude

The third subcategory of internal facilitators was gratitude. The dimensions ranged from little to great, as the participants described feelings of gratitude and appreciation toward the assistance and understanding they have received. In general, it was in reference to those experiences that made them feel understood and accepted, as evidenced by the answers below.

“My colleagues, they are, it’s like physical support. They always want to help. If they think I need help, they (are) always ready to help me.” (PT 1)

“If am not able to handle some items, especially, they come to my aid. Things that are heavy, they come to my aid, especially lifting, doing things that I am not able to do: they come to my aid to help me and things that I can’t do.” (PT 2)

Resilience

The last subcategory of internal facilitators was resilience. This happened when the participants revealed their capacity to recover rapidly from obstacles, exhibit toughness, and to accept reality. This also emerged when the participants talked about the acts or processes of personal determination when faced with questions or doubt, making judgements or decisions based on what they know of their own capabilities versus outside opinion or perception, or setting boundaries with themselves and others when questioned about their condition. The dimensions varied from low to high, as presented by the responses.

"Hmm, I just tell them, it's a swelling and it's one of the complications after breast cancer treatment. I wasn't well, a doctor gave me a drug and treatment and it's the side effect. So, it's just a swelling. So (I) am fine, they shouldn't worry." (PT 1)

"They don't actually know what it (lymphedema) is. Because they don't know it's out of breast cancer and I don't think I need to tell everybody that it's a result of this. They just accept the fact that it's a swelling and (I) am not in pain. They just accept that, and we just move on with that." (PT 1)

"The head of OPD is worried about my condition. as I may not have sufficient competence to perform OPD job due to my health problem. I do understand that and tell her I will do my best." (PT 1)

"They keep telling me to always get it bandaged; as long as I get the hand bandage, I had no pain and the swollen went down and I am able to go about my normal duty. The affected hand is weak and cannot support a lot of weight, but I am able to do my best." (PT 2)

"They don't know I have breast cancer and lymphedema; when there are things that I am not able to do, they come in to help me and I haven't told them anything. I think I don't have to tell or explain about BCRL." (PT 2)

BCRL Experiences of Facilitators at Work

BCRL Experiences of External Facilitators at Work

External facilitators are those factors and influences coming from a participants' environment which provide encouragement, support, or resources that facilitate adjustments and adaptations in performing in their role(s), whether at work or at home.

Resources

The first subcategory of external facilitators was resources. This emerged as the participants described availability and access to support after being diagnosed with BCRL. The dimensions ranged from few to many resources, as evidenced by their responses. Both participants were able to access the resources, as described below.

"Thus, I decided to consult with the head of ICU and the doctor, as well; then I got a new job and I work as an OPD nurse" (PT 1).

Participant 2 revealed that family support helped her accomplish her work (at home) by taking care of the tasks she could no longer perform as well: "They (her family) have supported me greatly. I had (a) problem with cooking; my husband does the cooking and packs them in the fridge. There are people who come around to clean my house, wash; they have helped me a lot (PT 2)

Time

The next subcategory of external facilitators was time. Time emerged as Participant 1 referred to the ongoing presence of BCRL and how her outlook changed from when she was initially diagnosed with BCRL to the present, including how her reaction to the perceptions of her and her condition by others has changed. The dimensions ranged from short-term to long-term, as evidenced by this remark.

“Because I know what is happening, so (I) am not bothered about what they think or their worries. I know (this is) the results of what has happened and the effect, so (I am) not bothered about their concern for me.” (PT 1)

BCRL Knowledge

The last subcategory of external facilitators was BCRL knowledge. This emerged when the participants shared their knowledge in taking care of themselves after being diagnosed with BCRL, especially regarding self-care when returning to work. The dimensions of BCRL knowledge ranged from fair to well-educated. Facts, information, and skills acquired by the participants through BCRL experiences or education were revealed by their responses. Participant 1 revealed she was well educated in the importance of BCRL knowledge, and Participant 2 illustrated knowledge via using bandages in symptom management.

“For me, the knowledge of lymphedema and how to prevent the development of lymphedema is most important.” (PT 1)

“I try to perform shoulder exercise whenever I have time or feel the swelling starting or have a feeling of fullness, heaviness, or tightness in the arm, chest, or armpit area.” (PT 1)

“It doesn’t affect them that much: as long as there is no pain in my arm, I am able to cope with all the demand at work. There hasn’t been any effect on them. I have to bandage my hand very often.” (PT 2)

BCRL Experiences of Barriers at Work

Experiences of barriers at work emerged as a category when the participants were faced with problems or other obstacles that did or could potentially affect their performance or ability to accomplish tasks related to their career/role. BCRL experiences of barriers at work were divided into two groups, internal barriers and external barriers.

BCRL Experiences of Internal Barriers at Work

Internal barriers referred to the negative thoughts or self-perceptions derived from BCRL. These could be the participants' self-developed internal ruminations, shame, or self-judgement regarding how they were perceived or performing, or reactionary thoughts/feelings caused by physical limitations. Internal barriers are considered to exist within the participant's mind and impact their ability to perform their work and can also affect overall mental health and wellbeing. In addition, internal barriers included societal expectations/perceptions that could lead or did lead to a reduction in position or workload that led to unpleasant feelings while at work.

Physical Limitations

Physical limitation was the first subcategory of internal barriers. This emerged as participants described their limiting conditions, such as: restrictive weakness, lack of capacity, handicaps, or complete inability to perform due to BCRL. The dimensions varied from mild to severe. Both participants were confronted with physical limitations related to BCRL, as described within their responses.

"I couldn't do much of work. I mean my performance has had some limitations. At ICU, all patients required total care and it was inevitable to avoid lifting things, such as turning positions for patients every two hours and complete bed bath or even restrain them sometimes. I noticed that when I used my affected arm more often, I had a feeling of fullness, heaviness, or tightness in the arm, chest, or armpit area on that arm, and then it was hard to hold the thing on that arm. I could not hold even a sponge to wash dishes. When it got worse, I could not carry the dish or a sponge or a bottle of normal saline solution, and lymphedema has a negative impact both on my work and activities in daily life." (PT 1)

"It affects my working time because, just like I said, I must use my right hand, which is affected, and I could not provide total care without somebody around me. I can't handle the bottle of IV fluid, even 100 ml. So, it has affected me seriously, in both the providing total care and helping my co-workers to perform some interventions in ICU." (PT 1)

"I know, as I have to perform shoulder exercise and hang my arm on the top back of a seat, and it looks inappropriate. It makes me look not professional." (PT 2)

"Ok, my arm is not that strong, am not able to use that arm effectively, even if there is no pain, I can't use my fingers. Usually they become stiff, I get muscle pull and I can't do serious activity with the arm. I can't lift heavy things. The arm is weak." (PT 2)

Unpleasant Feelings at Work

The second subcategory of internal barriers involved unpleasant feelings at work. This subcategory emerged when a participant expressed their unpleasant feelings due to experiences such as a reduction of responsibility, limited or inability to perform job duties, requiring more aid to perform job duties, or feelings derived from negative perceptions of co-workers regarding the participant's competency and ability. The dimensions vary from mild to moderate. Only Participant 1 dealt with this barrier, as she reported below.

"Hmm, it became worse after I was diagnosed with the lymphedema because I couldn't use my hand like I used to. I had to perform total care, but I could not do it: I had to ask my co-workers for help. It was hard for me to reach the requirement of an ICU job. I knew that I had to ask for some help from my co-workers and sometimes it was quite hard to wait for someone to give me a hand, as the critical patients do require immediate care. Sometimes I do hesitate to ask my co-workers, as well, as they need to do their job, too." (PT 1)

"I tell them about my limitation; I have to beg them or exchange some nursing procedure. I tell them, please can you help me do this and they do it. (Pause; sigh). So, it's uncomfortable and I felt useless sometimes." (PT 1)

BCRL Experiences of External Barriers at Work

External barriers included factors of, relating to, or connected with others, or any cause outside of a participant's mind and outside of their control. The primary subcategory that emerged was related to resources, in two facets, as further detailed below.

Resources

Resources were a subcategory of external barrier. The dimensions ranged from no to few resources. One facet of resources involved the unavailability of, lack of access to, or inadequacy of work-related resources that impacted the participants' ability to perform their job-related tasks or assignments. Participant 1 reported this happened when she needed help to accomplish her job requirements, but there was no one available to help, as supported by this response.

“I knew that I had to ask some help from my co-workers and sometimes it was quite hard to wait for someone to give me a hand, as the critical patients do require immediate care. Sometimes I do hesitate to ask my co-workers as well, as they need to do their job, too.” (PT 1)

A secondary facet of resources was regarding the lack of knowledge and information provided by the healthcare organization, pre- or post-treatment, on the risk and preventive measures of developing BCRL. Both participants revealed there was no one to inform them about the risk of developing BCRL and how to reduce the risk of the development of BCRL after completing breast cancer treatment. They shared their experiences and frustration at this lack of resources and how having those may have impacted them differently. Additionally, healthcare providers were seen as a potential and under-utilized resource that could be more proactive in guidance, support, and education of the risk of BCRL. They also voiced their concerns for new and future breast cancer survivors.

“I wouldn’t even wait for the person to get lymphedema first. I would rather say, the doctors and nurses should inform every breast cancer patient who has gone through the surgery that it’s likely that, at a point, your arm would be swollen for this reason, and you don’t have to take it for granted because it can paralyze you.” (PT 1)

“You know, I do (have) concern about my body image and one of health care providers told me how lucky that I am still alive, so just learn to live with it and accept it. I know, but I do need more options to take better care of myself and I just want to get treatment that can heal this complication sooner. I was really mad at them, and I would like to know, if this happens to their relative or family, I really want to know that they would give same advice.” (PT 1)

"Apart from the government insurance, there hasn't been much (support). At least I have my medication free; that's all the support I have got." (PT 2)

Limitations of the Study

This research was based on two participants' in-depth interviews. Most significantly, it required the capacity to conduct interviews that capture the participants' points of view. The findings are not generalizable to other survivors with BCRL, due to this being a pilot study with a sample size of two, and the individual characteristics of the participants.

Quality Standards

The content of the interviews was confirmed during the interview by following up with the participants in the form of member checks. Furthermore, the researcher worked and communicated with an experienced qualitative researcher during the data analysis to examine notes, memos, transcripts, and the analysis process, as well as any concerns that arose. Throughout this pilot study, the first author used individual self-reflective reviews of the research process. Reflexivity is a key notion in qualitative research in general, where it is seen as a way to increase credibility (Dowling, 2005). The co-author reviewed the coded data. Moreover, the results of this study may have transferability, in that the findings may fit other contexts as judged by readers or when readers find the report meaningful regarding their own experience(s) (Crooks, 2001).

Discussion

This pilot study employed grounded theory, as it was a valuable approach for initially conveying the meaning and significance of the return-to-work experiences of Thai women with BCRL. Participant interviews provided data on the experiences, issues and concerns, facilitators, and barriers in returning to work and accomplishing job duties. These participants frequently focused on the positive aspects of interactions between BCRL and work, incorporating these characteristics and sub-categories into their daily lives while realizing the personal and societal significance of returning to work while looking to their future with positivity. Both BCRL and its treatment have direct and indirect effects on work, with environmental and personal factors also shaping the return-to-work experience (Sun et al., 2021).

Issues and Concerns

The first category was issues and concerns among women with BCRL when they return to work. A woman whose work requires full use of an affected arm may not be able to complete her typical job duties and thus may be faced with limitations in transferring or adapting their skills. This may further result in the need to change their job (Participant 1). Moreover, some workplaces that require skills which involve hands-on or full physical mobility/labor may not provide options or choices for work for affected women. However, a woman whose work does not require full use of an affected arm or involves fewer physical tasks may still be able to fulfill their job requirements with little to no adjustment or assistance (Participant 2).

Participants also faced negative experiences due to the lack of BCRL awareness within the general public. These experiences were associated with the societal expectations and perceptions of survivors or people with illness, which could lead to the survivors with BCRL feeling conspicuous and misunderstood (Sun et al., 2021). Further, the results from this study revealed that in the Thai culture both participants were, as someone with an illness, expected to stay home rather than return to work.

BCRL Experiences of Facilitators at Work

Internal facilitators at work were important for all participants, as they assisted the participants in maintaining their career. Existential issues were expressed by participants and revealed their experience of thinking, feeling, and acting. These further developed into central motivating aims of life and sense of purpose derived from their profession and meaningful, satisfying work.

Self-esteem in both participants increased over time, as is demonstrated by previous studies where participants demonstrated acceptance and learning to live with the current symptoms of BCRL (Acebedo et al., 2019), while also learning about symptom management and accepting that they will have to confront and manage BCRL throughout their life (Cal & Bahar, 2016; Deborah, 2019; Rosedale & Fu, 2010; Thomas et al., 2015; Tsuchiya et al., 2015).

In this study, both participants were previously afraid that people may notice their affected arm or that BCRL and its symptoms could lead to demotion (Participant 1). This relates to and reinforces the findings of previous studies: that the visible symptoms of BCRL can cause a private health condition to become public and cause embarrassment (Deborah, 2019); that lymphedema symptoms can reinforce a sense of inferiority (Tsuchiya et al., 2015); and that women sometimes withhold symptoms and complaints (Rosedale & Fu, 2010). The two participants in this study revealed that they decided to set individual boundaries and they did not want to explain their illness to everyone. Moreover, the participants preferred independence to dependence.

BCRL Experiences of Barriers at Work

Based on participants' descriptions, physical impairment was comprised of decreased upper extremity mobility, strength, and fine motor coordination and was caused by BCRL and its symptoms. Physical limitations were the most important barrier for participants to reach their work requirements. Further, they led to unpleasant feelings and interpersonal effects related to decreased satisfaction with one's own work productivity, reduced spontaneity at work, undesired attention from others, and negative perceptions of body image.

In some situations, BCRL and its symptoms directly interfered with work activity due to changes caused by lymphedema negatively affecting arm function (example: Participant 1 and lack of a functional intermediary). A woman who wore compression garments reported she was treated as handicapped (Participant 1), as similarly reported by Winch et al. (2015) who detailed that for those with compression garments, there is the additional apprehension of being treated as injured/disabled in reaction to the garment (Winch et al., 2015).

The most common physical change was arm morbidity. Both participants mentioned that after being diagnosed with BCRL they tried to avoid using the affected arm. This finding related to a previous study's findings where women with BCRL were also aware of the need to avoid injury of the affected arm by primarily using the unaffected arm (Acebedo et al., 2019; Cal & Bahar, 2016). PT 1 indicated that her affected arm was on the right side, which made her life more difficult. This was also related to a previous study's findings that indicated that women who underwent surgery on their right (primary) arm have more difficulty in performing activities in their daily life (Cal & Bahar, 2016). Additionally, both participants informed the researcher that they stopped participating in some activities that involved other people, such as going to the gym or playing some sports, as they do not want to answer questions or talk about their illness.

There were also concerns about the loss of the overall benefits to physical health via physical activity, and to mental health from the reduced ability to physically engage comfortably with others, both platonically and sexually (Thomas et al., 2015).

Both participants illustrated another barrier regarding lack of support (from workplace peers and supervisors, clinicians, or family), which continues to be a potential barrier to returning to work for cancer survivors in general (Blinder et al., 2012). A study by Anderson et al (2022) illustrated that Hispanic/Latina survivors identified BCRL knowledge gap challenges and described coping with physical, psychosocial, and work activity changes. They described creative work adaptations and discussed BCRL's impact on both positive and negative interpersonal perceptions. Strong support from family, friends, and colleagues contributed to improved quality of life (QOL) and continuance of work activities.

Moreover, insufficient knowledge about lymphedema was the most frequent issue among participants. Often, survivors were uninformed about lymphedema and its symptoms (Acebedo et al., 2019). The finding from this study (Participant 2) also related to and further supported the findings in previous studies, such as Deborah (2019), which revealed that patients required understanding, empathy, kindness, and gentleness; they needed to feel comfortable in asking healthcare providers questions and in the knowledge that health care providers would support them. Additionally, patients reported that information and education were important needs and that, prior to their breast cancer surgery, they were uninformed about lymphedema and the possibility of developing it (Deborah, 2019; Maree & Beckmann, 2016). Other previous research noted that the best time to provide education about lymphedema is before breast cancer surgery (Deborah, 2019), but nurses can also provide information and education before the initial discovery of symptoms of BCRL for participants who have recently undergone breast cancer surgery (Deborah, 2019). Nurses should educate the patient on how to identify specific early signs and symptoms, so that care and treatment can begin immediately. According to Anderson et al (2022), there is a need for future research to integrate coping strategies and creative management approaches to BCRL, so that work activities can be optimized across the lifetime.

The result of this study can further provide healthcare providers with information, perspective, and incentive to develop survivorship care plans, educational plans, and systems of lifelong occupational support. These outcomes are necessary for optimal survivorship and work outcomes for survivors experiencing BCRL.

Conclusion

Participants in this pilot study reported that their experiences with breast cancer treatment and BCRL had a variety of effects on their return-to-work journey. Three categories emerged from the data. The first category is “issues and concern”, and it illustrated concepts such as career requirements, workplace and its condition, transferability of work skills, societal expectations of survivors and options or choices of work opportunity. Breast cancer survivors with BCRL returning to work are often impacted by the constant consideration of present or potential future issues from BCRL, leading to concerns on their ability to perform or maintain their position and nervous worrying about the future of their career. The second category is “BCRL experiences of facilitators at work” and they illustrated concepts such as internal and external facilitators. Internal facilitators included existential issues, self-esteem, gratitude, and resilience. External facilitators included resources, time and BCRL knowledge. The third category is “BCRL experiences of barriers at work” they illustrated concepts such as internal and external barriers. Internal barriers included physical limitations and external barriers included limited resources and unpleasant feelings at work. Most specifically, they regarded these barriers as impacting their efficacy in completing their work due to diminished physical function and changes in their work-life pattern. Women reported they needed their employment as a source of financial income for their families. Often, job duties required heavy lifting and repetitive use of the affected arm and hand. These women also endured psychological distress as a result of their employers' and co-workers' lack of understanding about BCRL. Overall, they suffered significantly from the physical and functional impact of lymphedema on their work. The difficulties they faced did not exist in isolation, as each participant discussed similar barriers. Participants in this study also described facilitators and barriers occurring within and outside of themselves, which could facilitate or inhibit the return-to-work experience. Both participants returned to work and both developed strategies to deal with their frustrations and limitations. It is important for healthcare providers to understand that successful outcomes rely on external factors/facilitators, as well as internal facilitators, as each will help in identifying interventions and programs to aid functioning or adjusting activities to meet work requirements and career achievement/goals.

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CHAPTER SIX

THE RETURN-TO-WORK EXPERIENCES OF THAI WOMEN WITH BREAST CANCER-RELATED LYMPHEDEMA

Narkthong. N., Armer, J. M., & Anbari, A. B. The return-to-work experiences of Thai women with breast cancer-related lymphedema.

Abstract

Purpose: This study aimed to examine Thai breast cancer survivors' perspectives on how breast cancer-related lymphedema (BCRL) affected their employment and related quality of life (QOL), as well as the culturally-influenced contextual facilitators and barriers that they faced as they return to work in Thailand.

Background and Significance: The most common cancer among women in Thailand and around the world is breast cancer. Many women diagnosed with breast cancer suffer from lymphedema, which can reduce their ability to return to work and adversely impact their employment.

Methods: Following informed consent procedures, 13 Thai women with BCRL ages 43-74 were recruited from a community. A grounded theory approach included semi-structured interviews and assessments of work demographics, lymphedema-related changes, interpersonal changes in work and in the future with lymphedema, environmental characteristics, and final reflections on the thoughts regarding the future and survivorship care plan with BCRL.

Results: The theory of Return-to-Work Experiences of Thai Women with BCRL revealed the association of lymphedema and return-to-work could be either a challenge or a way of maintaining hope to cope and live with BCRL. This idea of Return-to-Work Experiences of Thai Women with BCRL (Challenge vs Hope) emerged as the core category in the data analysis, with core aspects emerging: (1) changing/adjusting priorities in life; (2) challenges of returning to work with physical limitations; (3) seeking availability of resources and support; and was followed by a resolution as the last core aspect, (4) accepting and living with BCRL.

Discussion and Implications: This study suggests that breast cancer survivors with BCRL face potential barriers when returning to work, and that gaps remain in the availability of resources and support that might facilitate optimal survivorship. BCRL is identified as part of a dynamic cycle for these survivors in returning to work. In order to maintain a balanced approach for BCRL patients, professionals must acknowledge this dynamic relationship in future research. In order for survivors with BCRL to feel empowered, they must receive education and support to adapt to the work setting in their new reality.

Keywords: Breast cancer, lymphedema, survivorship, return-to-work, occupational rehabilitation

THE RETURN-TO-WORK EXPERIENCES OF THAI WOMEN WITH BREAST CANCER-RELATED LYMPHEDEMA

Introduction

The most common cancer worldwide is breast cancer, accounting for 12.5% of all new cancer cases (Breast Cancer Organization, 2023). In 2020, there were 22,158 new cases of breast cancer and 76,440 cases at five-year survivorship in Thailand (World Health Organization, 2021). Secondary lymphedema is one of the main treatment complications for breast cancer patients following breast cancer treatment (surgery, radiation therapy, and/or chemotherapy) (Armer et al., 2020). A person with lymphedema has an accumulation of protein-rich lymphatic fluid in the affected part of his or her body, which can impair their function, psychological well-being, family relationships, and work productivity, among many other factors (Armer et al., 2020).

Returning to work is one of many challenges breast cancer survivors face. In the context of breast cancer survivorship, especially as related to BCRL, a literature review by Eaton et al. (2020) found that BCRL can significantly impact employment and limit return-to-work. The cascading nature of the economic burden of BCRL on long-term savings, work opportunities, and insufficiency of insurance to cover lymphedema needs can drive financial deficits (Eaton et al., 2020). Even though there are recognized potential connections between lymphedema and negative work outcomes, there is almost no published research that investigates the precise reasons for the association (Sun et al., 2021). Both breast cancer and lymphedema have a significant negative influence on women’s work and careers (Boyages et al., 2016; Sun et al., 2021). Respondents reported changes in employment resulting from stress and/or physical impairment, which affected attendance and work performance (Boyages et al., 2016).

However, there have not been enough qualitative studies that have reviewed lymphedema patients’ lives through their individual experiences, perspectives, challenges, and barriers (Cal & Bahar, 2016). Importantly, in Thailand there is no previous study that has specifically explored the impact of the severity of lymphedema on work and career. This qualitative research was generated after noting the gap in previous studies, leading to our exploration of Thai breast-cancer survivors’ individual experiences with BCRL when they return to work. A grounded theory approach was applied to explore the experience of return-to-work and work-related barriers and facilitators to BCRL self-management of Thai survivors by using semi-structured interviews with individual participants in the community setting. Thus, it was determined that a primary qualitative study that identified patients’ experiences, by adhering to the nature of the qualitative approach, could benefit healthcare practitioners and survivors by offering a greater understanding of the phenomena and its complexities (Burckhardt et al., 2014).

Methods

Design

Grounded theory was utilized for this study because it allowed the researcher to analyze a wide range of human experiences in the context of their social environment (Strauss, 1993), in this case, return-to-work for survivors with BCRL. The purpose of grounded theory was to find connections between social events (such as returning to work) and examine how survivors' perceptions of work-related situations and factors affect outcomes.

Participants and Setting

The study was set in Thailand (all four Thai regions) and participants were recruited from the community and private breast cancer groups on Facebook, rather than from clinics or hospitals. Purposeful sampling and snowball sampling were employed in the study. Participants were recruited through announcements in breast cancer support groups, flyers, emails, social media, and in-person invitations.

Thirteen eligible participants were recruited having met the eligibility criteria: (1) age 18 or older; (2) breast cancer survivors who were more than 12 months post-surgery and -radiation treatment; (3) subsequently diagnosed with treatment-related lymphedema; (4) employed or self-employed at the time of developing lymphedema; (5) fluent in both oral and written Thai language; and (6) able to consent to participate in the study.

Data Collection

Recruitment and data collection commenced after the team obtained Institutional Review Board approval for research with human subjects from the University of Missouri. After potential participants were informed about the study, screened for eligibility, and consent (Appendix A) was obtained, data were collected through recorded semi-structured Zoom interviews or audio calls using LINE applications, a freeware app for instant communications on electronic devices such as smartphones, tablet computers and personal computers. The first author (NN) scheduled and conducted Zoom and audio call interviews at days and times convenient for the participants. Interviews lasted 60-80 minutes.

Data Management and Analysis

The team employed Microsoft Excel software to build a potential participant database for contacting participants and tracking due dates for data collection reminders and appointments. This database was administered by the first author and stored in the password-protected MU Teams “cloud-based” platform. The Excel file linking name and contact information for participants was stored behind the password protection of the folder and accessible only to the first author and team. All voice recordings were transferred to IRB-approved secure cloud storage. Moreover, to ensure confidentiality, the first author transcribed all voice recordings herself. To further ensure privacy, participants were asked to choose a pseudonym. Only the pseudonym was used on the audio recordings and transcripts**.**

Data Analysis

Sociodemographic data were analyzed by using descriptive statistics. From the beginning of data collection to the final analysis, qualitative data were regularly evaluated for meaning, common patterns, and emergent concepts. Patterns that appeared during the interview process were recorded in the interview guide and field notes. To determine descriptive categories, each word and sentence in the text was examined. Significant phenomena were labeled, and the code was recorded in the margin next to the relevant information. In the process of coding, the PI employed microanalysis of data (Corbin & Strauss, 1990) by breaking down the data line-by-line.

The grounded theory method contained three data analysis steps: open coding, axial coding, and selective coding (Strauss & Corbin, 1998). The objective for open coding was to extract the categories from the data, whereas axial coding identified the connections between the categories. In the third phase, selective coding, the core category was identified and described (Corbin & Strauss, 1998). The researcher created categories as they appeared in the data while conducting theoretical analysis and writing memos. The process of sorting memos was iterative, consistent with a constant comparison approach of data analysis, and designed to offer a logical framework for structuring the study and establishing and improving relationships between the data. Categories and data identified by the first author were reviewed by the co-authors for confirmation.

Results

Part 1: Sociodemographic Findings

A total of 13 Thai breast cancer survivors with lymphedema consented to participate in this study. Table 6 presents the sample demographic as a whole picture of this study, whereas Table 6.1 shows the sample demographic individually. Participants ranged in age from 43 to 74 years with a mean age of 57.5 years old (*SD*=9.5). Time after diagnosis of breast cancer, surgery, and lymphedema ranged from 2 to 10 years (*M* = 6.7, *SD*=2.7), 2 to 9 years (*M*=6.6, *SD*=2.6), and 0.6 to 8 years (*M*=4.4, *SD*=2.7), respectively. The majority (54%, *n*=7) of the participants resided in the southern part of Thailand and lived in urban areas. The majority (85%; *n*=11) of participants were Buddhist and were married. Level of education ranged from Intermediate School to Doctor of Philosophy; the majority (31%; *n*=4) of participants' level of education was a bachelor's degree. Social support also was self-reportedly high at 69% (*n*=9) and almost all participants reported their financial status as extremely adequate (85%; *n*=11). Nearly half of the participants (46%, *n*=6) reported one or more co-morbidities. All participants reported symptoms related to lymphedema; almost all participants (92%; *n*=12) reported two or more symptoms and only one participant (7%, *n*=1) reported one symptom.

Disease-Related Characteristics of the Sample

All participants had undergone breast cancer surgery, the majority more than six years earlier. The one participant who was less than 12-month post-cancer treatment is an IRB-approved alternative case who met all other inclusion criteria. The majority (39%, *n*=5) had a modified radical mastectomy with sentinel lymph node biopsy, followed by a modified radical mastectomy with axillary lymph node dissection (30%, *n*=4). Almost all participants (92%, *n*=12) also had completed radiation and chemotherapy, except one participant (8%, *n*=1) who declined chemotherapy as she could not tolerate the side effects. The majority of participants (54%, *n* =7) developed lymphedema on the side of their dominant limb. Almost all participants (85%, *n*=11) recalled detecting lymphedema by themselves, and they subsequently sought a medical diagnosis. Most of the participants had symptoms associated with lymphedema. The most frequently reported symptoms associated with lymphedema were tightness (77%, *n*=10), swelling (62% *n*=8), heaviness (46% *n*=6), stiffness (31%, *n*=4), and sleep problems due to symptoms associated with lymphedema (31%, *n*=4) (Table 6.2).

Employment-related Characteristics of the Sample

The participants' occupations included both sedentary jobs, such as office work, and more physically demanding jobs, such as a construction worker and housewife. The majority of participants (85%, *n*=11) continued in their previous occupations after lymphedema diagnosis, except a construction worker who worked on-site before her lymphedema diagnosis. Most of the participants (77%, *n*=10) reported no formal restrictions in terms of their work arrangements. In contrast, two women were restricted to light duty and two needed some workplace modification or modified work hours. Almost all participants (85%, *n*=11) did not take time off from work or took off only a few days in total for lymphedema treatment. All participants commuted to work within 5 to 15 minutes of driving distance. In terms of insurance coverage, a majority of them (64%, *n*=7) had the Civil Servant Medical Benefit Scheme; almost half (38% *n*=5) had the Universal Coverage Scheme; and a minority (15%, *n*= 2) had the Social Security Scheme, with full or deductible-only coverage for lymphedema treatment. One participant (8%, *n*=1) paid for their insurance or lymphedema treatment on her own (Table 6.3).

Table 6

Overall Sample Demographic

Characteristics	Sample (*N*=13)	
	M (range)	*SD*
Age (yrs)	57.5 (43-74)	9.5
Time since BC (yrs)	6.7 (2-10)	2.7
Time since Surgery (yrs)	6.6 (2-9)	2.6
Time since LE (yrs)	4.4 (0.6-8)	2.7
	(*n*)	*%*
Region		
South	7	53.80
North	3	23.10
Central Region	1	7.70
East	1	7.70
West	1	7.70
Urban	9	69.20
Rural	4	30.80
Religion		
Buddhist	11	84.60
Muslim	2	15.40

Characteristics	(*n*)	%
Marital Status		
Married	9	69.20
Single	4	30.80
Education Level		
Intermediate School	1	7.70
High School	2	15.40
Vocational Certificate	1	7.70
High Vocational Certificate	1	7.70
Bachelor’s Degree	4	30.80
Master’s Degree	3	23.10
Doctor of Philosophy	1	7.70
Financial Adequacy		
Extremely Adequate	11	84.60
Somewhat Adequate	1	7.70
Inadequate	1	7.70
Reported of Co-morbidity(ies)		
Yes	6	46.20
No	7	53.80
Hypertension	1	7.70
Diabetes	1	7.70
Dyslipidemia	1	7.70
Seasoning Allergic	1	7.70

Characteristics	(*n*)	%
Hypertension, Diabetes	1	7.70
Hypertension, Diabetes, Dyslipidemia	1	7.70
Lymphedema-affected Side		
Left	6	46.20
Right	7	53.80
Dominant	7	53.80
Nondominant	6	46.20
Breast Cancer Treatment		
Chemotherapy		
Yes	12	92.30
No	1	7.70
Radiation		
Yes	12	92.30
No	1	7.70
Type of Surgery		
MRM	1	7.70
Mastectomy+ ALND	3	23.10
MRM + ALND	5	38.50
MRM+SLNB	4	30.80
Symptoms of LE		
Yes	13	100.00
No	0	0.00

Characteristics	(*n*)	%
Reported > one Symptom	12	92.30
Reported one Symptom	1	7.30
A List of Symptoms		
Tightness	9	69.20
Swelling	8	61.60
Heaviness	7	53.80
Stiffness	4	30.80
Limit Range of Motion	3	23.10
Aching	3	23.10
Symptom-related Sleep Problems	4	30.80

*Abbreviations: breast cancer = BC, lymphedema = LE, a modified radical mastectomy = MRM, axillary lymph node dissection ALND, a sentinel lymph node biopsy = SLNB. The time since BC, surgery and LE are calculated by the self-reported surgery date, BC, LE diagnosis date and the interview date.

Table 6.1

Socio-Demographic Characteristics of the Sample

ID	**Age (yrs) (Q0)**	**Region (Q)**	**Religion (Q1)**	**Education Level (Q2)**	**Marital Status (Q6)**	**Household Size including participant (Q7)**	**Financial Adequacy (Q3)**	**Degree of Social Support (Q 8)**
01	60	South/Urban	Buddhist	Master’s degree	Single	2 (nephew)	Extremely Adequate	Excellent
02	49	North/Urban	Buddhist	Doctor of Philosophy	Single	2 (mother)	Extremely Adequate	Good
03	46	North/Rural	Buddhist	High Vocational Certificate	Married	4 (spouse and 2 children)	Somewhat Adequate	Good
04	55	South/Rural	Buddhist	Bachelor's Degree	Married	3 (spouse and mother)	Extremely Adequate	Excellent
05	62	South/Urban	Buddhist	Intermediate School	Married	3 (nephew and relative)	Extremely Adequate	Good
06	50	Central/Rural	Buddhist	High School	Married	4 (spouse and 2 children)	Inadequate	Excellent
07	71	South/Rural	Buddhist	Bachelor’s Degree	Married	3 (spouse and child)	Extremely Adequate	Excellent
08	74	East/Urban	Buddhist	High Vocational Certificate	Single	2 (sister)	Extremely Adequate	Excellent
09	55	North/Urban	Buddhist	Master's Degree	Married	4	Extremely Adequate	Excellent
10	66	West/Rural	Buddhist	Vocational Certificate	Married	6 (spouse, children, and daughter-in-law)	Extremely Adequate	Excellent
11	43	South/Urban	Muslim	Bachelor’s Degree	Single	2 (roommate)	Extremely Adequate	Excellent
12	62	South/Urban	Buddhist	Master's Degree	Married	5 (spouse and 3 children)	Extremely Adequate	Excellent
13	54	South/Rural	Muslim	Bachelor’s Degree	Married	3 (spouse and child)	Extremely adequate	Excellent

Age was calculated by interview date and birthdate.

Q25: Excellent degree of social support: great support is either given by or is available from family and friends.

Good degree of social support: more than average support is given by or potentially available from family and friends.

Fair degree of social support: compared to others, a similar amount of support is given by or potentially available from family and friends.

Poor degree of social support: while some support is available from family and friends, it's not consistently available.

Table 6.2
Disease-related Characteristics of the Sample

ID	LE side dominant/ non-dominant (Q10)	How LE was detected (Q11)	Duration of LE/ BC survival time (Q12)	LE anatomic area/symptoms (Q14)	Time post-surgery/ Radiation/ chemo (Q12)	Type of surgery/ Radiation/Chemotherapy (Q12)	Other Chronic Health Condition(s) (Q9)
01	Right Dominant	Self-detection and sought medical diagnosis	LE: 3 yrs BC: 10 yrs	Forearm, armpit, and elbow were swelling, aching, heaviness	Surgery: 10 yrs Radiation: 9 yrs Chemo: 9 yrs	Mastectomy, Axillary Lymph Node Dissection Radiation, Chemotherapy	No
02	Left Non-dominant	Self-detection and sought medical diagnosis	LE: 1 yr 6 mos BC: 2 yrs	Shoulder was heaviness and tightness led to sleep problem	Surgery: 2 yrs Radiation: NA Chemo: 1 yr 11 mos	Modified Radical Mastectomy, Sentinel Lymph Node Biopsy Chemotherapy	Seasonal allergy
03	Right Dominant	Referral by nurse, physical therapist, Or other clinicians.	LE: 7 yrs 10 mos BC: 8 yrs 6 mos	Shoulder limit range of motion fatigue, heaviness, tightness	Surgery: 8 yrs Radiation:7 yrs 11 mos Chemo: 8 yrs 5 mos	Modified Radical Mastectomy, Axillary Lymph Node Dissection, Radiation, Chemotherapy	Hypertension, Diabetes, Dyslipidemia
04	Right Dominant	Follow up with surgeon	LE: 6 yrs 6 mos BC: 7 yrs 6 mos	Wrist to elbow was swelling heaviness, tightness, stiffness, led to sleep problem	Surgery: 7 yrs 5 mos Radiation: 6 yrs 8 mos Chemo: 7 yrs 4 mos	Modified Radical Mastectomy, Axillary Lymph Node Dissection, Radiation, Chemotherapy	No
05	Left Non-dominant	Self-detection and sought medical diagnosis	LE: 5 yrs 5 mos BC: 7 yrs 6 mos	Elbow to neck, heaviness, tightness, aching, sleep problem	Surgery: 7 yrs 5 mos Radiation: 7 yrs Chemo: 7 yrs 4 mos	Modified Radical Mastectomy, Axillary Lymph Node Dissection, Radiation Chemotherapy	No
06	Left Non-dominant	Self-detection and sought medical diagnosis	LE: 7 yrs 4 mos BC: 8 yrs 7 mos	Under armpit, swelling, tightness, stiffness, sleep disturbance	Surgery: 8 yrs 6 mos Radiation: 8 yrs Chemo: 8 yrs 4 mos	Mastectomy, Axillary Lymph Node Dissection Radiation, Chemotherapy	Hypertension

ID	LE side dominant/ non-dominant (Q10)	How LE was detected (Q11)	Duration of LE/ BC survival time (Q12)	LE anatomic area/symptoms (Q14)	Time post-surgery/ Radiation/ chemo (Q12)	Type of surgery/ Radiation/Chemotherapy (Q12)	Other Chronic Health Condition(s) (Q9)
07	Left Non-dominant	Self-detection and sought medical diagnosis	LE: 3 yrs 4 mos BC: 5 yrs 10 mos	Arm and forearm, swelling, heaviness, tightness, blister	Surgery: 5 yrs 8 mos Radiation: 5 yrs 5 mos Chemo: 5 yrs 10 mos	Mastectomy, Axillary Lymph Node Dissection Radiation, Chemotherapy	No
08	Right Dominant	Self-detection and sought medical diagnosis	LE: 7 yrs 4 mos BC: 9yrs 6 mos	Arm and shoulder, limited range of motion, heaviness, stiffness	Surgery: 9 yrs 5 mos Radiation: 8 yrs 6 mos Chemo: 9 yrs 3 mos	Modified Radical Mastectomy, Radiation, Chemotherapy	Hypertension, Diabetes Type 2
09	Left Non-dominant	Self-detection and sought medical diagnosis	LE: 3 yrs 4 mos BC: 3 yrs 8 mos	Hand and forearm, swelling, aching	Surgery: 3 yrs 2 mos Radiation: 3 yrs 2 mos Chemo: 3 yrs 8 mos	Mastectomy, Axillary Lymph Node Dissection Radiation, Chemotherapy	No
10	Right Dominant	Self-detection and sought medical diagnosis	LE: 8 mos BC: 3 yrs 9 mos	Hand and forearm, swelling, tension, stiffness	Surgery: 3 yrs 8 mos Radiation: 3 yrs 1 mo Chemo: 3 yrs 6 mos	Mastectomy, Axillary Lymph Node Dissection Radiation, Chemotherapy	Dyslipidemia
11	Right Dominant	Self-detection and sought medical diagnosis	LE: 1 yrs 2 mos BC: 6 yrs 2 mos	Hand and forearm, limited range of motion swelling, tightness	Surgery: 6 yrs 1 mo Radiation: 5 yrs 6 mos Chemo: 5 yrs 11 mos	Modified Radical Mastectomy, Axillary Lymph Node Dissection, Radiation, Chemotherapy	No
12	Left Non-dominant	Self-detection and sought medical diagnosis	LE: 2 yrs 7 mos BC: 3 yrs 7 mos	Hand and forearm, swelling, tightness	Surgery: 3 yrs 5 mos Radiation: NA Chemo: NA	Modified Radical Mastectomy, Axillary Lymph Node Dissection,	No
13	Right Dominant	Self-detection and sought medical diagnosis	LE: 5 yrs 3 mos BC: 9 yrs 3 mos	Arm, tightness	Surgery: 9 yrs 1 mos Radiation: 8 yrs 6 mos Chemo: 8 yrs 11 mos	Modified Radical Mastectomy, Axillary Lymph Node Dissection, Radiation, Chemotherapy	Diabetes Type 2

*Abbreviations: lymphedema = LE, breast cancer = BC. The duration of LE is calculated by the self-reported LE diagnosis date and the interview date. BC survival time is calculated by self-reported BC diagnosis date and the interview date.

Table 6.3

Employment Characteristics of the Sample

ID	Occupation	Employment Status	Hours per wk working (Q4); Change since breast cancer and since LE	Time off between BC and RTW (Q5)	Time off due to LE (Q6)	Size of company # people	Time to commute to work (Q4, 5)	Health insurance
01	Banker (manager)	Early retired	45 hrs Early retired	4 wks	2 days	100	Drive 15 min	Social Security Scheme
02	Nursing instructor	Working full-time, no restriction	45 hrs no change	0	0	499-1000	Drive 5 min	Social Security Scheme
03	Sanitarian and a farmer (part time)	Working full-time, restrict to light duty	40 hrs, no change	6 wks	0	20	Drive 5 min	Civil Servant Medical Benefit Scheme
04	Collection officer	Working part-time, no restriction with assistance	50 hrs, before BC 30 hrs after BC	2 mos	0	50	Walk 10 min	Private Insurance
05	Tour guide	Working as a volunteer, no restriction	50 hrs, before BC 30 hrs, after BC 10 hrs, after LE	1 yr	0	50	Drive 10 min	Universal Coverage Scheme
06	Construction worker	Working part-time restrict to light duty	50 hrs, before BC 30 hrs, after LE	2 mos	0	50	Drive 10 min	Universal Coverage Scheme
07	Housewife	Working full-time as a housewife	40 hrs, before BC 30 hrs, after LE	1 mo	7 days	NA		Civil Servant Medical Benefit Scheme
08	Retired technical nurse	Working part-time With assistance	40 hrs, before BC 15 hrs, after BC (no change after LE)	1 mo	0	100-300	Walk 5 min	Civil Servant Medical Benefit Scheme
09	Director, infection control nursing	Working full-time, no restriction	40 hrs, no change	2 wks	3 days	100-499	Walk 10 min	Civil Servant Medical Benefit Scheme
10	A housewife	Working full-time restrict to the heat	60 hrs, no change	0	0	NA		Civil Servant Medical Benefit Scheme
11	In-patient Department nurse	Working full-time as IPD then move to OPD with assistance	60 hrs, before BC, 40 hrs, after BC	1 mo	5 days	499-1000	Ride 5 min	Civil Servant Medical Benefit Scheme
12	Deputy Director of Nursing	Working full-time, restricted to on-site events	40 hrs, no change	0	0	499-1000	Drive 10 min	Civil Servant Medical Benefit Scheme

ID	Occupation	Employment Status	Hours per wk working (Q4); Change since breast cancer and since LE	Time off between BC and RTW (Q5)	Time off due to LE (Q6)	Size of company # people	Time to commute to work (Q4, 5)	Health insurance
13	Out-patient Department nurse	Working part-time, no restriction with assistance (early retired from OPD nurse due to LE)	40 hrs, before/ after BC 30 hrs, after LE	2 mos	3 days	99-300	Drive 30 min	Civil Servant Medical Benefit Scheme

The findings of this study were developed from transcripts obtained from interviews with all participants. The model developed in a grounded theory study typically centers around a core theme to which all of the categories that were identified in the data are related (Merriam & Tisdell, 2015). Constant relative analysis of the interview transcripts revealed several categories and subcategories. The Return-to-Work Experiences of Thai Women with BCRL emerged as the central theme and core category. The Return-to-Work Experiences of Thai Women with BCRL (Challenge vs Hope) core aspects and categories were: (1) changing and adjusting priorities in life after BCRL; (2) challenges of returning to work with BCRL, availability; and (3) seeking out of resources and support for BCRL. These core aspects and categories lead to the final core aspect: (4) resolution by accepting and living with BCRL through time, resilience, and gratitude.

Return-to-Work Experience of Thai Women with BCRL (Challenge vs Hope)

Developing a core category as the main theme of the gathered data helps to link multiple categories and subcategories together and explains much of the data difference. The team began with interviews of a specific subset of breast cancer survivors, Thai woman with BCRL. From the transcripts and data gathered, the team was able to ascertain an emphasis on the importance of the role of and ability to work.

When cancer treatments end, cancer survivors look forward to returning to familiar routines and a sense of normalcy, such as returning to the workforce, and many cancer survivors can do so.

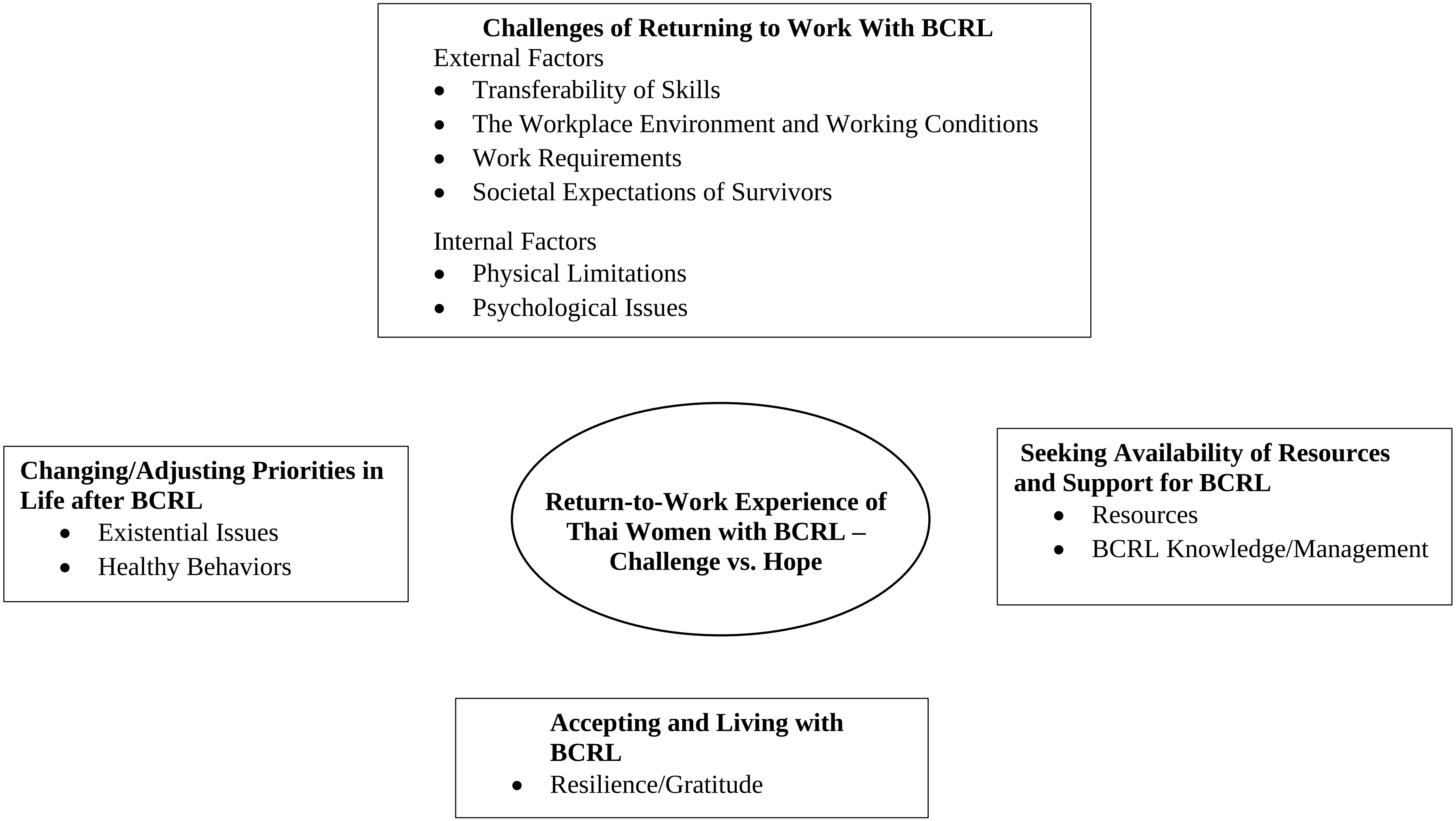
There are many benefits in returning to work, one of which is to help the cancer survivor mentally and emotionally progress further away from the idea, state, or role of being “unhealthy” by reestablishing and returning to what they normally did prior to diagnosis (Blinder et al., 2012). In some cases, however, returning to work may be further impacted by the development of BCRL.

Return-to-Work Experiences of Thai Women with BCRL (Challenge vs Hope) was then developed as the core category and explains the complicated phenomenon of returning to work with BCRL, as all participants from this study reflected on their work experience after being diagnosed with lymphedema. Based on their personal stories, their return-to-work experiences involved a variety of environments, perceptions, religions, facts, background knowledge, positions, and resources. We then moved to model how the categories and subcategories created causal conditions that influenced the core category of the return-to-work experience of Thai women with BCRL.

Despite modern advances that have led to improved prognosis and symptom management, BCRL and its treatments continue to evoke pain, suffering, and the stress and fear of developing advanced lymphedema. The return-to-work experiences of Thai women with BCRL presented challenges in living and coping with BCRL and maintaining hope in the face of those challenges. The idea of the Return-to-Work Experiences of Thai Women with BCRL (Challenge vs Hope) emerged as the core category in the data analysis, with the following core aspects also emerging: (1) changing/adjusting priorities in life after BCRL; (2) challenges of returning to work with BCRL; (3) seeking availability of resources and support for BCRL. These each led to the final core aspect: (4) resolution by accepting and living/coping with BCRL. A theory or model of how the core category and the categories interact/intersect is presented in Figure 1. Further, the women reported how their personal experience and other contributing factors influenced their work experience and the resolution of this experience, as reflected in the selected excerpts from the interviews.

Figure 6.1

A Model of Return-to-Work among Breast Cancer Survivors with Breast Cancer-related Lymphedema in Thailand



Challenges of Returning to Work With BCRL

External Factors
- Transferability of Skills
- The Workplace Environment and Working Conditions
- Work Requirements
- Societal Expectations of Survivors

Internal Factors
- Physical Limitations
- Psychological Issues

Changing/Adjusting Priorities in Life after BCRL
- Existential Issues
- Healthy Behaviors

Return-to-Work Experience of Thai Women with BCRL – Challenge vs. Hope

Seeking Availability of Resources and Support for BCRL
- Resources
- BCRL Knowledge/Management

Accepting and Living with BCRL
- Resilience/Gratitude

Changing/Adjusting Priorities in Life after BCRL

The first category of return-to-work experience of Thai women with BCRL to be discussed is adjusting priorities in life. Going back to work is not an option for every Thai breast-cancer survivor with lymphedema. In this study, participants reported why they decided to return/not return to work. These ideas are reflected in the subcategory ‘existential issues’ and ‘healthy behaviors.’

Existential Issues

Existential issues encompass an individual’s motivation and sense of purpose in returning to work after being diagnosed with lymphedema. Existential issues include aspects such as different levels of life expectations, the fight against death, life related to the future, religious beliefs and doubts, and increased awareness of values in life (Landmark et al., 2001). Participants reported their motivation to maintain employment, as they emphasized a sense of meaning originating from work. A variety of important reasons were found that motivated the participants to return to work, as work provided the practical benefit of being a source of income and employee health benefits, which then allowed them to take care of themselves and their families. Beyond the practical, participants often reflected that working helped provide meaning and enjoyment in their life along with a sense of self-sufficiency and pride.

“It is important for my household income, and I can raise my kids. Moreover, my part-time job is my hobby that I can make money.” (PT 4)

“I think income supports me by spending my own money, it makes me feel worthy. As my volunteer work, I am glad that I can support newly diagnosed patients with breast cancer to deal with it (breast cancer), to make up their mind.” (PT 5)

“Work means many things to me; let’s say work provides me with experiences, connections, income, many opportunities, and benefits for my retirement. I had worked in these fields since I graduated from nursing school more than 30 years ago. I am glad that I keep working until my retirement.” (PT 12)

Healthy Behaviors

While work had previously been considered a crucial element in their lives, after being diagnosed with breast cancer, some participants described that their attitude and priorities toward work changed, and they began to put more emphasis on their work-life balance and building good relationships at work. Supporting this, many women noted a change in their behavior, such as a lowering of previously high expectations, and that they were more flexible with co-workers and with themselves. Existential issues and lessons learned from breast cancer and from BCRL caused them to engage in behaviors that put more emphasis on the importance of their health, including having healthy relationships with work, other people, and themselves. This study finding is related to a previous study that highlighted that breast cancer patients seemed highly motivated to make lifestyle changes and changed their lifestyle habits in a significant way even without intervention (the consumption of fruit and vegetables and physical exercise increased significantly over the observation period) (Loripoor et al., 2015; Steinhilper et al., 2013).

“Also, after I was diagnosed with breast cancer, my priorities changed. I used to think my job was the most important, but I was wrong, I have realized that health is the most important. Once I was diagnosed with lymphedema, I wish I could take better care of my health and reset my priorities. As I said, your job could provide you with a high income, but it may trade with your health. So, I would like to tell you to take good care of yourself.” (PT 1)

“After I was diagnosed with breast cancer, I realized that I don’t have to be perfect. Expect everything to be perfect; yes, I used to be like that. Now, I realize that if I cannot let things go and keep holding everything, it may destroy my relationship with my coworkers.” (PT 9)

“I used to work very hard after I was diagnosed with breast cancer, I thought I would be fine and, again, I found that I have lymphedema. I have learned that I should have taken better care of my health. So, I think it is time to start focusing on my health.” (PT 12)

There were some participants who, after being diagnosed with lymphedema, made the decision to retire early or reduce their physical workload by adjusting the manner or type of work or working part-time. Participants informed the researcher that work was less important than their health and, as a result, they decided to change their job or quit their job. This result is reflected in a study by Fu et al (2013) which illustrated that removing or reduction of physical labor work or cutting back on hours may occur for a variety of reasons, including pain and limited arm movement restraining the capacity to complete activities; and feeling helpless due to loss of independence by having to rely on others to accomplish housework or job responsibility.

“I quit my job, as it was so stressful job. I am concerned more about my health conditions, as I don’t want them to get worse. I cannot work full-time, and my health status has not allowed me to deal with stressful work. I want to heal, so I quit my previous job.” (PT 5)

“I worked at the department of disease control for a year after I was diagnosed with lymphedema and now, I am a retired nurse. I have part-time work as a hotel nurse. I decided to retire early, 10 years sooner than I was supposed to. I made a decision after I had checked my benefits and my family agreed with me. I decided to retire early, as I don’t want to deal with stress, and I have enough benefits from my retirement.” (PT 13)

Participants reported that after being diagnosed with breast cancer and BCRL they realized that there is nothing more important than their family.

“Hmm, I think it depends on the situation. Let’s say, before I was diagnosed with breast cancer and lymphedema, I emphasized my work/career as the most important thing, but now my family is the most important.” (PT 9)

Challenges of Returning to Work with BCRL

Once Thai women with BCRL made the decision to return to either paid or unpaid work, it was inevitable for them to deal with challenges, which developed into this second category of the return-to-work experience of Thai women with BCRL. Many women expressed a variety of challenging experiences once they decided to return to work, due to their physical limitations. Once lymphedema occurred, women reflected that this complication and its symptoms interfered with their work performance. For some, their physical limitations inhibited them from keeping their previous job. However, many participants were able to work at the same job, as their work demands did not require physical abilities beyond their current capabilities.

Whether participants changed or did not change their job, it is evident that all Thai women with BCRL had problems in varying degrees with BCRL while they were working. Many participants reflected on unpleasant feelings when other Thai people viewed the participants negatively for having BCRL. Moreover, pain and distress caused by BCRL had psychological effects, such as stress, depression, or anxiety. These ideas are further shown in the two sub-categories of external factors and internal factors. These factors have been categorized according to the participants’ information.

External Factors

External factors are those uncontrollable work-related environmental, physical, societal, or economic factors taking place outside the participants’ control or influence that are affecting the participant’s ability to find or maintain work. Frequently, these factors may be controlled by the labor law of Thailand which lays down the foundation of the rights, duties, and obligations for both employers and employees. Additionally, further workplace requirements can be implemented by the employer within the private sector. Other factors are societal perceptions and how those influence expectations on who can and cannot work, how work should be performed, and whether someone is performing or has the capability to perform their duties adequately.

Transferability of Skills

This subcategory refers to the ability, experience, knowledge, and skills of breast cancer survivors with BCRL that can be transferred to a new job or work role, if required, or in making adjustments to their current work role. These qualifications helped participants to return to work and keep their career before and after being diagnosed with BCRL. Most participants were able to keep their work after being diagnosed with lymphedema, as their jobs were not physically demanding. While some participants did have to change jobs due to their physical limitations and restrictions after being diagnosed with BCRL, many of these were still able to keep and maintain their work within their overall career field, as they could transfer their skills and knowledge to new job roles within that career. For example, two participants reported a change in job/role from their previous work as registered nurses, which required them to perform physically to provide bedside care/ total care. When BCRL limited their physical capabilities in performing those duties, they were provided options for continued employment.

“They recommend I have to find or should be transferred to a job that fits my limitations. They are happy for me that I was transferred from an Inpatient Department nurse (IPD nurse) to an Outpatient department nurse (OPD nurse), as they think I have more time to take care of myself and also fewer bedside care and nursing procedures at OPD.” (PT 11)

“I worked at the department of disease control for a year after I was diagnosed with lymphedema and now, I am a retired nurse. I have part-time work as a hotel nurse. You know, I work as a hotel nurse. The manager told me that I can work with them as long as I want. They know my limitation, but they offer me to work with them if I want to.” (PT 13)

The Workplace Environment and Working Conditions

This subcategory refers to the requirements of a physical location where participants work for an employer, the social environment and aspects of their workplace and co-workers, and the physical requirements necessary for participants to perform their job. In some cases, participants received information about BCRL from healthcare providers and decided that their health status and condition would not be compatible with their previous work environment.

“As a construction worker, I was responsible for a number of on-site tasks, such as removing debris, erecting scaffolding, loading and unloading building materials, and assisting with operating heavy equipment. It requires strong physical health to complete each task. After being diagnosed with lymphedema, I have to avoid the heat, I could not work as a construction worker as a part-time job anymore.” (PT 6)

“As an IPD nurse, I think this job requires you to be a healthy person: I meant you are healthy, and you can deal with an 8-hour shift rotation schedule like you have to work a night shift or an evening shift. So, my previous job requires healthy and young people to work in this job.” (PT 11)

Work Requirements

Work requirements refer to activities involving mental or physical effort done in order to achieve a purpose or result. Participants reported that they were suffering from their condition, and they could not work as effectively as before. Though most participants reported that they could still complete their tasks, they had to spend more time to complete them than they did before being diagnosed with BCRL. Two participants mentioned the emotional and mental impact of being unable to perform or complete their previous work requirements.

“Also, I am a breast cancer survivor with lymphedema; during COVID-19, I am not allowed to go outside, and I couldn't go to the breast cancer center; that makes me feel sad.” (PT 5)

“As far as the doctor and my head of IPD are concerned about patient safety, as well. My current boss is worried about my condition, as I may not have sufficient competence to perform an OPD job due to my sickness.” (PT 11)

Moreover, heavy workloads that were manageable prior to, but not after, BCRL were one of the factors that made it more difficult for participants to complete their tasks and take care of themselves.

“As you may know, working as an OPD nurse is very busy and overwhelming, especially in a public hospital. Sometimes, I have to skip lunch or get off work pretty late. So, don’t expect me to take a break or perform shoulder exercises during work.” (PT 11)

“I have never worked part-time. My full-time was super busy; I had worked overtime, but I did not get paid for overtime. Also, I sometimes had to skip/postpone the rehabilitation appointment because it was a busy day.” (PT 12)

Societal Expectations of Survivors

This subcategory refers to the negative or discriminatory attitudes that Thai people have toward Thai women with BCRL due to a general lack of knowledge and social stigma involving people with illness in the workplace. This can lead to misunderstandings, pre-conceived notions, or unfair treatment of breast cancer survivors with BCRL. This furthered the difficulty in returning to work and the hope of finding a sense of normalcy for some participants.

“Some people might use their sickness to take benefit from other people, like begging for more opportunities to work or donating some money. Thai people believe in giving and donating, as they think it is a good deed. You are not supposed to return to work; you must take care of yourself. You risk your life if you return to work. People think that cancer weakens us, and we should not work; we should save our lives.” (PT 4)

“Most people believe that if you have cancer, including breast cancer, you will eventually pass away from it or its treatment. In general, many people think breast cancer survivors may not be able to return to work or after you were diagnosed with any kind of cancer.” (PT 12)

In Thai culture, women are also expected to fulfil their roles as a wife, a mother, or a daughter. Two participants reported they could not fulfill the role society expected due to BCRL; as a result, this made them feel guilty.

"I cannot do some chores, like cooking, cleaning, and gardening. My mom cooks for me and she is pretty old, but still healthy. It is a shame that I am supposed to take care of my mom." (PT 4)

"My daughter told me that she will apply to the university in our hometown, as she would like to stay close to me and look after me. It makes me feel both happy, but also sad, that she would go to the big-name university, rather than worry about me." (PT 5)

Participants also stated their unpleasant feelings when they were overprotected by Thai people.

"I feel uncomfortable when people treat me like I am sick. I would like to tell them that, yes, I was diagnosed with BCRL. I am ok right now." (PT 1)

"It seems like many people think that breast cancer survivors cannot return to their normal lives. They (Thai people) think that breast cancer survivors are fragile, need extra care, have to be careful about everything. Also, when you are diagnosed with cancer, people always pity you. It is ok for caring and worrying about me, but not too much, as it makes me feel awkward." (PT 3)

Participants reported experiences of body shaming. They shared that people embarrassed them by making inappropriate or negative comments about BCRL.

“I was frustrated. I don't like it when someone asks me if I gain weight, I do not gain weight. I told them that my affected arm is bigger than the other because of the complication after breast cancer treatment.” (PT 5)

“Yes, it bothered me when I went shopping at a fresh market and a vendor asked me what happened to my arm. Some people stared at my arm and made me have unpleasant feelings.” (PT 7)

Internal Factors

Internal factors are the experiences that impact, influence, relate to, belong to, exist within, or are derived from the participant’s mind, feelings, or sense of self that can be managed by the participant. These were found to be most evident in the participants’ reactions to their physical limitations or psychological issues. These experiences can have a negative impact on mental health and reduce the participant’s capability to return to work, but also influence their emotional and psychological well-being in general.

Physical Limitation

BCRL may cause physical limitations which reduce a breast cancer survivor's ability to perform social, familial, and occupational tasks and, as such, to obtain rewards and fulfillments typically derived from those activities. As a result, most participants reflected on their feelings about BCRL and how it impacted their emotional well-being. All participants reported that their normal lives are disrupted and changed by BCRL treatment and its symptoms. Participants were aware of the need to protect their affected arm which led them to subsequently lead a more cautious lifestyle. Moreover, as a result of their limitations, they expressed their feelings of “demotion, uselessness, and insult” when they were at work.

“Some of our clients are bedridden, and I cannot help their caregivers and my student turn patient’s position. It (BCRL) bothers me as I cannot work fast, like before. I need to take a break. I cannot do gardening.” (PT 2)

“I love gardening, and I still love it, as it is my hobby. I cannot do gardening much after I have lymphedema. I cannot do mopping, gardening, and cooking. I have to protect my affected arm from the heat, so I have to wear long sleeves, as I want to protect it from the sun rays.” (PT 8)

Psychological Issues

Participants reported that BCRL caused them to be more cautious with their life, made them frustrated, and caused them to make sacrifices to protect the affected arm. Participants reflected that they have tried to be more careful with their affected arm and that it is a constant concern and source of worry and stress, as they want to keep it safe.

“I cannot do gardening because it makes my affected arm get worse. I was unhappy and frustrated as I cannot do things like I used to. I must be more careful when I use my affected arm. I have to stop gardening as I don’t want my affected arm to get injured or get worst.” (PT 2)

“Sometimes it does not work perfectly, as my dominant hand is my affected arm. So, I have to be more careful and aware when I am doing something. I have to remind myself that I cannot use my affected arm like before.” (PT 5)

Seeking Available Resources and Support for BCRL

In the third category of Return-to-Work Experiences of Thai Women with BCRL, participants detailed their experiences when seeking available resources and support. Women frequently used the word “hesitant, dependent, or useless” to describe how they felt when others failed to understand their ongoing symptom burden, limitations, and an intensified need to find meaning in their lives. Among the participants, two different types of support were identified that helped them to find a sense of personal meaning, which is discussed in the next section. The first type of support identified was BCRL knowledge and management, which referred to support from health care professionals, such as doctors, psychologists, nurses, and social workers. Participants sought professional help in several ways, as they wished to manage their BCRL properly. The second type of support identified was resources, which referred to assistance, care, and help from friends, co-workers, neighbors, and family.

BCRL Knowledge and Management

Participants who did not receive their cancer treatment from cancer centers and private hospitals reported that they were not informed about the risk or preventive measures for BCRL. All participants emphasized the importance for newly diagnosed patients with breast cancer to receive facts and information about BCRL, including education, preventative measures, and management skills. Moreover, participants expressed the need that this information be provided to breast cancer survivors before they are diagnosed with BCRL, rather than after, as it could help them to reduce the risk of developing BCRL to begin with.

“When I was diagnosed with breast cancer, I don’t think I got any information from anyone about lymphedema. I myself, as a breast cancer survivor, don’t even know that I would have lymphedema after breast cancer treatment. I found it by myself when my right scapular had hurt so bad and my right shoulder was full and heavy; then I went to see a doctor, then I was diagnosed with lymphedema.” (PT 1)

“I joined the breast cancer group, and there are 300 breast cancer survivors in the group. I asked people in the group if anyone had a swollen arm, tightness, or heaviness on the surgical side. Yes, only me that have lymphedema, and I found it myself.” (PT 5)

After being diagnosed with BCRL, most participants reported that they did receive more information about BCRL from healthcare providers like nurses, doctors, and physical therapists. All participants reported that they did not receive specific information, advice, or intervention from an occupational therapist, which would have been useful in providing specific information related to their work.

“I am around people who have experience and knowledge about lymphedema. I have a good relationship with a physical therapist. She provides me with a lymphatic massage at home every week. Also, my daughter tells me how to take care of and protect my affected arm”. (PT 5)

“I went to get treatment at the Breast Cancer Center and health care providers (oncology nurses) there are so nice. They provided me with information about breast cancer treatment and its complications that may occur after completing the cancer treatment. Hmm, they did not provide me any advice about returning to work; they just told me that I may have lymphedema after breast cancer treatment.” (PT 6)

Participants that were able to surround themselves with people or co-workers who had knowledge of BCRL reported a positive environment and feeling at work.

“My workplace has healthcare providers who work at a cancer center. They always encourage me to perform shoulder exercises.” (PT 3)

“All my co-workers are healthcare providers, so they always provide me with information to prevent the progression of lymphedema. Also, my workplace has a rehabilitation center, so it is convenient to get lymphedema treatment.” (PT 12)

However, for some participants, learning more about BCRL and the efforts involved with trying to manage it conflicted with their ability to perform their work. They either had to make sacrifices in their work performance or proper management of their BCRL. This resulted in negative experiences at work, as they increasingly tried to take more precautions to protect the affected arm and learned to avoid some tasks, slow down when they worked, or quit some BCRL treatments altogether, such as wearing a compression garment. A participant who was in ongoing BCRL treatment perceived that wearing the compression garments during work interfered with her professional appearance.

“When I used my affected arm like typing or working on the computer for a whole day, I can feel its fullness. So, I remember to stop working and take more breaks to perform shoulder exercises before my affected arm starts hurting. Gardening is my favorite hobby, and I cannot do gardening, as I have to protect my affected arm.” (PT 2)

“I could not wear any garment or bandage during work, as it irritated my affected arm and caused of itch.” (PT 4)

“Lymphedema lowers my confidence. Moreover, when I had to wear a compression garment, I thought I looked sick, and I was not looking good or professional.” (PT 12)

Participants also reported how work interfered with their BCRL management. To find more time to do BCRL management properly, some participants found it necessary to reduce their workload, such as taking early retirement or changing to work part-time.

“I deal with it (my affected arm) easier after my retirement, as I also have more time to perform shoulder exercises and go to rehabilitation whenever I need to.” (PT 12)

“I decided to quit my former job as an OPD nurse because of the heavy workload and multiple frustrations. I did not have time to take a break and I did not have time to pay attention to my affected arm much. I talked to my doctor, and it is a great decision I have made. Also, I know I do have to take better care of my affected arm, so it would be smart to find a new job that fits my limitations.” (PT 13)

Resources

The participants thought that being able to access or find resources for support helped them to complete their tasks, keep their job, or find new jobs. Physical and emotional support from their family, friends, and co-worker were some of the positive resources that helped these women accomplish returning to work.

“Yes, my job required me to do the same tasks (chores, mopping, ironing, cooking, and cleaning) thing, but, once, I was diagnosed with breast cancer-related lymphedema, only my daily activities were changed. I have to hire a housekeeper to clean up my home.” (PT 1)

“My team was so thoughtful, they offered to help me. I did not ask, they just did so many tasks for me during the pandemic. As I mentioned earlier, they offered to help me carry stuff and my boss knew: sometimes when we had community events, my boss told me not to go, as it might be risky for my health conditions.” (PT 12)

In contrast, three participants experienced a lack of resources or support which made it difficult to meet job requirements.

“I cannot lift heavy things. I have to wait for someone to help me do it. I cannot complete all my tasks by myself. I need someone to help me to do things.” (PT 4)

“I have to wait for my husband to help me carry things and I also cannot work as a food seller by myself because I cannot do the whole task.” (PT 6)

“I used to do many things by myself, like riding a motorbike; currently, I have to wait for my husband. Sometimes he’s not available, so I have to change my plan.” (PT 10)

Having a good relationship with family and partners further facilitated Thai women with BCRL by having a strong support system outside of work.

“My relatives and my neighbors always help me and ask me if I need help. They are so nice; they are worried about me.” (PT 4)

“My family never expects me to work hard; they always support me. My family helps me to complete my work like my husband helps me to work together because he knows that I have to be careful about my affected arm and I am not allowed to carry heavy things.” (PT 6)

Understanding limitations and receiving both physical and psychological support from co-workers (or family as co-workers) further facilitated the return-to-work experience.

“I just work with my husband, so I don’t have any problem. My husband and my family understand me; they support me. My family always supports me by lifting things, doing chores, cheering me up, checking on me, calling me, and showing me how much they love and care about me. My daughter calls me every day to check on me.” (PT 4)

“I think people whom I work with have enough information about lymphedema. So, they clearly understand what happened to me. Moreover, they do know what I can, and I cannot do.

They let me be a part of all their work, even though I don't get any income from working there. I am so happy to help people who have just been diagnosed with breast cancer.” (PT 5)

Accepting and Living with BCRL

The last category of Return-to-Work Experience of Thai Women with BCRL is accepting and living with BCRL. This category emerged as the participants accepted and embraced BCRL as a part of their life. Women often reported that it took them a while to accept BCRL and train their minds to focus on positive things that happened after being diagnosed with BCLR. Upon acceptance, participants recognized that BCRL would not “change their lives” if they “accept it as a part of their lives and it won’t get worse if they constantly take care of it.” Moreover, they realized that they did not need to explain their condition to everybody solely to make others feel better or more comfortable. Many women reported that they also employed their religious practice to help them train their minds to deal with uncertainty. Two subcategories of accepting and living with BCRL were Time and Resilience/Gratitude.

Time

Participants found acceptance as time went by and they better learned to live with and manage the reality of their BCRL.

“It took me a while to accept it and learn to live with it. It took me a year to accept that I have breast cancer.” (PT 1)

“I spent my time for a year accepting and living with it. I still feel uncomfortable with it, but I have accepted it as a part of my life.” (PT 10)

For some participants, time and aging helped them to manage acceptance, as they viewed illness as an inevitable part of getting older. Additionally, having more life-experience better prepared them with the ability to cope.

“Hmm, not really, but I do believe in natural law, and I am getting older, so I just accepted it easier than many survivors.” (PT 1)

“I think I have dealt with my sickness well, as I was diagnosed with breast cancer when I was old. It is easy to believe that it is normal to get sick when you grow old.” (PT 8)

With the passage of time after being diagnosed with BCRL, participants obtained more information, self-awareness, and personal experience in dealing with their BCRL. Time helped them to accept their condition and maintain positive and hopeful outlooks, while also managing in the present and preparing realistically for the future.

“Not, really. It may not be gone, but if I take good care of myself, it will not get worse.” (PT 1)

“I don’t think it will change my life. I just learn to live with it and take care of it.” (PT 2)

Resilience/Gratitude

Resilience - the ability to resist the manifestations of clinical distress, impairment, or dysfunction which is often associated with critical incidents, acts of terror, mass disasters, and personal trauma - describes the capacity of Thai women with BCRL to recover rapidly from obstacles and difficulties. To strengthen their resilience, many participants decided to set personal boundaries. For example, they were not required to explain their condition to everyone, which helped them to return to a sense of normalcy and helped to prevent experiencing an invasion of privacy by people.

“I don’t have to tell them much about my sickness as I still can work. I think it is my personal thing, so I don’t share it with my co-worker. They just know that I was diagnosed with breast cancer and received breast cancer treatment.” (PT 2)

“I personally don’t share my sickness with my relatives and my neighbors, especially during the time I have been diagnosed with breast cancer and also lymphedema. I want to keep it private.” (PT 7)

Participants reflected that once they could accept their condition, it helped them live with BCRL more serenely. Participants perceived their acceptance as a gesture of gratitude: as opposed to acting as the victim and asking, “why did this happen,” they chose to reflect and learn about their own capabilities and strength from BCRL, and they appreciated the opportunity to grow as a result.

“I used to hide my affected arm and wore long sleeves to cover it. I did not want to answer people’s questions. I wanted to keep my privacy. It took me a while to make up my mind and now those feelings do not bother me anymore. Now, when people ask me, I tell them that it is a side effect of my cancer treatment.” (PT 1)

“I still feel uncomfortable with it (BCRL), but I have accepted it as a part of my life. I used to focus on how people think about me, but now I have learned to focus on myself. I am trying to take care of my body and mind.” (PT 10)

After being diagnosed with lymphedema, participants reported that they have learned to focus more on positive life changes. Participants expressed that, in this way, their overall view of life has changed: they could find life more meaningful and could resolve to keep doing their best while living with lymphedema.

“My bright side is my body tries to warn me that it’s time to take better care of my health. Anyway, I think being a breast cancer survivor has taught me to learn to accept things in our lives, learn to let it go, and learn to live with it.” (PT 1)

“I think my family supports me more than before; I don’t know, I think it is because we are so scared of our time to spend together is shorter, so we have tried to be nicer to each other since I had been diagnosed with breast cancer.” (PT 7)

“Hmm, I don’t think it has changed in anything, my relationship with friend and co-worker(s) may be changed in a positive way. People showed me how they care more about me. Also, I want to spend my time with my family and friends to be more meaningful.” (PT 8)

Many women reported that they found strength and comfort in employing their religious practice to help them practice acceptance and serenity in living with BCRL.

“No, I don’t think about the future much. I just focus only on the here and now. I have learned that being conscious (mindfulness) is the most important. I follow Buddha’s teaching. I pray every night and every morning I wake up early to give alms to the monk.” (PT 8)

“So, I am trying to take better care of my body and my mind. I normally don’t pay attention to my religion. Now, I realize that it helps me a lot to survive by following the guidance and reading and learning more about Al-Quran.” (PT 11)

However, for those participants who had financial issues or difficulties and were not able to return to work as normal or at all, this resolution was not always obtainable. They continued to experience stress and shame at feeling unable to support themselves and their families financially, but also experienced negative and unpleasant feelings regarding their own sense of value, purpose, and meaning. This further emphasizes the importance of educating and improving knowledge of BCRL and its impact on the return-to-work experience, and overall quality of life experiences, of Thai women.

“As a mother, I am supposed to take better care of my kids. I should have made more income to support my family and I wish I could work like before. My kids are in high school, and they need financial support from me. It is hard to accept that I cannot work part-time to support my family. My husband keeps telling me to stop over-thinking and let things go. I cannot sleep well, and I am worried about my kids and my family’s income. I am trying to let it go, but my affected arm keeps reminding me to think about my limitations.” (PT 3)

“I'm worried that our family does not have enough income. I wish I could be able to work more, so I could make more money to support my family. Also, I wish I could take care of my family better if I were not diagnosed with breast cancer.” (PT 6)

Summary of Findings

This chapter presented the findings from the data analysis of this research study for 13 Thai women. The main goal of this research was to examine Thai breast cancer survivors’ perspectives on how BCRL affects their employment and related quality of life, as well as the culturally influenced contextual facilitators and barriers that they faced as they returned to work in Thailand. The participants engaged and adjusted in the process of returning to work after completing breast cancer treatment. Participants’ ability to be “normal” and participate in activities with the world had been adversely affected. Thus, they often felt that the opportunities and support that enabled them to continue with their lives when completing breast cancer treatments were important.

Discussion

Return-to-Work Experiences of Thai Women with BCRL (Challenges vs Hope)

The return-to-work experience of Thai women with BCRL was the core category that emerged in this study. This basic biopsychological process that emerged from this study describes several aspects that women process as they deal with BCRL treatment and its symptoms. The multiple and varying return-to-work experiences of Thai women with BCRL could act as a barrier or as a facilitator, depending on the perception of an individual woman and the context of her work environment. The categories that emerged indicate that, for these women, returning to work was a complex experience. When the process of returning to work was embarked upon, it was inevitable to deal with challenges and participants reevaluated their priorities in life. Three categories (changing/adjusting priorities in life; challenges of returning to work with BCRL; and seeking available resources and support for BCRL) developed as categorized answers to the research questions of this study, as they illustrated factors that can be barriers and/or facilitators for Thai women with BCRL. The final category, accepting and living with BCRL, was a response to and resolution of the prior three phenomenon in response to challenges faced and maintaining hope among survivors.

Changing/Adjusting Priorities in Life after BCRL

The first category of the experience of Thai women with BCRL returning to work is adjusting priorities in life, which was influenced by: the reason(s) for returning to work, the goals for breast cancer survivors with BCRL when returning to work, and how BCRL influences the decision to return to work. Many participants reported that they reduced their workload in effort to have a healthier lifestyle, which corresponds with prior evidence that indicates that people at risk of chronic diseases prioritize their goals and expectations to achieve satisfaction (Sharpe & Curran, 2006). One identified subcategory of adjustments to priorities is existential issues. Existential issues involve or relate to an individual’s sense of life purpose/perspective derived from their work, which may become influenced by BCRL. Many patients reconsidered the type of work they did and the amount of time they spent doing it. This "changing of priorities," as it has been called in prior research, has been found to both encourage and discourage certain cancer patients from returning to or remaining at work (Steiner et al., 2008). The results illustrated that there was something unique about each participant's experience with BCRL based on their values, marriage status, age, financial status, and benefits, as well as their view of the world and its resources.

Challenges of Returning to Work with BCRL

Even though, a majority of participants could continue their former jobs as their job had fewer physical requirements such as a lecturer (PT 2), a director (PT 9) and a deputy director of nursing (PT 12). Some of participants had to change their job but could continue their career as nurses such as PT 11 and PT 13. Many participants could not keep their previous jobs which had physical requirements For patients suffering from lymphedema, jobs requiring heavy lifting, physical exertion, or other physical strain are not suitable (Fu, 2008). The subcategory external factors, such as societal expectations of survivors (in the Thai culture) hurt survivors with BCRL when they return to work; the findings also illustrated that work demands interfered with BCRL management. For example, participants reported their feelings of guilt, as they could not fulfill their wife or mother roles. This result is associated with a study in Japan by Tsuchiya (2015) which found that the participants suffered from physical limitations that impaired their daily activities, leading them to feel guilty and question whether they should continue to fulfill their normal social roles. In addition, participants reported their unpleasant feeling due to negative or discriminatory attitudes that Thai people have about illness. This was related to the study in Japan (Tsuchiya et al., 2015) which revealed that many participants had encountered unsupportive reactions from others and experienced people's negative belief about cancer (“Still, cancer equals death to some people”). Moreover, according to participants’ information, this category illustrated a negative BCRL impact on work-related quality of life, in describing a subcategory of internal factors of physical limitations and psychological issues. The findings of a previous study indicated that BCRL is a serious outcome of breast cancer treatment with lifelong implications on function, psychosocial health, and quality of life (QOL) (Armer et al., 2020).

Seeking Available Resources and Support for BCRL

Most participants required resources and support to complete their work-related tasks as they hoped to live with BCRL serenely. Resources, such as support from family, friends, and co-workers, are crucial for participants. Resources facilitate survivors’ ability to complete their tasks and work demands. Some of the benefits of resources, such as family support and co-worker support, were that they provided encouragement, physical assistance, and comfort. According to a systematic qualitative review, family members should participate in survivors’ lymphedema self-management, help survivors prioritize self-management, and rebuild a balance between different roles (Fu et al., 2022). As a result of receiving support, participants reported being better off and being able to handle work challenges better. Many participants reported that they should receive BCRL knowledge at the right time, so they could deal with this complication effectively. A systematic review of qualitative studies by Fu et al (2022) illustrated that, overall, survivors received inadequate and delayed education on lymphedema self-management.

Accepting and Living with BCRL

Finally, participants chose to develop and embrace gratitude by appreciating the support and understanding received from others or by doing good things for themselves and for others. Receiving support from family, co-workers, and friends helps participants deal with BCRL and face the challenges of returning to work, which in turn helps them to maintain hope and support mental wellbeing. These findings related to a previous study that determined that individuals' ability to manage their emotions contributes to how they perform in their roles and how they manage their health (Van de Velde et al., 2019).

Accepting and living with BCRL had two subcategories: resilience/gratitude and time. This category was developed as the participants' return to work experiences revealed their ability to manage BCRL, adaptability to obstacles, resilience and accepting how BCRL affects their everyday lives. This further emphasizes the importance for survivors to receive sufficient resources and support to facilitate accepting and living with BCRL and that the entirety of the experience, the unique needs and characteristics of the woman living with BCRL and their context, must be considered in developing methods of prevention and management. This related to a previous study illustrated that it is important for women with breast cancer to adapt to this life-threatening disease and to cope with the side effects of treatment, regardless of their age, ethnicity, or stage of life (Sammarco, 2009).

Conclusion

In contrast to breast cancer survivorship, BCRL has received less public education and awareness. Although employers, colleagues, and clients did not understand BCRL well, participants often overestimated or underestimated survivors' abilities, as well. The results of this study have demonstrated a useful way of describing the meaning and impact of the life and work experiences of Thai women with BCRL based on grounded theory. With data excerpts from the interviews with participants, we explained and illustrated the subcategories of changing/adjusting priorities in life, returning to work with physical limitations, seeking resources and support, and accepting and living with BCRL. Returning to work after breast cancer will be improved, and long-term burdens of cancer will be reduced if factors driving return to work with BCRL are addressed.

Implications for Cancer Survivors

Our findings regarding barriers, contextual factors, and coping strategies will inform future studies aiming to develop evidence-based assessment and intervention strategies to maximize return to work. An interdisciplinary approach to assessment and intervention may be the most beneficial way to deal with the complexity of individualized care, which appears to be necessary based on the multiple interactions and factors observed. A team of nurses, physicians, psychologists, social workers, physical therapists, occupational therapists, physical therapists, and others could assist patients with their occupational goals.

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CHAPTER SEVEN

DISCUSSION OF THE FINDINGS

This chapter examines the subjective work experiences of Thai women with breast cancer-related lymphedema (BCRL), offers interpretations of the results, and integrates the findings with existing literature. The model that emerged from the data analysis was "return-to-work experience of Thai women with BCRL" (Figure 6.1). After being diagnosed with BCRL, Thai women crafted the return-to-work experience to overcome their limitations. This experience included hope or challenges. Thirteen participants in this study used it in some form or capacity to complete work they faced with BCRL, its treatment, or its symptoms in some capacity. This study found that BCRL had an influence on the return-to-work experiences of Thai women with BCRL. These experiences could be viewed as a barrier to returning to work due to physical limitations, as well as psychological issues associated with physical limitations and societal expectations, or as a facilitator to returning to work through BCRL knowledge obtained from healthcare providers, and the support of family, friends, and coworkers. This section will compare the results from this study with the literature review that was presented in Chapter Two.

Discussion

Return-to-Work Experiences of Thai Women with BCRL (Challenges vs Hope)

The return-to-work experience of Thai women with BCRL (Challenges versus Hope) was the core category of the model that emerged in this study. The four categories of the return-to-work experience of Thai women with BCRL that emerged during the data analysis were: (1) changing/adjusting priorities in life after BCRL; (2) challenges of returning to work with BCRL; (3) seeking availability of resources and support for BCRL; and (4) accepting and living with

BCRL as a resolution of this phenomenon. This basic biopsychological process that emerged from this study describes several aspects that women process as they deal with BCRL treatment and its symptoms. Return-to-work experiences of Thai women with BCRL were a phenomenon in this study, and these experiences could act as a barrier or as a facilitator, depending on the perception of an individual woman and the context of her work environment. It was difficult for individuals to handle the side effects of the BCRL and its treatment, as well as feelings of fear, anger, depression, and loneliness. Participants reported that they kept focusing on positive things in their life. Maintaining a positive attitude can be achieved by setting realistic, attainable goals. Another helpful way was to focus on activities that provide participants satisfaction such as working as a volunteer (PT 5). The best way to cope with BCRL is to maintain a positive attitude.

Many participants expressed that they were uncertain of the future of BCRL, as well as breast cancer. Hope was what kept many participants alive as they endured BCRL treatments, as well as social and personal challenges. Hope was supported by the positive attitudes of the healthcare providers, but can also be very fragile. Anything that demoralizes a person can negate the feeling of hope, which can make a difference in accepting or denying the next set of treatments if a failure occurs. The feeling of hope varies daily depending on the participant’s current physical status, psychological issues (depression or isolation), and treatment success or failure (Rosenbaum, 2023). The hope is to be kept alive, to live, and to recover through a resilient attitude, rather than a feeling of despair (Rosenbaum, 2023). Hope keeps one alive to fight for another day, a month, a year, and a return to better health. It affords another opportunity to respond to therapy and to live.

Returning to work is a part of returning to normality after the cancer experience, a situation that encompasses all life experience elements, from ideals and values to desires and dreams to relationships and plans. For those who have survived wounds and have had to deal with the challenges that come with living a life after them, it is a particularly vivid experience (Chen et al., 2017). The next section will draw a connection between the literature and the specific stages or subcategories of this biopsychosocial process of the return-to-work experience of Thai women with BCRL.

Changing/Adjusting Priorities in Life after BCRL

After being diagnosed with breast cancer and BCRL, many patients reconsider the type of work they do and the amount of time they spend on it. This "changing of priorities," as it has been called in research, has been found to both encourage and discourage certain cancer patients from returning to or remaining at work (Steiner et al., 2008). Evidence suggests that people at risk of chronic diseases prioritize their goals and expectations to achieve satisfaction (Sharpe & Curran, 2006**).** Moreover, there is a need to explore more about the relationship between adjusting priorities in life after BCRL and sociodemographic data which may guide future research to conduct interventions supporting an individual's goal.

This current study found that participants (PT 1, PT 13) who could use their career benefits, such as qualifying for retirement age, might be satisfied with their work life and they might not hesitate to choose early retirement. Alternatively, breast cancer survivors who were at working age might not be satisfied with their work-life yet, and also might not be qualified to use all of their career benefits. It is important to explore more about financial factors and the need for support to return to work among different ages of cancer survivors. In addition, economic effects and costs relating to work disability, work-related problems, and decreases in productivity of breast cancer survivors with BCRL need to be evaluated.

The findings from our study illustrated that participants (PT 3 and PT 6) reflected that BCRL and its symptoms had a negative influence on their work. PT3 could not keep their part-time work as a farmer, and PT 6 could not keep her previous work as a construction worker; as a result, they had to change their jobs and lost income. Health-related quality of life (H-RQOL) has also been emphasized as an essential aspect of employment in medical literature. Researchers have emphasized that people have had to adjust to returning to work after a diagnosis, such as changing employers, reducing their hours, or changing their workplace to adjust their aching limbs (Fong et al., 2018). It is important to provide cancer survivors with an opportunity to consult with occupational therapists and occupational therapy assistants which could help participants identify strategies to adapt. It can facilitate participants’ ability to perform tasks at work or in their homes.

Many participants (e.g., PT 11, PT 13) informed the researcher that they tried to reduce their workload by reducing hours and/or physical tasks and hiring or letting someone do household chores (PT 1). Participants emphasized protecting their affected arm and would like to take better care of their health. Removing the workforce or reducing hours happened for several reasons, such as pain and restricted arm movement that made it difficult to complete tasks, infections that prevented workers from reporting, restrictions on the use of compression sleeves or gloves in certain occupations, decreased mental health, worry about job security because one was unable to carry out assigned responsibilities, and depression, especially when one's professional responsibilities are disrupted, and feeling powerless as a result of losing one's independence and being forced to rely on others to complete household chores or fulfill professional obligations (Fu et al., 2013). It is important to emphasize that the severity of lymphedema and symptoms of lymphedema are considered as the factors that influence the decision to return to work among breast cancer with BCRL, especially survivors who are manual workers.

Challenges of Returning to Work with BCRL

BCRL influences both the physical and psychological well-being of all participants. BCRL may negatively impact a patient's mental health, health perception, and body image, which may restrict their participation in social life and job duties. As a result of swelling and infection in the dominant hand and arm, patients may be physically restricted in their activities and unable to engage in recreation, household, and mobility-related activities. The findings of a previous study indicated that BCRL is a serious outcome of breast cancer treatment, with lifelong implications on function, psychosocial health, and quality of life (QOL) (Armer et al., 2020). Additionally, Bulley et al. (2013) investigated the physical and mental stress connected to lymphedema, observing that participants with lymphedema experienced greater hardship than those without lymphedema, with a doubling in the rate of discontinuing work or reducing hours (Bulley et al., 2013). It is typical to have a changed perspective on work after receiving a cancer diagnosis. In the results from a qualitative study in Japan, all of the participants suffered from physical limitations that impaired their daily activities, and they felt guilty and questioned whether they should continue to fulfill their normal social roles (as mothers and wives) (Tsuchiya et al., 2015). Moreover, many participants in this current study had encountered unsupportive reactions from Thai people and experienced people's negative beliefs about cancer which was, similar to the previous study by Tsuchiya et al (2015) who reported: “Still, cancer equals death to some people.”

This study explored the return-to-work experience of Thai women with BCRL, and the results reflected on the employee’s perspective. Thus, the exploration of experiences of workability and employment of cancer survivors from other perspectives, such as employers and co-workers, is crucial. Moreover, there is a need for a study of health policy or public policy to support cancer survivors to return to work.

Seeking Availability of Resources and Support for BCRL

This study found that BCRL knowledge and management are necessary for participants. Although many participants reported that they recognized BCRL resources, self-management, and its treatment, there were only two participants who reported that they continued with the BCRL treatments. Ineffective BCRL management, serious complications, participant withdrawal from BCRL information-seeking behaviors, and decreased self-efficacy may result from incomplete BCRL education, poor understanding by others, and low self-efficacy (Ostby et al., 2018). Many participants reported that they had not received information about BCRL from healthcare providers until they were diagnosed with BCRL. According to the survey respondents in one study, BCRL education was not provided until after BCRL development (Ostby & Armer, 2015). Early diagnosis and treatment of lymphedema may mitigate symptoms (Armer et al., 2020); thus, it is important to provide more information on breast cancer treatments and its complications by healthcare providers.

Many participants informed the researcher that understanding co-workers helped them accomplish their tasks. A supportive work environment is an important facilitator to return to work among breast cancer survivors with BCRL. According to a previous meta-analysis of the impact of cancer on workers, work conditions that were not supportive, manual work, cancer types such as breast cancer patients were found to be significantly less likely to be employed six months following diagnosis, compared to healthy controls (Mehnert, 2011). Association with an unfavorable outcome, fatigue and physical symptoms, and perceived employer discrimination as a result of cancer and treatment were barriers to returning to work (Mehnert, 2011). Participants from this current study reported that they never had a chance to consult with an occupational therapist. Further research should conduct the evaluation and development of counseling interventions and rehabilitation occupational interventions to facilitate patients' return to work and adaptation to changes in the workplace.

In this study, the effects of BCRL indicated a significant change in these women's lives. Some of the participants chose to conceal BCRL because they understood the societal stigma that can occasionally surround cancer survivors. To be protected, they chose to hide their condition. If at all possible, they tried to stay hidden and avoid interacting with others. Second, a lot of them decided to conceal to shield their families. They started to worry about their family members (PT 7) and how they might respond. They believed that if they informed them of their situation, they would grow more desperate. So, some of these women decided to keep their suffering a secret from others (PT2 and PT 7). The women in the study avoided making a crucial choice about whether to disclose their problem or keep it private. By choosing to share, these women began to broaden their circle of friends and found a way to receive support for their needs while they dealt with the situation. When this happened, individuals sought friends or support systems. According to a previous study, the sharing of anxieties and confidences empowers women to consider and deal with the issues introduced into their lives as a result of breast cancer (Radina et al., 2005). This viewpoint is similar to that raised by Lindop and Cannon (2005), who propose that seeking out help is crucial to the survival and well-being of these women.

Survivors' decision to return to work was significantly influenced by their family, friends, and significant others. The return- to-work of survivors may be facilitated by positive involvement, according to studies, which may help survivors feel like they are not struggling alone (Tamminga et al., 2012). It is essential to keep in mind that interventions should target barriers and facilitators for individuals at various stages of the return-to-work process to improve work return among breast cancer survivors with BCRL. The process might be improved with better direction from medical specialists, occupation therapists, and information for employees and supervisors.

Accepting and Living with BCRL

The majority of the participants in this study were also carers in their families, which created stress among these women. Some of the participants discussed distress about their family worrying about them, maintaining normalcy for their family, and being able to meet their responsibilities. Inadequate finances or other resources in addition to employment status can potentially impact people with serious illnesses. Three of the participants in this study expressed concerns about their finances. This concern has been found in other studies. Aishing-Giwa et al (2004) reported that financial status was an important determinant in the quality of care for patients.

Participants reflected that sometimes it was inevitable to use their affected arm to complete some tasks in their daily activities. Moreover, their workload may not have allowed them to perform shoulder exercise during a weekday. The women's struggle to manage BCRL symptoms revealed how difficult BCRL treatment is. The women also encountered stresses beyond the impacts of treatment, such as worry and unfavorable feelings that came along with it or not getting the support they sought from friends, family, or professionals. When they struggled to adjust to going back to work with BCRL, it seemed like life was a constant battle. The participants' family seemed to be great supporter of cancer survivors. Moreover, survivors' family need to understand BCRL and its treatments which could facilitate women with BCRL to return-to-work successfully. According to a previous study, families who were more flexible in modifying daily tasks and who have preexisting resources for coping with stressors had more positive outcomes than those families who were rigid and coped with stressors poorly (Radina & Armer, 2001).

However, many participants reported that they grew spiritually and learned to live with BCRL and accepted it to be a part of their lives. Positive behavioral changes to maintain and promote health (acquiring health information and adopting health-promoting behaviors), spiritual development (attention to God and sense of purpose in life, revising values and priorities, strengthening moral and behavioral traits), and personal growth and flourishing (feeling empowered, confident, and efforts to achieve goals and desires) were examples of these changes after breast cancer (Loripoor et al., 2015).Women reported that it took them a year or longer to accept and live with BCRL. Moreover, many participants in this study reported that they employed their religious practice to help them practice acceptance and live with lymphedema peacefully. The religious approach was one factor among important ways of coping with breast cancer (Taleghani et al., 2006).

Summary Self-Reflective Review of the Research Process

As part of the research, reflexivity is created throughout the dialogue. Qualitative research is characterized by reflexivity, which is seen as a means of increasing credibility (Dowling, 2006). During my research, I was fortunate to meet people who reported having dealt with chronic illnesses and who seemed to be doing well. The opportunity to meet and speak with such interesting people makes me feel quite privileged. The most interesting aspect of doing this study, in my opinion, was learning how my assumptions influenced not only the research question, but also how I communicated with the participants throughout the first few interviews. When I asked the participants questions in the interview, I was looking for what would lead to an "interesting" and "in-depth" discussion about their challenges and concerns about returning to work, as well as a better understanding of how the BCRL had affected their working lives. I did not always use the exact questions from my interview protocol. When I started conducting the interview, I let my participants tell me their stories and I then asked more questions to explore detail and gain deeper information. For example, when my participants told me about how they had to change their previous jobs after having lymphedema, I asked them how they felt, who helped them get through this, and how it impacted their life and their surroundings. I would say it was not a pre-prepared question, but also showed how to apply and modify some questions to fit the context and situation. An individual experience is unique. I understand now why deep listening is one of the important skills for a qualitative researcher.

As I conducted the interviews in Thai language, I learned more about how to conduct a grounded theory study in a language other than English. It is important to find a qualified translator to potentially reduce the loss of meaning and thereby to enhance the validity of cross-cultural qualitative research. I followed the recommendation of a side-by-side procedure (Nurjannah et al., 2014), in which the researcher and the translator discuss possible wordings. In addition, during the data analysis, I had phone and email contact with the supervisor frequently to review notes, memos, transcripts, and the analysis process or any issues that arose.

The disparity between what I thought would be the most significant questions to ask and what participants thought were the most important topics to discuss emphasizes the importance of qualitative research. This is especially important when working with a subject about which little is known and where the environment is constantly changing. The most important or interesting information for the individuals being examined is frequently undervalued or ignored in investigator-driven research (Bos, 2020). In analyzing outcomes, we often employ our own prejudices towards certain actions and the significance behind them. When I spoke with the participants, I learned that they had solutions that I hadn't considered before. The primary suggestion that participants would participate in therapies or programs to assist women with BCRL who returned to work in reducing their chance of developing lymphedema was found in only three participants. It could be assumed that there were limited treatments or programs to reduce the risk of developing BCRL after complete breast cancer treatment among women who are at risk of developing BCRL. According to most participants, they did not mention engaging in interventions or programs.

In my opinion, such examples illustrate the importance and significance of this study. These findings reveal a disconnect between some of the study's basic assumptions and what the women with BCRL believed was necessary to reclaim their limitations. It also shows how conversing with people who have first-hand experience with the phenomenon being investigated can help us gain a better knowledge of it and, as a result, improve our capacity to work with survivors. After experiencing BCRL, these women seemed to be caught in a dynamic process. It is important for professionals to recognize the dynamic process for future research, to maintain a balanced intervention approach for patients with BCRL’s lifestyle. A patient's sense of empowerment and participation depends in part on professionals’ opinions, understanding, and experience.

Conclusions

Unlike breast cancer survivorship, BCRL has been less a part of decades-long public education and awareness campaigns. Despite a limited understanding of BCRL by employers, colleagues, and clients, participants often reported overestimations or underestimations of their abilities. The grounded theory of the return-to-work experience of Thai women with BCRL provides a helpful way of describing the meaning and impact of the life and work experience of women with BCRL. The sub-categories of changing/adjusting priorities in life, challenges of returning to work with physical limitations, seeking available resources and support, and accepting and living with BCRL were also explained and illustrated with data excerpted from the interviews with participants. Breast cancer survivors' return to work will be improved and the long-term burdens of cancer will be reduced if the factors driving return to work with BCRL are addressed.

Clinical Implications

According to this dissertation's conclusions, every individual survivor of BCRL has different challenges to deal with, hope for, or cope with, and understanding evolved with time. Support from family and healthcare providers are important facilitators of the journey to return to work among these women. It is important to emphasize that management of lymphedema and the general quality of life of survivors would benefit from both the adoption of patient-centered care and long-term counseling. The results demonstrate that a variety of factors may have affected each participant's unique return-to-work experience. Participants frequently felt that present clinical education on BCRL was neither very useful nor specific to their needs. As a result, one of the most important conclusions from this study is the importance of patient-centered care for occupational rehabilitation among survivors with BCRL.

Due to the complexity and uniqueness of each survivor, a team with interdisciplinary expertise is needed to assist the patient in achieving their goal of occupational rehabilitation and job satisfaction. This team might include psychologists, social workers, physical and occupational therapists, and health care providers. Respect should be shown for a person's willingness or incentive to work, one of the most crucial elements to consider is willingness to work. The comfort of asking for help, perceived limitations in oneself, and spiritual beliefs are other aspects of each person's personality that should be taken into account. Additionally, patients’ families need to be involved in programs or interventions.

According to the participants, understanding BCRL from family, friends and co-worker comforted them. This related to a previous study that illustrated improved quality of life and ongoing work activities were facilitated by strong support from family, friends, and co-workers (Anderson et al., 2022). This current study provides factors that influence return-to-work experience of Thai women with BCRL. It is important to emphasize that a better understanding of factors encouraging patients to become experts in their condition may lead to improved long-term outcomes and reduced cost pressures on lymphedema services in the future (Jeffs et al., 2016).

Strengths of the Study

In this study, participants lived in every region of Thailand and varied in age, income, occupation, and educational level. The diversity of participants assisted in capturing detailed knowledge of a situation concerning a range of issues, including facilitators and barriers from participants such as cultural, economic, and healthcare system factors. In the context of their different backgrounds and situations, the study identified how participants conceptualized their situation, and how they dealt with BCRL when they decided to return to work.

This study embarked as a pilot study (with two participants), followed by 13 participants being interviewed in-depth for the current study. A grounded theory research is a substantial endeavor that calls for a range of skill sets. Most critically, it necessitates the capacity to conduct thorough interviews that record participants' whole points of view. As a researcher, interviewing skills and abilities might not always be insightful in the very first interviews, but carrying out a pilot study improved the researcher’s interviewing skills. When this study started, further interviews were conducted to work on the development of main categories.

Limitations of the Study

As a qualitative study, the small sample size and the demographics of the participants mean that the results cannot be generalized to other populations. However, these findings can potentially support clinical work with other populations by helping understand potential factors and coping strategies mobilized during the return to work with BCRL.

The participants and my interactions with them defined the information that resulted from the interviews. It is possible that the women who were interested in participating in such a study were different in some fundamental way from women who were not interested. Also, some may experience fewer or more facilitators and barriers than others and some may deal better. I do not know if these hypotheses are true, but it is interesting to note that these women possessed a combination of coping resources, worldview, and the environment that allowed them to cope. Lastly, grounded theory studies are specific to the population studied. However, the results of this study may have transferability, in that the findings may fit other contexts as judged by readers or when readers find the report meaningful regarding their own experience (Crooks, 2001). For example, this study might be applied to breast cancer survivors with BCRL in other settings.

Recommendations for Future Research

The advantage of this study is to provide better information for healthcare providers when assessing treatments and coping strategies and to improve the quality of care among women with BCRL who return to work. These findings underscore the need to create holistic care and tailor interventions. For nursing intervention, a multi-step approach is recommended to prevent and manage these issues to, first, attempt to reduce the risk of BCRL; and then, when needed, to support to accept, adapt to, and manage BCRL, especially when survivors with BCRL return to work.

Support from others was a key coping strategy for the women with BCRL in the study to adjust and return to normal activities in their lives. It would be worthwhile to conduct future research on how BCRL treatment/interventions and survivors' preferred coping strategies affect different relationships, especially family relationships. In addition, further research is needed to determine which interventions are most effective, specifically for women with BCRL when they return to work.

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Appendix A

Consent to Participate in a Research Study

Project Title: The work experiences of Thai women with breast cancer-related lymphedema.
Principal Investigator/Researcher: Natsayakarn Narkthong, Ph.D. (c), RN, MSN, CLT and Jane M. Armer, Ph.D., RN, FAAN (adviser).
IRB Reference Number: 2071603

You are being invited to take part in a research study. The purpose of this study is to better understand women's experiences of returning to work, or continuing to work, after developing limb swelling following breast cancer treatment. The goal of this study is to develop ways to help women with lymphedema have positive work outcomes and improved quality of life and to help health professionals better support them.

To participate in the study, you must be 18 years of age or older and be a breast cancer survivor with lymphedema who has been employed or self-employed. You will be asked to complete a survey with information about yourself and to participate in an interview with the nurse researcher via Zoom which may take 60-90 minutes. You will be asked to choose a first name other than your own to protect your identity. The information you provide will be kept confidential and only the research team will have access to it. Your participation is voluntary, and you may stop being in this study at any time.

If you have questions about this study, you can contact the University of Missouri researcher at 617-2306754 or nnqc4@umsystem.edu. If you have questions about your rights as a research participant, please contact the University of Missouri Institutional Review Board (IRB) at 573-882-3181 or muresearchirb@missouri.edu. The IRB is a group of people who review research studies to make sure the rights and welfare of participants are protected. If you want to talk privately about any concerns or issues related to your participation, you may contact the Research Participant Advocacy at 888-280-5002 (a free call) or email muresearchrpa@missouri.edu.

You can ask the researcher to provide you with a copy of this information sheet and consent for your records, or you can save a copy of this information sheet and consent if it has already been provided to you. We appreciate your consideration to participate in this study.

APPENDIX B

Demographic Data Collection Tool

BCRL_RTW Demographic Data Collection Tool (Sun et al., n.d.)

Pseudonym _________________ Participant ID # _______________ (to be completed by the researcher)	Date of taking this survey___________

Date of Birth _______________

Q 1 What is the religion that you consider yourself to be_________________________

Q 2 What is the highest level of formal schooling you have completed or the highest degree you have received?

Q 3 How would you describe your financial resources, as far as being adequate for your needs and the needs of your household?

o Extremely adequate

o Somewhat adequate

o Neither adequate nor inadequate

o Somewhat inadequate

o Extremely inadequate

Q 4 How did/do you commute to work daily since diagnosis of lymphedema

Q 5 How long does it take to commute to work (in minutes) each day on average?

At the time of lymphedema diagnosis _______________,

Currently, if different______________.

Q 6 What was your marital and relationship status at the time of your lymphedema diagnosis?____________________

Q 7 How many persons have been living in your household SINCE your diagnosis of lymphedema? __________

Q 8 How do you evaluate their health “before lymphedema” and “after lymphedema” as excellent, good, fair, poor? _________________

Q 9 What other chronic diseases/health conditions do you have? [See the doctor for or take medicine for?]

____

Q 10 Which side of your body was treated for breast cancer?_______________________

Q 11 How did you initially know/suspect that you had developed lymphedema or something was wrong with your extremity

Q 12 Breast cancer treatment

Date of diagnosis with breast cancer_________________

Date of surgery____________________

Type of surgery for treatment of breast cancer___________________-

Date of last radiation________________

Date of last chemotherapy___________

Date of lymphedema diagnosis_____________________

Date of other treatment complications__________________

Q 13 Is your side affected by lymphedema your dominant extremity (including the hand, the arm, axilla, and shoulder)?

o Yes

o No

Q 14 Have you experienced any symptoms below or any other symptoms or discomfort since you were diagnosed with lymphedema?

____

Please describe the **location, since, when and any thoughts about the causes**

____

____

____

____

Appendix C

Interview Protocol

The work experiences of Thai women with breast cancer-related lymphedema.
Researchers: Natsayakarn Narkthong, Jane M. Armer.

The interview is a semi-structured interview consisting of the following questions:

Work demographics

• • What kind of work do you do (have you done)?

What does work/employment mean to you? (define, explain)

• How long have you worked in these fields?

• Tell me about a typical day at work for you, around the time you were diagnosed with breast cancer.

• How do you describe your work?

- What type of job(s) are/were you doing (describe the job content and tasks):

    Before diagnosis with breast cancer?

    Before diagnosis with lymphedema?

    After diagnosis with lymphedema?

- What are the reasons, if you work part-time, rather than full-time?

- What are/were the physical/functional/activity demands of your work:

    Before diagnosis with breast cancer?

    Before diagnosis with lymphedema?

    After diagnosis with lymphedema?

    Describe why you were off work due to breast cancer treatment if you were.

Describe why you were off work due to lymphedema, if you were. (How does lymphedema affect your working time?)

Lymphedema-related Changes

• Tell me about a typical day at work for you after you developed lymphedema.

How has this has been different than before you were diagnosed?

• What changes do you experience from lymphedema physically?

• What changes do you experience from lymphedema emotionally/psychologically?

• What changes do you experience from lymphedema interpersonally (family, friends, neighbors)?

Interpersonal Changes in Work

- How does it feel to talk about lymphedema to the people you work with?
- How do you feel your relationships with people at work have been affected by your lymphedema?
- What are your colleagues’ attitudes after they came to know you have lymphedema?
- What support, if any, have your colleagues given to you?
- What interpersonal challenges have you experienced in the workplace since experiencing lymphedema?
- How do you feel your company/workplace treated/supported you after you developed lymphedema?
- What ways of coping help you deal with interpersonal challenges?

What ways of coping have not worked for you in dealing with interpersonal challenges?

Work-related Outcomes

- Please give me some specific examples of how lymphedema is affecting you in your work or how it has affected you in the past. (Please tell me if you have/had a disability that prevents you from accepting any kind of work or caused a layoff from a job after diagnosis with breast cancer and lymphedema.)

How has lymphedema affected you in the workplace in the following areas:

- How does lymphedema affect your ability to carry out physical tasks?
- How does lymphedema affect your self-confidence and self-esteem?
- How does lymphedema affect your mental focus and emotional well-being?
- How do you feel lymphedema has affected your work productivity?
- How do you feel people in your workplace evaluate your productivity, compared to before you had lymphedema (if you stayed in the same job)?
- How do you think the changes caused by lymphedema affect your ability to meet work demands?
- How do you feel people in your workplace think about changes in your ability to meet work demands due to lymphedema?
- How have you coped with meeting workplace demands after experiencing lymphedema?
- What ways of coping have worked for you in coping with workplace demands?
- What ways of coping have not worked for you in meeting workplace demands?

Environmental, Cultural Characteristics

- How do you feel the Thai society and culture considers women who are breast cancer survivors with lymphedema?
- How do you feel being a Thai woman has influenced your breast cancer-related lymphedema and returning to work?
- What lymphedema social support resources have been available to you?
- How was information on lymphedema been made available to you?

- What have the clinicians (PT, physician, nurses, etc.) advised and supported you, if they have, for return to work after you were diagnosed with lymphedema?
- How has your family supported you, if they have after you developed lymphedema and returned to work?
- How have your community/neighborhood/friends supported you, if they have after you developed lymphedema and returned to work? In what ways have they helped you?

Final reflections on the experience

- What have you learned from the experience of having lymphedema during these past months/years?
- If you were to advise newly diagnosed patients with breast cancer-related lymphedema, what suggestions/advice would you give to them?
- How do the situations and difficulties you may be experiencing now compare to the beginning of your lymphedema experience?
- What changes in your outlook toward work have you experienced after having lymphedema?
- What do you think about your future with lymphedema? How do you think lymphedema may change in the future?
- How do you foresee lymphedema may change your life?
- Is there anything else you would like to tell me about your experience with lymphedema in the workplace that we have not discussed?

VITA

Natsayakarn (“Gift”) Narkthong was born in Thailand. Gift earned her degree of Bachelor and Master of Nursing from Faculty of Nursing, Prince of Songkla University in 2006 and 2014, respectively. She practiced as a registered nurse and clinical research nurse from 2006 to 2012. In 2019, Gift matriculated into the PhD program at Sinclair School of Nursing, University of Missouri. She is the recipient of the PEO International Peace Scholarship and the Ministry of Science and Technology of Thailand (MSTT) scholarship. She has been a certified lymphedema therapist since August 2022. Upon her return to Thailand after graduation, Gift has the goal to improve care for breast cancer survivors with lymphedema.