THE EFFECTIVENESS OF AN INTERACTIVE THEATRE INTERVENTION ON IMPROVING PATIENT ADHERENCE TO SELF-MANAGEMENT REGIMENS FOR 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 dissertation entitled:

THE EFFECTIVENESS OF AN INTERACTIVE THEATRE INTERVENTION ON IMPROVING ADHERENCE TO SELF-MANAGEMENT REGIMENS FOR BREAST CANCER-RELATED LYMPHEDEMA

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Dedication

This dissertation is dedicated to my husband, Paul and sons, Jacob and Sam, without whom I could not have accomplished this. Not enough words can thank them for their endless encouragement, support and perseverance during my countless trips to Columbia and across the world. It is also dedicated to all my friends and family, who also supported me throughout this journey, including: Linda, Dan, Ben, Joe, Christy, Marsha, Lindsey, Justin, Mike, Chris, Joy, Fred, Barb, Karen, Logan, Neil, Kathy, Lynn, and Chris. A special thanks to the Hulett family, who took me in and became my adopted Columbia family. My Dad, Billy Timmerman has been a cheerleader from the beginning and my only regret is that I cannot share this in person with my Mom, Dona, and my brother, Randy. Lastly, I must thank my dog, Mia, who sat on my lap throughout my entire education.

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LIST OF ABBREVIATIONS

MU	University of Missouri
BCRL/LE	Breast cancer-related lymphedema/lymphedema
QOL/HRQOL	Quality of life/Health-related quality of life
CSM	Common Sense Model of self-regulation
IT	Interactive theatre
LBCQ	Lymphedema breast cancer questionnaire (tool)
BMI	Body Measurement Index
MLD	Manual lymphatic drainage
BCLINK	The Breast Cancer and Knowledge Study
SLNB	Sentinel lymph node biopsy
ALND	Axillary lymph node dissection
XRT/RT	Radiation therapy
BIS	Bioelectrical impedance spectroscopy
TDC	Tissue dialectric
LAS	Lymphangioscintigraphy
CDT	Combined decongestive therapy
LVA	Lymphaticovenular anastomosis
ALNT	Autologous lymph node transplantation
ACOSOG	The American College of Surgeons Oncology Group
ARM	Axillary reverse mapping
ALT	Aqua lymphatic therapy
CAM	Complementary and alternative medicine

LLLT	Low-level-laser therapy
IPC	Intermittent pneumatic compression
NIR	Near infrared (fluorescence imaging)
MSBR	Mindful-based stress reduction
RCT	Randomized clinical trial
PAL	Physical and Lymphedema (PAL study)
LYMPHA	Lymphatic microsurgical preventive healing approach
FACT-B+4	Functional Assessment of Cancer Therapy-Breast (tool with 4 items lymphedema-related
FLI-C	Functional Living Index-Cancer (tool)
EFCC	Ellis Fischel Cancer Center
ALFP	American Lymphedema Framework Project
ISL	International Society of Lymphology
ILF	International Lymphedema Framework
EWMA	European Wound Management Association
PROSURV-BCRL	Prospective Surveillance-Breast Cancer-Related Lymphedema
NLN	National Lymphedema Network
MDS	Minimum data sets
NCCN	National Comprehensive Cancer Network
ULL	Upper Limb Lymphedema (tool)
WCLS	Wesley Clinic Lymphedema Scale (tool)
WHEL	Women’s Healthy Eating and Living (study)
CITI	Collaborative Institutional Training Initiative (IRB training)

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ABSTRACT

Breast cancer survivors are at lifetime risk for the development of breast cancer-related lymphedema (BCRL), a chronic, potentially-debilitating, and -disfiguring condition that requires life-long symptom management. Adherence to BCRL self-management is critical to preventing BCRL progression and complications; however, barriers to effective self-management, including complexities of treatment, can negatively affect adherence. Preliminary work for this study has identified physiological, psychological, and psychosocial barriers to successful BCRL self-management. One of the main barriers identified was lack of BCRL education and support for both patients and health care providers, suggesting a need for alternative methods of providing education and support. Currently, printed information is commonly used for patient education and support. This randomized study compared printed information about BCRL to printed information about BCRL and attendance at an Interactive Theatre (IT) performance (n = 36 participants; 19/17). Circumferential and perometric measures were taken at baseline to document BCRL status and valid, reliable questionnaires relevant to symptom management, self-efficacy, and self-regulation were administered pre- and post-intervention. An interactive approach to BCRL education and support with self-management has potential to improve patient outcomes of adherence and coping with BCRL.

CHAPTER ONE

Overview of Breast Cancer-Related Lymphedema (BCRL)

There are an estimated 246,660 new breast cancer cases that will be diagnosed in women during 2016 (American Cancer Society, 2015) and according to the Surveillance, Epidemiology, and End Results Program (SEER) data, there are currently 3.1 million breast cancer survivors in the United States (Howlader et al., 2015). Depending on BCRL criteria and type of measures used, from 41% to 94% of 3 million breast cancer survivors in the United States may develop breast cancer-related lymphedema (BCRL) (Armer & Stewart, 2010).

BCRL is a chronic, potentially debilitating condition with a variety of causes that restrict the flow of lymphatic fluid, causing swelling of the soft tissues and extracellular spaces (Lasinski et al., 2012). BCRL occurs most often in women who have undergone axillary lymph node dissection, sentinel lymph node biopsy, and/or radiation therapy for treatment of breast cancer (Armer, Fu, Wainstock, Zagar, & Jacobs, 2004). Lymphedema can occur within months to 20 years post-operatively. After emergence, it is a life-long condition that requires on-going management of symptoms with daily treatment regimens to prevent progression and manage serious symptoms that may include swelling, loss of sensation, pain, reduced range of motion, and infection (Armer et al., 2008; Armer, Stewart, & Shook, 2009b). For many breast cancer survivors, their second most common fear following breast cancer treatment is developing BCRL, with the first being breast cancer recurrence (Bernas, Askew, Armer, & Cormier, 2010).

Background and Significance

Patients have concerns about the lack of knowledge about BCRL by health care providers and the inconsistency with BCRL education, especially in regard to risk-reduction activities and treatment. There is a need to better understand the experiences of women with BCRL in order to develop innovative strategies that facilitate improved patient outcomes of adherence to BCRL self-management and patient perceptions of self-efficacy. The lack of evidence-based research relevant to BCRL risk reduction, treatment, education, and support create a wide variety of practice patterns and clinical uncertainty. A review of the literature reports average BCRL self-management rates between 40% and 50% over the last two decades; a finding which warrants further research to find better ways to improve sub-optimal adherence rates (Boris & Lasinski, 1994; Lasinski, 2013; Ridner, Dietrich, & Kidd, 2011).

Non-adherence to BCRL self-management regimens has been attributed to several barriers. One study using mailed surveys (N = 51) reported that 33% of participants spent 15 minutes or less on self-care; 18/51 participants required help with self-care; and of 48 that received information, 3 felt it was inadequate (Ridner et al., 2011). Another study reported findings in which 9 of 14 participants did not perform BCRL self-care due to lack of time and 6 of 14 participants struggled with performing self-care due to putting the care of others first (Radina, Armer, & Stewart, 2014). The complexities of BCRL self-management treatment are a barrier to adherence due to cumbersome and time-consuming treatment regimens. In a study conducted with 141 women with BCRL who were prescribed an average of 3.6 ± 2.1 BCRL self- care modalities, 13% reported an average adherence rate of <25%; 24% reported 25-49%

adherence; 32% reported 50-74% adherence; and 31% reported ≥ 75% adherence during the study. These averages were consistent throughout the study (Brown, Cheville, Tchou, Harris, & Schmitz, 2014).

In addition, physiological, psychological, and psychosocial factors have been correlated to low adherence to performing BCRL self-care management regimens (Fu et al., 2013; Ridner et al., 2011). In a systematic review of the literature between 2004-2011 (N = 23 articles), negative psychological and psychosocial impact were reported in all 12 of the qualitative studies reviewed (Fu et al., 2013). The magnitude of the relationships between negative psychological and psychosocial factors and decreased quality of life (QOL) with BCRL has been documented as a cause of non-adherence to self-management (McWayne & Heiney, 2005; Paskett & Stark, 2000; Ridner, 2005; Ridner et al., 2012b; Ridner et al., 2012c). In a cross-sectional, mixed methods QOL study with 128 breast cancer survivors (age-matched within 3 years), of whom 64 had BCRL and 64 did not, all QOL measures were reported to have significantly lower scores ($p<0.01$) for the lymphedema group. The Functional Assessment of Cancer Therapy (FACT) with the FACT-B+4 subscale for breast cancer lymphedema, the Upper Limb Lymphedema 27 (ULL 27), and the Wesley Clinic Lymphedema Scale (WCLS) were used as QOL measures (Ridner, 2005). It was suggested that poor adherence may partially explain the psychosocial and physical difficulties that are experienced by women with BCRL and a reported 50% non-adherence rate to self-management of BCRL may be due in part to feelings of inadequacy in managing BCRL symptoms (Ridner et al., 2014). Psychological and psychosocial parameters to measure the impact of BCRL should be used in regard to assessing BCRL adherence (Fu et al., 2013).

Psychosocial benefits and spiritual support are improved in women who interact with others (Burckhardt, Belzner, Berg, & Fleischer, 2014). Beliefs in self-efficacy and the ability to control lymphedema are cognitive belief variables that also have a correlation with adherence (Sherman & Koelmeyer, 2013).

The barriers to BCRL self-management and subsequent poor adherence to self-management regimens have continued to contribute to poorer social well-being, decreased QOL, and unnecessary health care costs due to physical and psychological complications of BCRL progression and diagnosis at a later stage (Ferguson, Llanos, & Bruce, 2013; Stout et al., 2012).

Purpose of Research

Preliminary work for this dissertation study included an audio-taped focus group of breast cancer survivors with BCRL (N=9) to discuss barriers to self-management of BCRL and mailed surveys (N=15) to breast cancer survivors with BCRL to identify perceptions of BCRL education and support throughout survivorship. Based on the preliminary work findings, which identified a deficit in the current standard of providing education and support using printed information about BCRL, this dissertation research study was developed using interactive theatre as an innovative approach to providing BCRL education and support and compares the effectiveness of an interactive theatre intervention bundled with printed information about BCRL to printed information alone. The study is being used to answer the following research questions:

1. What is the effectiveness of an interactive theatre intervention bundled with printed information about BCRL on adherence to self-management regimens among breast cancer survivors with BCRL compared to printed information

about BCRL alone?

2. What is the effectiveness of an interactive theatre intervention bundled with printed information about BCRL in improving patient perceptions of self-efficacy and self-regulation compared to printed information alone?

Theoretical Framework

The theoretical underpinnings of this study apply Leventhal's Common Sense Model (CSM) of Self-Regulation (Leventhal, Meyer, & Nerenz, 1980a) and Transformational Learning Theory (TLT) (Mezirow, 2000). Concepts of the CSM are illustrated in Figure 1.1 which include representation of illness, coping, and appraisal (Leventhal et al., 1980a).

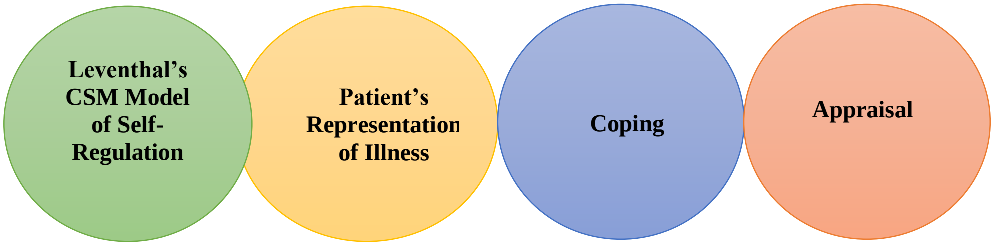

Figure 1.1: Concepts of CSM of Self-Regulation Model

The adaptability of the CSM is one of its main benefits and has been used with a variety of patients who struggle with chronic disease. CSM has been used as a framework in determinants of types of medication adherence (Unni & Farris, 2011). The CSM model has also been used for patients with head and neck cancer in predicting longitudinal judgement-based outcomes based on illness and treatment beliefs (Llewellyn, McGurk, & Weinman, 2007). In addition, interventions that address patients' illness and treatment representations were found to have improved patient adherence and outcomes in a study of 243 patients who were interviewed after an encounter with their physician and again one month later. Although a correlational study, it was found that addressing the patients' representation of illness and treatment was more highly correlated to adherence than the physician's interpersonal skills in attaining adherence (Phillips, Leventhal, & Leventhal, 2012). Measures of patient perceptions of their illness, patient understanding, physician interpersonal skills, patient satisfaction, patient adherence, and problem resolution were conducted with pre- and post-patient interviews in regard to emergency room usage. Causal modelling was used to compare the relationship of providers who reported using CSM-related behaviors and interpersonal skills to patient adherence and problem resolution. Fit indices were used to test the fit of the hypothesized model, which indicated a good fit and support of the hypothesis. Health provider CSM behaviors were positively correlated with patient's perceptions of agreement with the provider on the presenting problem and its treatment ($r = .37$, $p<.001$), change in understanding of the patient's problem pre- and post-interview ($r = .49$, $p<.001$), patient satisfaction ($r = .32$, $p<.001$), patient adherence ($r = .25$, $p = .007$), and resolution of the health problem (both relative, $r = .24$, $p = .005$, and absolute $r = .17$, $p = .04$) (Phillips et al., 2012).

The interactive theatre intervention in this study facilitates patient engagement in problem-solving the BCRL issues that are raised in the script. As the participants watch the performance, they think of their own representation of illness, or in this case, BCRL, based on personal experiences, symptoms, and personal issues that impact the way that they cope with the condition. The participants' representation of BCRL also include their perceptions of the cause of their BCRL, which include the opinions and dialogues with significant others, health care providers, and media sources.

Unfortunately, the basis of the opinions and information from others may be inaccurate, which lends to ill-coping strategies, especially in regard to consequential beliefs about how BCRL will impact them physically and socially and to what degree they will be able to control it (Leventhal, Diefenbach, & Leventhal, 1992). It is anticipated that participants in the bundled IT intervention group of this study will undergo experiential learning and understanding of their own representation of illness (BCRL) and coping strategies with a subsequent appraisal of the effectiveness of their current self-management strategies.

In addition to the participants' representation of illness and evaluation of coping mechanisms used to manage BCRL, a readiness to learn with sufficient cognitive ability is a prerequisite for critical reflection and critical discourse (Mezirow, 2000). A shared paradigm with transformational learning and subsequent self-regulation used interactive theatre in this study to facilitate a behavior change of improved adherence to self-management regimens for BCRL. The diagnosis of a chronic disease, such as BCRL, brings about crisis and a disturbed and disoriented view of reality. By watching the IT intervention, this mindset is transformed and reconstruction of meaning occurs through learning and reflection on the transformative images and audience-character interactions. Transformational Learning Theory (TLT) demonstrates learning as a result of a human's contact with information that combines with existing knowledge based on the person's experience (Mezirow, 1991). The development of TLT by Mezirow was based on the work of Paulo Freire in the 1970's. Mezirow's version of TLT emphasizes critical reflection in learning and was introduced in 1978. It is this version which is combined with CSM in this integrated framework.

Interactive Theatre

Interactive theatre (IT) is a heuristic tool used to address challenging dynamics in a number of settings. The methods for IT draw on the techniques from Augusto Boal's Theatre of the Oppressed, which builds on Paolo Freire's Pedagogy of the Oppressed (Burgoyne et al., 2007). In this study, IT was used as a form of participatory research that used focus group data to develop the script, which was presented to a larger audience made up of the same subculture of constituents. The performance was given by actors from the University of Missouri Interactive Theatre Troupe (MU ITT) followed by an audience discussion with the characters (Talkback). The performance was then given a second time, during which some of the audience members yelled, "STOP!" and intervened on stage, replacing a character of their choosing to try out their own ideas in changing the direction of the script (Burgoyne et al., 2007). The script was written as one scenario that included educational information about BCRL and highlighted some of the barriers to BCRL self-management. It was written as an unresolved story that facilitated the participation of the audience and characters in a collective problem-solving experience and a sharing of real-life experiences (Quinlan, 2010).

A number of topics have used IT, including: (a) faculty development and awareness of multicultural dimensions of teaching (Burgoyne, Placier, Taulbee, & Welch, 2008); (b) patient-physician communication (Skye, Wagenschutz, Steiger, & Kumagai, 2014; Tang, Skye, & Steiger, 2009); (c) patient autonomy in cancer care (Khoury, Saab, & Haidar, 2010); (d) use of success stories from African-Americans in controlling hypertension (Fix et al., 2012); (e) reducing risk-behavior in teens (McDonald, Williams, & Carter, 2011); and (f) diabetes management (Okazaki, 2015). The MU IT production of "Dialogues in Breast Cancer" has been performed since 2011, and focuses on communication between patients and physicians with difficult discussions, including the delivery of a cancer diagnosis. This IT performance was used in both the classroom setting for medical and nursing students and for lay audiences. The acceptability and feasibility of using IT was established with favorable evaluations (87.8%) from breast cancer survivors at two support group performances (n = 41). In addition, 85.4% answered that they felt IT could be helpful with other topics, such as lymphedema; therefore, IT was used for this dissertation research study. Evaluations of the IT performance using a Likert scale (1-Strongly Disagree; 2-Disagree; 3-Neutral; 4-Agree; and 5-Strongly Agree) were distributed for completion after the performances. Of 36 completed evaluations, 97.2% of the participants strongly agreed that IT was an effective teaching strategy.

Chapter Contents

The subsequent chapters (2-4) of this dissertation are synergistic with the overall project. Chapter 2 is a manuscript that includes a review of contemporary literature relevant to barriers to BCRL self-management and BCRL education and support, and findings from qualitative analyses of focus group interviews and survey data that were collected as preliminary work for this study. Chapter 3 is a manuscript that provides a comprehensive overview of BCRL, current treatment, and future research consideration with a prospective surveillance model for breast cancer patients who are at risk for BCRL. A multidisciplinary approach to surveillance with preoperative baseline measures and an educative-supportive component shows promise toward earlier detection of BCRL; however, more rigorous outcome studies are needed. Chapter 4 is a literature review manuscript that details the complexities of adherence and post-cancer lymphedema management. An in-depth review of the physiological, psychological, and psychosocial aspects of lymphedema and the impact of adherence are discussed. Although the number of studies in the manuscript that use a measure for adherence are limited, an encouraging finding was the recognition of psychological and psychosocial factors that are now beginning to emerge as indicators for adherence. In summary, the collective set of these manuscripts contribute to the body of knowledge relative to the current barriers that women with BCRL face; current methods in providing education and support; comprehensive information about BCRL; and the complexities of treatment that served as the foundation for this dissertation study. Chapter 5 is an edited version of the *University of Missouri Center for Patient-Centered Outcome Research* proposal that was submitted to partially fund this dissertation research. The chapter includes the methodology used for this research. The results of this study are reported in Chapter 6. Lastly, Chapter 7 is the conclusion that reflects on the limitations of the study, future directions, and implications for practice.

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CHAPTER TWO

Perceptions of Barriers to Self-Management of Breast Cancer-Related Lymphedema and the Need for Education and Support

Ostby, P. L., Armer, J. M., Smith, K. & Stewart, B. (2016). Perceptions of barriers to self-management of breast cancer-related lymphedema and the need for education and support. (Manuscript submitted for publication)

An estimated 246,660 new breast cancer cases will be diagnosed in 2016 and an estimated 3 million women living with breast cancer in the United States (American Cancer Society, 2015; Howlader et al., 2015). Of the 3 million breast cancer survivors in the United States, from 41% to 94% may develop breast cancer-related lymphedema (BCRL) within 60 months of surgery; however, this varies depending on the methods of assessment and criteria used for diagnosis of lymphedema (LE) (Armer & Stewart, 2010). BCRL is a chronic, potentially debilitating condition that restricts the flow of lymphatic fluid, causing swelling of the soft tissues and extracellular spaces (Lasinski et al., 2012). BCRL occurs most often in women who have undergone axillary lymph node dissection, sentinel lymph node biopsy, and/or radiation therapy and some chemotherapy agents for treatment of breast cancer (Armer et al., 2013). Breast cancer survivors can develop lymphedema within days or up to 20 years post-operatively. Once symptoms present, it is a life-long condition that requires on-going management of symptoms with daily treatment regimens to prevent progression and manage serious symptoms (Armer et al., 2008). The goal of therapy is to move lymphatic fluid to an area where it can drain to reduce swelling. Treatment for BCRL most often begins with intensive treatment under the supervision of a specialty-trained therapist followed by a transitional phase, in which patients learn to administer their own treatment (Lasinski, 2013). For many breast cancer survivors, developing BCRL is their second most common fear, with the first being breast cancer recurrence (Bernas et al., 2010).

Literature Review

A search of contemporary literature relative to barriers to self-management, BCRL education, and patient support was independently assessed by the first author. Inclusion criteria for the review were: (1) studies from scholarly, peer-reviewed sources; (2) studies pertaining to patient perceptions of barriers to BCRL self-management; (3) studies that included educational and support interventions to help women learn about BCRL and risk-reduction; (4) studies published between 2009-2016; and (5) studies published in the English language. Exclusion criteria were: (1) studies with a focus solely on treatment modalities. The search terms, “breast cancer”, “lymphedema” or “lymphoedema”, “self-care”, “patient education”, and “patient support” with “and” as a Boolean operator, were applied to 6 database indices, which included: Academic Search Complete, CINAHL, ERIC, MEDLINE, PubMed, and PsycARTICLES. The number of articles retrieved in a progressive search revealed the following: (1) breast cancer - 32,150 articles; (2) lymphedema - 280; (3) self-care - 4; (4) patient education - 18; (5) patient support - 2; and barriers - 2. The literature is sparse in the areas of educative-support systems for BCRL. The four studies in the barriers and patient support categories were duplicative; therefore, a total of 18 articles were used to describe current findings relevant to perceived BCRL barriers, BCRL education, and support (Table 1).

Table 2.1

Literature summary for BCRL barriers

Authors/ **Reference #**	**Aim/Design**	**Sample**	**Topic**	**Findings**
Fu MR, Rosedale M. Breast cancer survivors' experiences of lymphedema-related symptoms. *J. Pain Symptom Manage.* 2009;38(6):849-859. (Reference #9)	To explore and describe breast cancer survivors' experiences of BCRL symptoms. Design: Descriptive/phenomenological Data from 3 interviews of each participant (102) were conducted and analyzed.	Women breast cancer survivors with BCRL from the US. (N = 34)	Treatment burden	Symptom distress from BCRL encompasses temporal, situational, and attributive dimensions among breast cancer survivors.
Fu MR, Ridner SH, Hu SH, Stewart BR, Cormier JN, Armer JM. Psychosocial impact of lymphedema: a systematic review of literature from 2004 to 2011. *Psychooncology.* 2013;22(7):1466-1484. (Reference #10)	To evaluate the level of evidence of contemporary peer-reviewed literature published from January 2004 to December 2011. (Systematic Review)	N = 23 studies	Psychosocial Impact of Lymphedema	Quantitative studies (n=11) were statistically significant in showing poorer social well-being with lymphedema patients including perceptions of body image, appearance, sexuality, and social barriers. Qualitative studies (n=12) reported negative psychological and psychosocial impact including negative self-identity, psychological distress, social isolation, public insensitivity, and perceived social abandonment.

Hulett J, Armer J, Stewart B, Wanchai A. Perspectives of the Breast Cancer Survivorship Continuum: Diagnosis through 30 Months Post-Treatment. *Journal of Personalized Medicine.* 2015;5(2):174. (Reference #11)	Aim 1: To analyze and disseminate qualitative data findings from the first 30 months of the Missouri Breast Cancer and Lymphedema Project, which was conducted from 2001 to 2010; and Aim 2: To examine breast cancer survivor qualitative data to potentially find new insights from long-term survivors. Design: Qualitative analysis of data obtained with a longitudinal design with repeated measures using responses to the Lymphedema Breast Cancer Questionnaire (LBCQ).	Breast cancer survivors older than 18 years of age, newly diagnosed with their initial breast cancer (stages I–IV), and no previous history of primary or secondary lymphedema up to 2.5 years post breast cancer diagnosis and treatment. (N = 379)	Psychological, physiological and lifestyle changes.	Most participants shared that the most influential factor in survivorship was having social support systems. Of 332 responses in the area of health literacy, only 5.3% of the participants mentioned the need to monitor for lymphedema and to see a lymphedema therapist.
Ridner SH, Sinclair V, Deng J, Bonner CM, Kidd N, Dietrich MS. Breast cancer survivors with lymphedema: glimpses of their daily lives. *Clin J Oncol Nurs.* 2012;16(6):609-614. (Reference #12)	To investigate symptoms and daily patterns in breast cancer survivors with lymphedema and association with distress. Design: Mixed methods study using Lymphedema Symptoms Intensity and Distress Survey–Arm (LSIDS-A), BMI, lymphedema volume measures and four 20- minute expressive writing sessions with participants completed on-site and online.	Breast cancer survivors with lymphedema; aged 21-80. (N = 53)	Physiological and psychological distress	Symptom distress identified most often with decreased social activity, appearance concerns, feeling less sexually attractive, difficulty sleeping, lack of interest in sex, and decreased physical activity.
Cormier J, Xing Y, Zaniletti I, Askew R, Stewart B, Armer J. Minimal limb volume change has a significant impact on breast cancer survivors. *Lymphology*. 2009; 42:161-175. (Reference #14)	To define the incidence, risk factors, symptoms, and quality of life (QOL) outcomes associated with post-operative limb volume changes of various degrees. Design: Prospective cohort study using perometric arm measures at 1, 3, 6, 9, 12, 18, 24, and 30 months, post-operatively and valid and reliable questionnaires to assess QOL associated with limb volume changes.	Women over 18 years of age diagnosed with breast cancer. (N = 279)	Psychological and psychosocial factors/QOL	Limb volume change at 5% occurred in up to 61.3% of breast cancer survivors and was associated with a significant increase in symptoms and a reported change in QOL. change in reported quality of life.

Ridner S, Deng J, Fu MR, et al. Symptom burden and infection occurrence among individuals with extremity lymphedema. *Lymphology*. 2012; 45:113-123. (Reference #15)	To examine differences in symptoms and infection status of patient with upper and lower extremity lymphedema. Design: Quantitative; The National Lymphedema Network sponsored online survey of self-report lymphedema data from March 2006 through January 2010.	Although 2749 surveys were completed, the analysis was based on (N = 1837) N = 723 with upper extremity lymphedema and n = 1114 with lower extremity lymphedema. 66% of respondents reported having secondary lymphedema, which is most often from cancer-treatment.	Symptom Burden and Education	There is an association between symptom burden and infection, although symptoms and infection were more severe with lower extremity lymphedema. The study also concluded: (1) family members and health care providers should become aware that lymphedema symptoms can be managed; (2) supportive interventions should be implemented for daily management of lymphedema symptoms as well as early detection monitoring; and (3) patients need to be aware of increased risk for infection and symptoms that signal complications.
Ridner SH, Dietrich MS. Self-reported comorbid conditions and medication usage in breast cancer survivors with and without lymphedema. *Oncol. Nurs. Forum.* 2008;35(1):57-63. (Reference #16)	To compare comorbidities and medication usage in breast cancer survivors with and without BCRL. Design: descriptive cross-sectional with use of self-report survey.	Women breast cancer survivors. (N = 128) (n = 64 with BCRL) (n = 64 without BCRL)	Symptom Burden	Breast cancer survivors with BCRL experienced more comorbid conditions.

Armer JM, Henggeler MH, Brooks CW, Zagar EA, Homan S, Stewart BR. The health deviation of post-breast cancer lymphedema: symptom assessment and impact on self-care agency. *Self-Care, Dependent-Care & Nursing.* 2008;16(1):14-21. (Reference #5)	To explore 4 approaches to assessment and diagnosis in defining BCRL, using anthropometric measures and self-report interviews and surveys. A second aim was to develop a clinical research program for lymphedema based on the concepts of Self-Care Deficit Nursing Theory (SCDNT). Design: Prospective longitudinal mixed methods	Women breast cancer survivors followed over 24-months post-breast cancer surgery (N = 140 of 300 who had passed the 24-month measurement)	Patient Education	Nurses can improve in helping patients meet self-care treatment goals by understanding the burden that is placed on patients with BCRL and the importance of self-report.
Brown J, Cheville, A, Tchou, JC, Harris, SR, Schmitz, KH. Prescription and adherence to lymphedema self-care modalities among women with breast cancer-related lymphedema. *Supportive Care in Cancer.* 2014;22(1):135-143. (Reference #17)	To examine prescription and adherence to BCRL self-care modalities. Design: Secondary analysis of women who participated in a 12-month weight-lifting trial. This study used a questionnaire to quantify number of self-care modalities and adherence at 3, 6, and 12 months.	Women breast cancer survivors with BCRL (N = 141)	Treatment Burden	At 12-months, adherence was sub-optimal at 69%. Findings indicated a need for further study in preparing patients with the abilities, education, skills, and resources to successfully manage BCRL.
Fu M, Chen C, Haber J, Guth A, Axelrod D. The Effect of Providing Information about Lymphedema on the Cognitive and Symptom Outcomes of Breast Cancer Survivors. *Ann. Surg. Oncol.* 2010;17(7):1847-1853. (Reference #26)	To investigate how BCRL information affects cognitive and symptomatic outcomes for breast cancer survivors with BCRL. Design: Four valid and reliable instruments were administered in person (Demographic and Medical Information interview instrument, a Lymphedema Education Status interview instrument, a Knowledge Test for cognitive outcomes, and the Lymphedema and Breast Cancer Questionnaire). Data analysis included descriptive statistics, t tests, chi-square (v2) tests, and regression.	Women breast cancer survivors with BCRL (N = 136)	Patient Education	57% of the participants received information about BCRL. Participants that received BCRL information reported less BCRL symptoms and scored higher on the knowledge test.

Tam EK, Shen L, Munneke JR, et al. Clinician awareness and knowledge of breast cancer-related lymphedema in a large, integrated health care delivery setting. *Breast Cancer Res. Treat.* 2012;131(3):1029-1038. (Reference #27)	Of 2,469 invited, 887 participants responded to a 10-minute web survey in which knowledge scores were calculated. Associations of selected covariates with BCRL knowledge score and the associations of selected covariates with clinician referral for BCRL were modeled using logistic regression (odds ratio [OR] and 95% CI).	Eligible participants were all active surgeons, oncologists, primary care physicians, and nurse practitioners (NP). (N = 887)	Health Care Provider Education about BCRL	Clinicians with a higher knowledge score were more likely to make BCRL referrals. With increasing numbers of breast cancer survivors, BCRL education for clinicians is warranted.
Ridner SH, Dietrich MS, Kidd N. Breast cancer treatment-related lymphedema self-care: education, practices, symptoms, and quality of life. *Support Care Cancer.* 2011;19(5):631-637. (Reference #20)	A cross-sectional examination of BCRL education, self-care practices, barriers, burdens, and benefits.	Women breast cancer survivors who had been professionally treated for BCRL. (N = 51)	Patient Education	Most patients received BCRL information as part of treatment, but many felt it was inadequate. Another finding indicated a lack of education provided by nurses and other health care providers. Barriers and burdens were reported as: time management, the lack of knowledge about equipment, symptom self-management, and control and psychological distress.
Armer JM, Brooks CW, Stewart BR. Limitations of self-care in reducing the risk of lymphedema: supportive-educative systems. *Nurs. Sci. Q.*	To examine the self-care limitations related to carrying out self-care measures to reduce BCRL risk through a secondary analysis of a behavioral-educational intervention study. Design: Qualitative survey	Women surgically treated for breast cancer (N = 14)	Patient Education/ Psychological/ Self-Efficacy	Motivational interviewing or solution-focused approaches were indicated to help nurses design educative-

2011;24(1):57-63. (Reference #30)				supportive programs. Limitations to self-care included lack of knowing, lack of decision-making abilities, and lack of action.
Ridner SH, Rhoten BA, Radina ME, Adair M, Bush-Foster S, Sinclair V. Breast cancer survivors' perspectives of critical lymphedema self-care support needs. *Supportive Care in Cancer*. 2016:1-8. (Reference #31)	To obtain breast cancer survivors' perspectives on barriers and facilitators to lymphedema self-management and support needs perceived as critical to managing chronic conditions Design: Qualitative, descriptive using focus group interviews	Breast cancer survivors with stage II lymphedema after breast cancer treatment, excluding patients undergoing chemotherapy and/or radiation therapy or in hospice. (N = 21)	Patient Support	Overarching themes included: (1) lack of social support; (2) lack of resources; and (3) lack of recognition or knowledge of BCRL forcing self-advocacy
Ayse C, Bahar Z. Women's Barriers to Prevention of Lymphedema After Breast Surgery and Home Care Needs: A Qualitative Study. *Cancer Nurs.* 2016; Publish Ahead of Print. (Reference #28)	To understand the barriers to lymphedema management and home care needs after breast cancer surgery Design: Qualitative descriptive using focus group interviews	Breast cancer survivors with BCRL (Turkish speaking) (N = 14)	Physiological, psychological, psychosocial, and patient support.	Dedicated websites (76%) were rated as the most commonly used source for information for patients with both primary and secondary lymphedema. Although information was not viewed as accurate, the second most common sources were physicians and primary health care providers (55.5%), support groups on the internet (33.6%) and family and friends (32.1%).

Deng J, Fu MR, Armer JM, et al. Self-reported information sources and perceived knowledge in individuals with lymphedema. *Lymphology.* 2013;46(4):173-183. (Reference #32)	To explore self-reported experiences of patients with lymphedema related to: 1) sources of lymphedema information, including frequency of use, participants' understanding of the information and perceived accuracy, preferences of information source(s), and time spent searching for information; and (2) perceptions of lymphedema knowledge levels Design: Quantitative survey	Patients with primary and secondary lymphedema. (N = 1542) (n = 1025 with secondary lymphedema) (n = 517 with primary lymphedema)	Patient Education	Providing information about lymphedema risk from nursing staff at the time of breast cancer diagnosis facilitated patient awareness and practice of BCRL risk-reducing activities; however, reminders at 3 months were significant in relation to long-term adherence.
Sherman KA, Koelmeyer L. The Role of Information Sources and Objective Risk Status on Lymphedema Risk-Minimization Behaviors in Women Recently Diagnosed with Breast Cancer. *Oncol. Nurs. Forum.* 2011;38(1): E27-E36. (Reference #33)	To assess the role of education sources in minimizing risk of BCRL with women diagnosed with breast cancer. A second aim assessed the objective risk status on knowledge and practice of BCRL risk-reducing activities. Design: Questionnaire at the time of breast cancer surgery and 3-months post-operatively	Women recently diagnosed with breast cancer at increased risk for developing BCRL post axillary dissection. (N = 106)	Patient Education	
Sherman KA, Miller SM, Roussi P, Taylor A. Factors predicting adherence to risk management behaviors of women at increased risk for developing lymphedema. *Support. Care Cancer.* 2015;23(1):61-69. (Reference #35)	To assess cognitive and emotional factors influencing adherence to BCRL risk-reduction activities. Design: Longitudinal study using cognitive variable measures	Women who had undergone breast cancer surgery and lymph node surgery (N = 103)	Patient Education and Support	

Perceptions of barriers associated with BCRL reported in the literature were placed in the following categories: (1) psychological distress; (2) psychosocial factors; (3) physiological factors; (4) symptom and/or treatment burden; (5) lack of education; and (6) lack of support.

Psychological and psychosocial barriers.

The impact of BCRL symptoms and the burden of daily self-management often result in psychological and psychosocial symptoms such as anxiety, depression, emotional distress, and sexuality issues (Fu & Rosedale, 2009; Norman et al., 2009) A systematic review examining psychological and social impact on patients with lymphedema reported operational domains as negative self-identity, emotional disturbance, and psychological distress (Fu & Rosedale, 2009). Social impact domains included marginalization, public insensitivity, social isolation, financial burden, and perceived diminished sexuality (Fu et al., 2013). In addition, poorer social well-being was reported as statistically significant in a comparison of patients with lymphedema to those without (Fu et al., 2013).

A qualitative study (N = 379) used repeated administration of the Lymphedema Breast Cancer Questionnaire (LBCQ) up to 2.5 years' post-breast cancer diagnosis and treatment. Reported contributors to psychological distress included altered body image, imposed lifestyle and occupational changes, and negative impact on family and interpersonal relationships (Hulett, Armer, Stewart, & Wanchai, 2015). Ridner et al. (2012) conducted another study that used expressive writing with breast cancer survivors with BCRL and reported women with lymphedema "felt as though their bodies had been possessed and altered by a menacing invader." Reported findings also identified associations between symptoms and distress which demonstrated participant uncertainty with their lack of body and self-confidence (Ridner et al., 2012d, p. 613). Symptom distress identified most often was associated with decreased social activity, appearance concerns, feeling less sexually attractive, difficulty sleeping, lack of interest in sex, and decreased physical activity (Ridner et al., 2012d).

Physiological barriers.

Physiological symptoms of BCRL are measured by severity using a grading system established by The International Society of Lymphology (ISL). The grading system classifies lymphedema into four stages: 0–3, with no swelling represented by Stage 0; and lymphedema signs and symptoms with the most severity represented by Stage III (International Society of Lymphology, 2013). Symptoms of BCRL mainly affect the arm, hand, breast, and trunk; however, even minimal limb volume changes (5.0% - 9.9%) have been reported to impact QOL (Cormier et al., 2009).

An online self-report survey sponsored by the National Lymphedema Network (NLN) was conducted between March 2006 and January 2010 of subjective symptoms in patients with upper and lower extremity lymphedema (N = 1,837). Findings reported the most common symptoms with patients who had upper extremity lymphedema (n = 729) were swelling (96.8%), a feeling of extremity heaviness (76.2%), current pain (67.3%), stiffness (65.8%), numbness (63.9%) and decreased range of motion (48%) (Ridner et al., 2012b). In addition to reporting comparison of symptoms and infection risk, the study concluded: (1) family members and health care providers should become aware that lymphedema symptoms can be managed; (2) supportive interventions should be implemented for daily management of lymphedema symptoms as well as early detection monitoring; and (3) patients need to be aware of increased risk for infection and symptoms that signal complications (Ridner et al., 2012b).

Symptom and treatment burden.

Symptom burden that is BCRL-related is a significant barrier to successful self-management; however, comorbidities, especially in breast cancer survivors over 65 years of age, also represent major contributing factors as a physiological barrier to BCRL management (Ridner & Dietrich, 2008). In a study comparing women with BCRL (n = 74) to breast cancer survivors without BCRL (n = 75), reported findings identified obesity (BMI > 30), orthopedic problems, hypertension, and arthritis as more prevalent in the lymphedema group (Ridner & Dietrich, 2008). Symptom burden, whether it be physiological and/or psychological, represents a barrier to BCRL management, which is critical in preventing progression and/or serious complications.

The treatment for BCRL involves self-care modalities that can be few and simple to numerous and complex, depending on the severity of lymphedema. BCRL treatment can be cumbersome, time-consuming and may reduce quality of life (QOL) (Armer et al., 2008; Brown et al., 2014; Heppner et al., 2009; Ridner et al., 2011; Ridner et al., 2012c; Rosedale & Fu, 2010). Treatment for BCRL may consist of several self-care modalities including: manual lymphatic drainage (MLD), using a combination of massage techniques; compression bandaging of the extremity; exercises; compression garments; and meticulous skin care (Lasinski, 2013; Lasinski et al., 2012).

In a study of 140 breast cancer survivors over a period of 24-months, a proposed plan for a clinical research program for lymphedema patients identified the importance of the nurses’ role in helping patients meet BCRL self-care treatment goals by understanding the burden that is placed on patients with BCRL and the importance of self-report (Armer et al., 2008). Lifetime self-management is required because there are no current surgical or medical interventions that can provide a cure (Ridner et al., 2012c).

The number of self-care modalities or “workload” and its impact on patient functioning represents treatment burden (Ridgeway et al., 2014). In a study aimed to examine prescription and adherence to BCRL self-care, women breast cancer survivors (N = 141) were administered a questionnaire at 3-, 6-, and 12-months. Findings from the study indicated that with an average number of three self-care modalities, adherence was non-optimal and there is a need for further study in preparing patients with the abilities, education, skills, and resources to successfully manage BCRL (Brown et al., 2014). Treatment burden has been linked to negative clinical outcomes, such as higher hospital admission rates for complications, such as infection (Ridgeway et al., 2014). There are many interrelated variables that create obstacles to successful self-management of BCRL, especially the complexity of the prescribed regimen (Ostby & Armer, 2015). The consequences of treatment burden may result in negatively impacting patients’ QOL as well as their families (Fu, Chen, Haber, Guth, & Axelrod, 2010; Ostby et al., 2014).

Lack of education and support.

There are limited studies relevant to BCRL education and support, and with no standardization, practice patterns vary.

Many times, it is the lack of BCRL knowledge on the part of health care providers that prevents adequate patient education. The Breast Cancer and Knowledge

Study (BC LINK) utilized an online survey (N = 887 of 2,469 invited) of oncologists, primary care physicians, surgeons and nurse practitioners regarding BCRL knowledge, education, and referral patterns. Oncologists and surgeons scored highest in all categories, with only 36.2% of primary physicians reporting ever having made referrals for BCRL. In addition, it was reported that nurse practitioners were less likely to make referrals for BCRL than physicians (Tam et al., 2012). With breast cancer survivors living longer, many oncologists and surgeons are returning their patients back to their primary care physicians for follow-up throughout survivorship; therefore, a problem may exist if primary care physicians lack knowledge regarding long-term treatment effects, such as BCRL.

Patients are voicing their dissatisfaction with: (a) not being offered BCRL education by health care providers; (b) inadequate information; and/or (c) conflicting information (Cal & Bahar, 2015; Kwan et al., 2012). In a study to conduct a cross-sectional examination of BCRL education, self-care practices, barriers, burdens, and benefits (N=51), it was reported that of 48 responses, 94% received some self-care information from their therapist after lymphedema had been diagnosed (Ridner et al., 2011). Other than lymphedema therapists, physicians (22%), followed by other sources, such as the internet or someone else with lymphedema, were reported as sources of BCRL education. Nurses were not cited as providing education and, other than lymphedema therapists, 39% reported never receiving education from anyone (Ridner et al., 2011).

Education alone is inadequate as it does not offer a supportive component to address psychological well-being and coping skills in maintaining adherence to BCRL self-management (Armer, Brooks, & Stewart, 2011). In a secondary analysis of a behavioral-educational intervention study (N = 14) that examined limitations related to BCRL self-care, it was reported that the majority of factors limiting patients' self-care abilities were related to energy, patterns of living, time management, inadequate resources, and limited physical abilities (Armer et al., 2011).

Two recent qualitative studies using focus groups have emerged in an effort to address patient perceptions of BCRL from a supportive perspective. The aims that guided the first study (N = 21) were to obtain perspectives from breast cancer survivors with lymphedema on barriers and facilitators to lymphedema self-management and identify support needs that participants felt were critical to managing chronic medical conditions (Ridner et al., 2016). Three central themes were identified: (1) lack of social support; (2) lack of resources for self-care activities; and (3) self-advocacy by default (Ridner et al., 2016). Subthemes from the study were indicative of the perceived marginalization that occurs with BCRL. The second study was conducted in Izmir, Turkey, with breast cancer survivors who were diagnosed with BCRL (N = 14) (Cal & Bahar, 2015). A qualitative analysis of focus group data supported a prospective approach to BCRL management at the time of breast cancer diagnosis and the need for education and support involving family and social networks in the home environment (Cal & Bahar, 2015). The themes identified from the focus group interviews included: (1) coping with lymphedema; (2) effects of lymphedema on life; and (3) lymphedema development. Subthemes were derived from each category that supported findings of insufficient information and counseling before lymphedema development were reported. In addition, familial support and meeting with other women experiencing BCRL was reported to have a positive effect on managing BCRL (Cal & Bahar, 2015). It is of interest that themes and barriers to BCRL education, management, and support are synonymous with women from different cultures who are separated by large geographical distances.

There are limited studies that examine the format and types of education that are favored by patients with lymphedema. In a study comparing patients with primary and secondary lymphedema, dedicated websites (76%) were rated as the most commonly used source for information by patients with primary or secondary lymphedema (Deng et al., 2013). Subsequent to dedicated websites, the next top information sources were physicians and primary health care providers (55.5%), support groups on the internet (33.6%), and family and friends (32.1%) (Deng et al., 2013). Although physicians and primary health care providers were listed as the second most common education source, it was also reported that the quality of information was moderate and patients felt marginalized by health care providers that were not well informed about lymphedema (Deng et al., 2013). Findings from this study suggested that internet users may in fact be seeking information about lymphedema on their own due to the lack of resources provided. It is not clear whether patients with secondary lymphedema were provided information at the time of their cancer diagnosis or at the time that lymphedema symptoms emerged. Volume and timing of information is another area that needs more study. Many patients report receiving BCRL education and information from their lymphedema therapist after BCRL symptoms emerge, thereby denying patients with prospective surveillance and education about lymphedema risk and risk-reducing activities (Ostby et al., 2014).

The advantage of exposing women to BCRL information at the time of breast cancer diagnosis was reported in a study of 106 women who had recently been diagnosed with breast cancer. A questionnaire was used to measure cognitive representations, including the ability to control lymphedema through self-management, perceived lymphedema risk and consequences, and self-regulatory ability to manage lymphedema-related distress (Sherman & Koelmeyer, 2011). Findings reported that the exposure of lymphedema risk information at the time of diagnosis facilitated awareness and practice of risk-minimizing behaviors (Sherman & Koelmeyer, 2011). This study represents an important aspect of not only providing education, but demonstrates the role of nurses in motivating patients to adhere to BCRL risk-minimizing activities (Sherman & Koelmeyer, 2011).

Self-efficacy is one's belief that he/she can affect a situation or condition and self-regulation is the ability to control emotion, behavior, and distractions that may interfere with pre-set goals to control any given health threat (Leventhal, Leventhal, & Breland, 2011). Additional research to assess cognitive and emotional factors influencing adherence to BCRL risk-reduction activities was conducted with women who had undergone breast and lymph node surgery (N = 103) (Sherman, Miller, Roussi, & Taylor, 2015). The Cognitive-Social Health Information Processing framework was used to assess cognitive and emotional factors that influence adherence to BCRL risk-reduction activities. Women were then given printed information from the American Cancer Society about breast cancer and BCRL risk and cognitive and emotional variables were reassessed at 6- and 12-months (Sherman et al., 2015). Findings reported that women who understood lymphedema risk and felt confident in managing their risk were more adherent to risk-reduction activities (Sherman et al., 2015).

The following premises were drawn from this review of contemporary literature: (a) patients are voicing the need for accurate information from health care providers at the time of breast cancer diagnosis; (b) a supportive component to care throughout survivorship should be included with BCRL education; (c) assessment of cognitive and emotional factors should be included in educative-supportive programs; (d) research studies are needed to further explore alternative types of education and care from which patients can choose; and (e) patient-centered interactive approaches to education may be more effective than current strategies. The research questions for this study were as follows:

1. What are the perceived barriers associated with BCRL management for female breast cancer survivors with BCRL?
2. What perceptions do female breast cancer survivors who are diagnosed with BCRL have in relation to BCRL educational content, practices, and support?

Methods

Study design.

The study is descriptive and qualitative. Two groups of participants were recruited, with one group participating in focus group interviews and one group participating with the completion of a survey composed of 11 open-ended questions. The focus group session questions guided participant discussion relevant to barriers to self-management of BCRL. The survey was developed and reviewed by two researchers for content. Questions were open-ended, requiring narrative answers that focused on experiences and perceptions relevant to BCRL education and support throughout survivorship. The aims that guided the study were to: (a) identify barriers to BCRL self-management; and (b) to explore patient perceptions of BCRL education and support.

Focus group sample and setting.

Subsequent to the investigators' university institutional review board (IRB) approval, potential participants were contacted via telephone by the first author. A telephone script was used for potential participants which described the purpose and expected outcomes of the study. Inclusion criteria for participants were: (a) female breast cancer survivors who have had surgical and/or radiation therapy for breast cancer treatment; (b) have medically-diagnosed BCRL (self-report) who have been prescribed a self-management regimen by a trained therapist; and (c) have no history of lymphedema prior to breast cancer diagnosis. Potential focus group participants were given date, location and time; made aware that the focus group interviews would be audio-recorded; and that the de-identified data would be used in developing an interactive theatre script about lymphedema for a randomized intervention study. The voluntary nature of the study was emphasized for the study participants. Approximately 50 of 350 breast cancer survivors who are currently participating in survivorship studies at the University of Missouri Sinclair School of Nursing (MUSSON) Lymphedema Research Laboratory who agreed to be contacted about future studies were screened, at which point recruitment goals were achieved. Potential participants from a community breast cancer support group were also invited. Sample size for the focus group was based on recommendations of approximately 6-10 participants for 1.5-2 hours (Richards & Morse, 2013). The focus group was held at a Midwestern US university in a private, quiet conference room without risk of interruption. Nine focus group participants meeting the inclusion criteria were in attendance at the focus group session.

Survey sample.

University of Missouri IRB approval was given for the survey study. The same recruiting procedures and inclusion criteria were used for survey participants as were utilized with focus group participants.

Focus group procedure.

The focus group was moderated by the first and second authors, both trained in qualitative methodology. The session began with introductions by first name, a review of the voluntary nature of the study and its purpose, as well as a discussion of the ground rules for the session. Ground rules included: (a) emphasis that participants could choose not to participate at any time; (b) that the session would be kept to the time allotted; (c) that the session would be audio-recorded; (d) to be mindful of contributing constructive discussion; (e) to avoid side conversations; and (f) to not be afraid to respectfully challenge others with questions. Each participant completed a demographic form which was de-identified with a numerical code. An interview guide with semi-structured questions was used to facilitate discussion (**Error! Reference source not found.**). The f ocus group was audio-recorded using two digital recorders and a multi-directional tabletop microphone. Once the audio recordings were verified, one audio-recording was erased. Two trained research assistants supervised the recording equipment and recorded field notes. The session lasted for 2 hours, at which time data saturation was achieved. Focus group discussion encompassed topics specific to barriers to BCRL self-management, physiological, psychological, and psychosocial issues, including struggles with patient advocacy, self-efficacy and self-regulation. At the conclusion of the focus group session, participants received a modest gift card in appreciation of their participation and time.

Table 2.2

Focus Group Interview Guide Probes

Interview Guide Probes – Focus Group

1. What can you tell me about your lymphedema diagnosis?
    a. Feelings

2. What do you think caused your lymphedema?

3. Were you told that you might develop lymphedema?
    a. When? (Pre-op, Post-op, Not at all, Not until you were diagnosed?)

4. Do you think you would have reacted differently if you were told? If you were told at a different time during your diagnosis and treatment of breast cancer?
    a. What do you have to do to control symptoms?
    b. Feelings

5. How long before you noticed your lymphedema?
    a. What did you do?
    b. Did you know what it was?
    c. Did you know who to call?
    d. Did you ignore it?

6. Tell me what you have done to decrease your symptoms?

7. Do you feel like you are controlling the symptoms?

8. What do you consider a barrier in controlling your symptoms?
    a. Time
    b. Pain
    c. Expense
    d. Unable to do it? Why?
    e. Don't think you can do it?
    f. Don't think it will help?

9. How does lymphedema affect your daily life?

10. Psychological impact? Clothes? Social? Decrease in family time? Support? What kind? Do you need it? What kind of support do you want?

11. If you have had BCRL for a long time, do you take care of it differently

now that when you were first diagnosed? Are you as careful? Why or why not?

12. How did you know that you had lymphedema?

13. What was it like when you first learned you had lymphedema?

14. How have other people commented on your lymphedema/or sleeve?
    a. At work?
    b. In personal life?

15. How does having lymphedema make you think about what activities you do?

16. How does having lymphedema make you think about what you wear?

17. What challenges do you feel have been the most difficult to overcome?

18. Has anyone surprised you with a reaction to your having lymphedema?

*Adapted with permission from Fu M. Managing lymphedema in breast cancer survivors [dissertation]. Columbia: University of Missouri; 2003

Survey procedure.

Surveys (N=15) were mailed to participants’ homes with a prepaid, addressed return envelope. All participants received a telephone call to notify them what date the surveys were mailed. Twelve surveys were returned. Table 3 provides details of the survey questions.

Table 2.3

Survey Questions

Lymphedema Survey

This is a survey about lymphedema (swelling which may occur after cancer treatment). You are being asked to participate in a research study because you have identified you have lymphedema. This research is being conducted to understand barriers to self-management of lymphedema and to learn what types of education and support that patients need and want. Completion of this survey is voluntary. You may choose not to participate without penalty. All surveys are anonymous and confidential.

1. How were you told that you might develop lymphedema?
    b. When were you told? (for example: when you were diagnosed with breast cancer; when you were diagnosed with lymphedema; not at all)
    c. By whom?

2. In what ways were you provided with information about lymphedema?
    a. From whom?
    b. How effective do you feel the information was in providing education in learning about lymphedema and reducing risks or treating symptoms already present?
    c. How helpful was the education you received in supporting you to maintain your self-management regimen?

3. In what ways were you provided with resources and support?
    a. How has support continued throughout your survivorship?

4. What do you do to manage your lymphedema symptoms?

5. In what ways is your self-management regimen for lymphedema hard to maintain?

6. What do you think is the best way to provide education about lymphedema?

7. What do you think is the best way to provide support in helping you to maintain your regimen?

8. How do you think you need support?
    a. Do you want support?
    b. When?
    c. What kind?

   - d. From whom?

9. What do you think are barriers to your management of your lymphedema?

10. How well do you think you are managing your lymphedema symptoms?

11. How do you think lymphedema affects quality of life?
    - a. How do you think quality of life is different with people who have lymphedema than those who don't?
    - b.Why?

*Adapted with permission from Fu M. Managing lymphedema in breast cancer survivors [dissertation]. Columbia: University of Missouri; 2003

Focus group analysis.

Descriptive statistics were used to analyze the demographic variables using SASv9 software (SAS Institute Inc., Cary, NC, USA). The focus group recording was transcribed verbatim by a trained research assistant, followed by a review for accuracy and corrections by the first author.

A thematic line-by-line inductive content analysis of the data using Corbin and Strauss' (Corbin & Strauss, 2008) coding canon for Grounded Theory was conducted for the focus group data, including analytic memos with subsequent assembling of central themes and subthemes. Agreement on independently generated codes, themes, and subthemes was achieved by triangulation with two other researchers. Subsequently, data were analyzed using Dedoose v6.1.8 software for summarization of data (SocioCultural Research Consultants, LLC, Los Angeles, CA, USA).

Survey data analysis.

SAS v9 software (SAS Institute Inc., Cary, NC, USA) was used to analyze demographic and health characteristics of survey data. Mean and standard deviation were computed for continuous variables and frequency and relative frequency were computed for categorical values. Survey responses were categorically grouped according to item content, followed by thematic derivation and summarization using Dedoose v6.1.18 software (SocioCultural Research Consultants, LLC, Los Angeles, CA, USA). Responses were then quantified using percentages.

Results

Demographics.

All participants in both study groups had at least a high school education, with a mean age of 66.76. Participants were identified as White (non-Hispanic) (95.2%) and African-American (4.8%). The majority of the participants (n=18) had undergone mastectomy and axillary dissection for breast cancer with the mean of 16.6 years since breast cancer diagnosis and a mean number of 12.34 years since lymphedema diagnosis. Details of demographic and health characteristic information for focus group and survey participants is provided in **Error! Reference source not found.**and Table 5, respectively.

Table 2.4

Focus Group Demographics and Health Characteristics (N=9)

Variable	N	Mean	Median	Std. Dev	Minimum	Maximum
Age	9	62.67	58.00	11.34	49.00	84.00
Highest grade in school attended	9	13.44	12.00	1.74	12.00	16.00
Breast Cancer Diagnosis (years)	9	12.44	13.00	7.35	3.00	24.00
Lymphedema Duration (years)	9	9.10	10.00	6.93	0.25	20.00

Variables	Results freq (%)
Ethnicity	
Black	1 (11.1)
White (non-Hispanic)	8 (88.89
Chemotherapy	
Yes	7 (77.78)
No	2 (22.22)
Radiation Therapy	
Yes	6 (66.67)
No	3 (33.33)
Mastectomy	
Yes	7 (77.78)
No	2 (22.22)
Lumpectomy	
Yes	2 (22.22)
No	7 (77.78)
Axillary Dissection	
Yes	9 (100)
No	0 (0)
Comorbidities[a]	
Yes	5 (55.55)
No	4 (44.44)

aComorbidities listed included: heart failure (n=1; (20%), atrial fibrillation (n=1; 20%), epilepsy (n=1; 20%), diabetes (n=1; 20%), GERD (n=1; 20%), Parkinson's (n=1; 20%), hypothyroidism (n=1; 20%), hypertension (n=3; 60%), 2 or more of the previously mentioned conditions (n=4, 80%).

Table 2.5

Survey Demographics and Health Characteristics (N=12)

Variable	N	Mean	Median	Std. Dev	Minimum	Maximum
Age	12	69.83	72.50	12.03	54.00	85.00
Highest grade in school attended	12	13.83	13.00	2.12	12.00	18.00
Breast Cancer Diagnosis (years)	12	8.33	7.00	5.65	3.00	22.00
Lymphedema Duration (years)	12	6.47	6.00	5.47	0.25	20.00

Variables	Results freq (%)
Ethnicity	
White (non-Hispanic)	12 (100.00)
Chemotherapy	
Yes	11 (91.67)
No	1 (8.33)
Radiation Therapy	
Yes	7 (41.67)
No	5 (33.33)
Mastectomy	
Yes	11 (91.67)
No	1 (8.33)
Lumpectomy	
Yes	1 (8.33)
No	11 (91.67)
Axillary Dissection	
Yes	12(100.00)
No	0 (0)
Comorbidities [a]	
Yes	9 (75.00)
No	3 (25.00)

aComorbidities listed included: epilepsy (n=1; 11.11%), diabetes (n=2; 22.22%), GERD (n=1; 11.11%), Parkinson’s (n=1; 11.11%), hypercholesterolemia (n=1; 11.11%), hypothyroidism (n=1; 20%), back pain (n=1; 11.11%), osteoporosis (n=1; 11.11)), hypothyroidism (n=3; 33.33%), hypertension (n=6; 66.66%), 2 or more of the previously mentioned conditions (n=6; 66.66%)

Focus group.

Three central themes were identified including: (1) the lack of BCRL patient education from health care providers; (2) lack of understanding by others; and (3) decreased self-efficacy. Subthemes under lack of BCRL education were: (a) timing and volume of information; and (b) lack of health care provider knowledge of BCRL. Subthemes under lack of understanding by others included: (a) feelings of marginalization; and (b) non-therapeutic communication. Decreased self-efficacy subthemes included: (a) treatment burden; and (b) lack of follow-up support.

Theme 1: Lack of BCRL patient education from health care providers

Seven of nine participants (78%) voiced the need for better methods of communicating the risk of BCRL at the time of breast cancer diagnosis. None of the participants were aware of risk-reducing activities, except to avoid constriction with blood pressure cuffs, IV infusions and blood draws on the side of their breast cancer treatment. As one participant shared recommendations she'd received about lymphedema risk and treatment, another participant stated, "I didn't get that memo." The other participants stated, "We didn't get that memo!" Another participant expressed, "No recollection of being told about lymphedema" and "…I think I was well-informed of the cancer itself and treatment, but not about lymphedema."

Subtheme: Ill-timed and too much information

Participants voiced a need to know about lymphedema at the time of breast cancer diagnosis, but seemed to want it at a different time than when given breast cancer treatment information. The need for information was more helpful for the immediate need, such as breast cancer surgery. The overwhelming shock of the cancer diagnosis allowed little ability to grasp new information other than what was needed immediately for cancer treatment. Two participants felt baseline arm measures at the pre-operative visit was a good time to discuss the risk of BCRL. Examples from participants related to the amount of information were expressed as follows: "You get so much stuff at once;" "…I just really didn't know about lymphedema and I probably had literature with all the stuff but you're overwhelmed. I didn't read everything;" "…they handed me all kinds of stuff and then I have stack, a literal stack of papers, binders to put stuff in, just hoarding…" Printed information was viewed as helpful; however, timing and volume of information was perceived as detrimental to patient education that was meaningful.

Subtheme: Health care provider lack of BCRL knowledge

With the exception of lymphedema therapists, all of the participants voiced the need for improved health care provider knowledge of BCRL, given the lack of interest and minimization of the condition. Five of nine (56%) participants were told, "not to worry about it." The following participant statements also gave insight on how influential communication can be on the patient-provider relationship. Participant statement examples included, "Yeah, and if it's not related to your oncologist, to your cancer, then the oncologist says, 'you need to see your primary physician. I don't deal with that.' That's aggravating. They need to work together;" "…I said something about baseline and they said, 'Oh, we only took a couple [lymph nodes], just a few, you don't have to worry about it'…;" "I think the doctor should talk to you about it." The participants also agreed that education about BCRL incidence was neglected. One participant stated, "I think being 5 years out, I thought

I was past it." Another said, "…that's what I tell everybody; it can happen at any time because mine is 5 years out!" Two participants have taken it upon themselves to educate other women about lymphedema. One participant is a volunteer at a local hospital and another has started an online support group. Their efforts are applauded; however, forced self-advocacy is an unintended outcome that risks inaccuracy of medical information and an incomplete knowledge base of resources. A health care provider's lack of interest and communication may be indicative of a knowledge deficit about BCRL.

Theme 2: Lack of understanding by others

Participants in the study commented on the desire for people to understand lymphedema. Psychological distress relative to encounters with the public, family, and friends were voiced as commonplace. One participant commented, "…people that you know will comment and ask, 'How are you doing today?' or 'Is it better today?' It gets a little embarrassing; you get tired of answering…." Another participant stated, "It's uncomfortable and you get a lot of strange questions."

Subtheme: Feelings of marginalization

There is inadequate knowledge about BCRL as a chronic condition which tends to elicit irrelevant questions such as, "What's wrong with your arm?" or "Did you get burned?" Participants discussed how insignificant they were made to feel as a result of insincerity by others. Comments were shared including, "Then they say, 'How are you doing?' and then you wonder, do you really care?;" "... how can I talk about lymphedema? So much negativism associated with the fact… you know they just start looking at you." Although a source of frustration with feelings of marginalization, three (33%) participants used public encounters as a teaching opportunity. One participant stated, “And I figure if somebody can learn from me wearing a sleeve and asking questions, maybe they’ll do something to prevent it.” Another participant viewed questions about their lymphedema as positive act of caring, stating, “…it’s certainly nice to have people interested in you.”

Subtheme: Non-therapeutic communication

There was unanimous agreement on the importance of caring communication that takes place in facilitating collaboration between patients and health care providers; however, communication is also important within patients’ network of family and friends. The participants unanimously agreed that a trusting relationship and respect for confidentiality is important when discussing illness or chronic conditions. One participant stated, “I didn’t even talk about it with my mother-in-law… she never even knew I had breast cancer, but she was the type of person that called everybody and told them everything.” An additional aspect of communication may be influenced on the age of family members and cultural differences relative to serious conditions. One participant shared, “I was over at my mom and dad’s, (85 and 89 years of age). [When I spoke of my cancer and lymphedema], my Dad said, ‘Shut up! Don’t talk about it, you’re gonna bring it back!” This comment indicated that the stigma of cancer and chronic conditions can be a hindrance to communication and support.

Theme 3: Decreased self-efficacy

In addition to education, confidence in one’s effectiveness to self-manage BCRL is a large contributor to successful treatment. Participants agreed with the concept of self-efficacy; however, most felt that they could do better in adherence to self-management regimens. One participant stated, “I give myself a B. I could do manual lymphatic drainage and I could wear my sleeve more when I’m gardening”. Another agreed saying, “I think I’ve been lazy…”

Subtheme: Treatment Burden

The average number of treatment modalities used by the participants for BCRL management was three, of which wearing a compression sleeve and glove was the most common. Participants agreed that the most common barrier to treatment was the lack of time, weather, physiological symptoms, and lack of help. One participant stated, “I don’t want to, because I think I’m not doing anything.” Additional comments included, “I think just that uncomfortableness of the garment. I don’t really care for the way it feels.”; “Well, they’re [sleeve] hot.”; “Yeah, it’s hot.”; “I don’t always wear my sleeve when I’m gardening because it’s hot out.”; My hand swells up with my glove on or off.”; “I can’t do it.”

Subtheme: Lack of follow-up support

There is a need for ongoing support throughout survivorship. Patients with BCRL are responsible for self-management after intensive therapy with a lymphedema therapist, but there is no protocol beyond initial treatment. One participant stated, “I don’t do the manual lymphatic drainage thing. I did it for a long time, then I just kind of quit that.” Follow-up for re-evaluation of BCRL with arm measures and appropriate fitting of orthotic equipment should be implemented at mutually agreed upon intervals. Participants agreed that a prospective model of surveillance would be beneficial. One participant stated, “I think one thing that would have kept me on the program more is if I had follow-ups.”

Survey.

The survey questions identified participant perceptions relative to: (a) how, when and by whom were participants told they might develop BCRL; (b) ways that educational information and support/resources were given and by whom; (c) how effective educational materials were for learning and in maintaining self-management regimens; (d) types of self-management modalities used; (e) problematic elements of self-management; (f) best ways to provide education and support in helping to maintain self-management regimens; (g) how support has been continued throughout survivorship; and (h) feelings about differences in quality of life (QOL) between breast cancer survivors with and without BCRL. Of fifteen surveys mailed, twelve were returned (80%). Item responses indicated that the best way to provide both education and support was through interaction with others (81% and 77% respectively). Since the most common method used by health care providers is through printed information, this study identified a disconnect between what health care providers are doing and what the participants felt was most helpful. Education about BCRL was not consistently provided and 53% of the participants defined education as a “referral when symptoms emerged.” For the women who received education, it was provided at the time of BCRL diagnosis, thus denying them education regarding BCRL risk-reducing activities and precautions at the time of breast cancer diagnosis. Support was defined as “prescriptions” and “referrals” (51%); therefore, it is unclear whether patients were exposed to support other than medical treatment. Consistent with contemporary literature, participants responded that decreased QOL was more prevalent in women with lymphedema compared to those without. A detailed summary of survey responses is reported in Table 6.

Table 2.6

Survey Summary Data

Questions	freq%
How were you told about BCRL?	
Item left blank	**(1) 7%**
None provided	**(1) 7%**
Received printed information	**(2) 17%**
Verbally mentioned	**(2) 17%**
Referral when symptoms emerged	**(6) 51%**
Who provided your BCRL education?	
Lymphedema Class	**(1) 8%**
Physician	**(2) 17%**
Nurse	**(2) 17%**
None	**(3) 25%**
Certified Lymphedema Therapist (CLT)	**(4) 33%**
Was the BCRL education helpful?	
"You hear so much, I just shut down"	**(1) 7%**
"Very helpful"	**(1) 7%**
"Effective".	**(1) 7%**
"50% of literature helpful; "Not much said"	**(1) 7%**
"Fair, but not told everything"	**(2) 14%**
"None given"	**(3) 22%**
"Good, but CLT helped more"	**(3) 22%**
What is the best way to provide BCRL education?	
Baseline CLT visit [at time of breast cancer diagnosis]	**(1) 7%**
Well prepared printed information	**(1) 7%**
Printed information and discussion	**(1) 7%**
Support Groups/Websites/blogs	**(1) 7%**
Periodic educational sessions	**(2) 14%**
Physician discussion at the time of breast cancer diagnosis	**(6) 50%**
How has support been provided throughout survivorship?	
CLTs are most supportive	**(1) 6%**
"I feel like they all blew me off"	**(1) 6%**
"None. It is not discussed at appointments at this	

time”	**(1) 6%**
“I know to get help immediately if I have a flare-up.”	**(1) 6%**
“Not for many years until a support group was formed”.	**(1) 6%**
“Little available, but since 2002, more has become available.”	**(1) 6%**
“Clinic referrals” and “prescriptions for equipment”	**(6) 51%**
What is the best way to provide support?	
Financial support	**(1) 6%**
Item left blank	**(2) 17%**
Follow-up CLT visits every 6-12 months	**(3) 24%**
Interacting with others (support groups, blogs, “getting involved with people who have it”; having a supportive physician; interactive theatre; “Just knowing you’re not alone”.	**(6) 53%**
Do you need support?	
“Not for the most part.”	**(1) 8%**
“What I know after the interactive theatre performance is sufficient”	**(1) 8%**
“I think I have enough.”	**(1) 8%**
Yes	**(4) 33%**
Item left blank	**(5) 42%**

Discussion

A review of the literature, focus group interviews and responses from mailed surveys are consistent in identifying issues that are critical to successfully managing BCRL and in providing effective educative-supportive programs throughout survivorship. The lack of BCRL education, lack of understanding by others, and decreased self-efficacy may contribute to unsuccessful BCRL management and the development of serious complications. Self-management is only effective if it is performed and follow-up support is critical to helping women who struggle with BCRL on a daily basis (Armer et al., 2008; Brown et al., 2014; Cal & Bahar, 2015; Fu et al., 2013; Ridner et al., 2011; Ridner et al., 2016; Rosedale & Fu, 2010). In addition, there are few alternative interventions used to provide education other than printed information and none that are currently used to impact adherence (Ostby & Armer, 2015). The lack of understanding by others revealed that negativity and poor communication with others, including friends and family, contributed to the participants' withdrawal from BCRL information-seeking behaviors and decreased self-efficacy. Women who are more knowledgeable and confident of their effectiveness in BCRL self-management are more likely to maintain adherence, resulting in less complications and prevention of BCRL progression (Fu et al., 2010; Sherman & Koelmeyer, 2013; Sherman et al., 2015).

The majority of survey participants indicated that BCRL education was not provided until they developed BCRL. One major finding in the study demonstrated that 81% of the survey participants indicated that interaction with others worked best for learning about BCRL and 77% of participants preferred interaction with others as the best means for providing support. Given that 51% of participants defined support as “prescriptions” and “referrals,” suggests that participants may not be able to identify preferred types of support because they are unaware of options and need help to understand and select the types of education and support that will best fit their needs.

Study Limitations.

The homogeneity of the participants in regard to race, age is a limitation of this study. Small sample sizes prohibited generalizability as well.

Conclusions.

Suboptimal BCRL self-management adherence rates of 50% may be directly or indirectly related to the lack of interactive patient-centered programs that provide education and support throughout survivorship. There may be discrepancies between what is offered to patients and what they perceive as most helpful in the way of coping with BCRL. Nurse researchers can be instrumental in conducting patient-centered research that will provide evidence-based alternatives to education and support for chronic treatment-related conditions, such as BCRL. Patients need to have options so they can choose what works best for them. This study provided preliminary work for a current randomized study comparing printed information about BCRL with printed information and an interactive theatre intervention, using the focus group data from this study as the basis for the interactive theatre script.

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CHAPTER THREE

Surveillance Perceptions of Barriers to Self-Management of Breast Cancer-Related Lymphedema and the Need for Education and Support

Ostby, P. L., Armer, J. M., Dale, P. S., Van Loo, M. J., Wilbanks, C. L., & Stewart, B. R. (2014). Surveillance Recommendations in Reducing Risk of and Optimally Managing Breast Cancer-Related Lymphedema. *Journal of Personalized Medicine, 4*(3), 424–447. http://doi.org/10.3390/jpm4030424

Abstract

Breast cancer survivors are at increased risk for the development of breast cancer-related lymphedema (BCRL), a chronic, debilitating, and disfiguring condition that is progressive and requires lifelong self-management of symptoms. Up to 40% of 2.5 million breast cancer survivors in the United States will develop BCRL during their lifetimes. Ongoing surveillance, beginning with pre-operative assessment, has been effective in identifying subclinical lymphedema (LE). A prospective model for surveillance is necessary in order to detect BCRL at an early stage when there is the best chance to reduce risk or slow progression. Although surgical methods are first-line considerations when definitive breast cancer surgery is performed, physical methods for monitoring and assessment such as circumferential arm measures, perometry, and bioimpedance; exercise programs; educational programs; prophylactic and early-intervention compression garments; referral for complete decongestive therapy; and interactive engagement for symptom self-management are all interventions to consider in the development of a BCRL surveillance program. The importance of interdisciplinary collaboration is integral to the success of an effective personalized medicine program in breast cancer-related lymphedema surveillance.

Keywords: breast cancer-related lymphedema; surveillance; risk-reduction; self-management

Introduction

Definition.

Lymphedema is a chronic, debilitating condition with a variety of causes that can be diagnosed as a primary congenital condition, or it can be secondary from trauma to lymphatic structures. Secondary lymphedema can occur from scarring associated with wound healing, cancers causing tumor compression on lymphatic channels, surgical trauma to the lymphatic channels, fibrosis or scarring of the channels caused by radiation therapy, and infection (Armer et al., 2004; Chang & Cormier, 2013; Földi, Földi, Ströbenreuther, & Kubik, 2012; Lasinski et al., 2012; National Cancer Institute, 2014; Shah, Arthur, Riutta, Whitworth, & Vicini, 2012). Trauma to the lymphatic channels inhibits the ability for the lymphatic fluid to travel back to the blood circulatory system resulting in protein-rich lymphatic fluid accumulation in the extracellular spaces and swelling of the soft tissues (Armer et al., 2004; Földi et al., 2012; Lasinski et al., 2012). The most common cause of secondary lymphedema in the United States is breast cancer treatment, including sentinel lymph node biopsy (SLNB), axillary lymph node dissection (ALND), mastectomy, or radiation therapy (XRT) for treatment of breast cancer (Armer

& Stewart, 2010; Földi et al., 2012; Francis et al., 2006; Khan, 2009; Shah et al., 2012; Wilke et al., 2006). However, BCRL symptoms have been reported with all treatment modalities, including the absence of either ALND or SLNB (Armer et al., 2004).

Incidence.

Although the emergence, incidence, and prevalence of BCRL are not fully understood, every breast cancer survivor is at risk (Földi et al., 2012; Norman et al., 2009). Because there is no single standardized measure or universal criteria used to diagnose BCRL, reports vary with regard to BCRL incidence (Bernas, 2013; Lacomba et al., 2010). In addition, BCRL can occur within days or up to twenty years postoperatively in breast cancer survivors, which makes follow-up difficult in cases of delayed development (National Cancer Institute, 2014; Ridner et al., 2011). In one cohort of 263 women followed over a 20-year period, Petrek et al. (2001) reported that 77% of cases studied who developed lymphedema did so within three years after surgery; however, prevalence has been correlated to length of follow-up after breast cancer treatment (Petrek & Heelan, 1998).

It is estimated that over 40% of breast cancer survivors may meet the criteria for BCRL over the course of their lives (Armer & Stewart, 2010; Radina et al., 2014). In a study of 627 patients diagnosed with breast cancer who underwent 664 mastectomies between 2005-2013, a two-year cumulative rate of BCRL incidence was reported as 10% for SLNB+RT; 19% for ALND without RT; and 30% for ALND+RT (Miller et al., 2014). Regardless of varying BCRL incidence rates, there are hundreds of thousands of women worldwide that struggle on a day-to-day basis with BCRL symptoms and millions who live in fear of developing it. Symptoms of BCRL vary in severity, with the greatest opportunity for successful management and prevention of progression in the subclinical stage (Stout Gergich et al., 2008).

Symptoms.

Physical symptoms include swelling, leathery skin changes, heaviness, numbness, stiffness, and pain interfering with daily activities and negatively impacting functional well-being. Symptoms present prior to the first occurrence of lymphedema have been most commonly reported as a feeling of tightness (e.g. jewelry or clothing too tight) and heaviness of the extremity (Armer, Radina, Porock, & Culbertson, 2003; Fu et al., 2013). Altered body image and feeling a loss of one's previous self before breast cancer are major factors in causing psychological symptoms such as anxiety, depression, low self-esteem, and emotional distress (Armer et al., 2011; Fu et al., 2013). Symptom distress and the burden of symptom management have been reported as a factor in decreased quality of life for breast cancer survivors with BCRL (Armer et al., 2003; Fu & Rosedale, 2009).

The International Society of Lymphology (2013) has classified lymphedema into four stages; 0-3 with no swelling represented by Stage 0 and lymphedema signs and symptoms with the most severity represented by Stage 3. Lymphedema severity (mild to severe) is classified by limb volume change based on contralateral limb comparison in unilateral cases (Table 1).

Table 3.1

Clinical staging and severity according to the International Society of Lymphology (ISL) Consensus Document. Used with permission from the ISL Executive Committee (International Society of Lymphology, 2013).

Clinical Stage	Description
	A subclinical stage where swelling is not seen despite underlying changes in the lymphatic system
I	The initial stage of swelling which can be transient and where simple elevation can alleviate swelling
II	Swelling is constant and pitting without resolution using elevation
III	The tissue has become hard and fibrotic with associated skin changes
Severity	Based on volume differences between affected and contralateral limb in unilateral presentation Mild = < 20% increase; Moderate = 20-30% increase; Severe = > 38% increase

Once a diagnosis of lymphedema is made, it requires a lifetime of treatment. There is no cure for lymphedema and an integrated approach across disciplines is needed for early lymphedema management including early detection, education on risk-reduction and self-management, and psychological and psychosocial support (Armer et al., 2009a; Sherman & Koelmeyer, 2013). The inclusion of all individuals, practices, and centers that care for patients with breast cancer is imperative to providing the needed components of care for the best patient outcomes in managing breast cancer treatment, risk-reduction measures and early detection of lymphedema (National Lymphedema Network, 2013; Ridner et al., 2011; Stout et al., 2012).

Assessment and Management of LE

Assessment.

There is a lack of consensus for standardized protocols in regard to measurement techniques. However, circumferential arm measurements, perometry, and water displacement are commonly used to detect and monitor arm swelling, although water displacement method is used less often due to its innate limitations and perometry is becoming more frequently used in breast centers (Armer, 2005; Armer & Stewart, 2005). Arm circumference measurements using a non-stretch tape measure is the most common means to measure limb girth (and volume through formula calculation) to monitor for change over time (Armer et al., 2013). Both arms are measured at the hand and from the wrist to the axilla at specified anatomical landmarks. The most common criteria for LE diagnosis is a change of 2 cm. difference between the affected and unaffected extremity at one anatomical point (Armer, 2005; Bernas et al., 2010). Perometry uses infrared light and optoelectronic sensors to assess limb volume and shape and records data for comparison over time (Armer, 2005; Bernas et al., 2010). Lymph fluid volume differences of 10% or 200 mL between pre-op baseline and/or contralateral limb is the common criteria used in the diagnosis of LE (Armer, 2005; Armer et al., 2008). Water displacement method offered sensitive and accurate volume measures and was able to accommodate for varying limb shapes due to swelling; however, it was contraindicated in patients with open skin lesions and hygienic precautions are not practical in many clinical settings (Armer, 2005; Armer & Stewart, 2005). More recently, bioelectrical impedance spectroscopy (BIS) and tissue dielectric (TDC) have been used as assessment tools for LE. BIS estimates extracellular fluid volume by measuring resistance of body tissues to low alternating electric currents over various frequencies (Bernas et al., 2010; Ward, Czerniec, & Kilbreath, 2009). Resistivity coefficients for intra- and extracellular water of arms ($n = 66$) were used to predict water volumes using BIS in women with lymphedema ($n = 13$). BIS measures were highly correlated ($r = 0.80$-0.90) with total arm perometry measures and deemed an appropriate measure to detect or monitor BCRL (Ward et al., 2009). TDC uses a probe connected to a control unit which displays tissue water changes when the probe is placed on the skin. Mayrovitz reported averaged TDC measures of the volar surface of the forearms were comparable to a single TDC measure, showing differences of +1 unit at a 95% CI (Mayrovitz, Davey, & Shapiro, 2013).

Additionally, patient symptom report should always accompany objective measures and can be invaluable in detecting subclinical LE. Heaviness, swelling (Armer et al., 2003), and tingling and numbness (Norman et al., 2009) have been reported as the most common signs of impending development of LE. Once lymphedema has been diagnosed, it is important to rule out tumor recurrence or abnormalities with the venous systems. This is usually done using lymphangioscintigraphy (LAS) prior to treatment (Bernas, 2013).

Treatment.

There are no universally-applied, evidence-based treatment protocols to guide the treatment of BCRL (Armer et al., 2013; Bernas et al., 2010; Feldman et al., 2012; National Lymphedema Network, 2013). Complete decongestive therapy (CDT) is currently considered the international standard of care for BCRL (International Society of Lymphology, 2013; Lasinski et al., 2012; National Lymphedema Network, 2013; Ridner et al., 2011). Patients are triaged to receive a combination of components that make up the CDT regimen. With the goal of therapy to move lymphatic fluid to an area where it can drain and reduce swelling, these components may include: manual lymphatic drainage (MLD), compression bandaging of the extremity, compression garments, exercise, and meticulous skin care (Armer et al., 2013; Cheifetz & Haley, 2010; International Lymphoedema Framework, 2006; International Society of Lymphology, 2013; National Lymphedema Network, 2013). Manual lymphatic drainage is a hands-on light, lymphatic massage that stimulates superficial lymphatic vessels to move lymph fluid from the extremity to an area where the lymphatics can drain properly (Földi. M., Földi, & Kubik, 2003; Lasinski et al., 2012).

Non-invasive components of care.

Compression bandaging includes several layers of short-stretch bandages that cover the entire limb and create an effective gradient pressure to move lymph fluid out of congested areas (Földi. M. et al., 2003; Lasinski et al., 2012; National Lymphedema Network, 2013). Compression garments are personal garments that are properly fit by a trained specialist and worn on the affected extremity to maintain or prevent progression of swelling. These garments are worn long-term. Some women with BCRL have a garment for day wear and one with a stronger compression gradient to wear during sleep (Lasinski et al., 2012; National Lymphedema Network, 2013). Exercise is prescribed depending on the severity of BCRL symptoms. Remedial exercises are prescribed initially when the goal is to reduce swelling in the extremity. Aerobic, strengthening, and flexibility exercises are prescribed in the self-management phase (Lasinski et al., 2012; National Lymphedema Network, 2013). Skin care is essential for lymphedema management and includes meticulous hygiene and ongoing observation for breaks or texture changes in the skin (Armer et al., 2013; Bernas et al., 2010; Lasinski et al., 2012; National Lymphedema Network, 2013). It is imperative that providers educate patients about the signs and symptoms of infection (cellulitis) in order to identify and treat it at the earliest onset. Risk of infection is greater in patients with lymphedema due to the propensity of microbial growth in an environment of excessive protein-rich lymph fluid and dysfunctional lymphatics (Bernas et al., 2010; Feldman & Semel, 2011; Rockson, 2001). In the majority of patients, there is no antecedent event identified; therefore, knowledge of flu-like symptoms and the classic signs of acute inflammation are essential to facilitate early diagnosis of infection (cellulitis) and prompt treatment to prevent further impairment of lymphatic transport. Reducing the risk of infection and cellulitis can be enhanced by following the National Lymphedema Network risk-reduction guidelines (Feldman & Semel, 2011; National Lymphedema Network, 2013). Education about risk-reduction measures to avoid exacerbation of BCRL should also be included in patient teaching (Armer et al., 2013; National Lymphedema Network, 2013). The first initial phase of intensive treatment under the supervision of a specialty-trained therapist is followed by a transitional phase, in which patients learn to manage and implement their own treatment, using individual or bundled components. Promotion of adherence to long-term control with self-management regimens is critical.

Surgical treatment.

Advances in surgical procedures are currently under investigation for both prevention and treatment of lymphedema using excisional operations, lymphatic reconstruction, and tissue transfer (Armer et al., 2013; Bernas et al., 2010; Chang & Cormier, 2013; Cormier et al., 2010); however, surgery is not considered first line treatment for LE. Patients that undergo surgery must be counseled on the surgical risks and understand that lifelong compression garments are usually prescribed post-operatively and as maintenance (Armer et al., 2013; Chang & Cormier, 2013; Cormier et al., 2010). Currently, surgical treatment with excisional operations, such as debulking procedures and liposuction, has been used with success to alleviate symptoms from severe lymphedema. Experimental work in creating lymphaticovenular anastomosis (LVA) to bypass lymphatic obstruction is the newest in surgical advances with supramicrosurgical lymphatic reconstruction. Tissue transfer procedures involving lympho-lymphatic anastomosis and lymphatic grafting and use of other types of tissue such as omentum, muscle, or skin flaps have been used to channel lymphatic flow (Armer et al., 2013; Chang & Cormier, 2013; Cormier et al., 2010; Shah et al., 2012); however, Vignes et al. (2013) reported 15 complications in 10 patients who received autologous lymph-node transplantation (ALNT), warranting more studies to determine the indications and contraindications for ALNT. Cormier et al. (2012) performed a systematic review of 20 surgical studies and reported that, while promising, no studies show a clear benefit of surgery over CDT for the treatment of BCRL. Damstra et al. (2008) also reported the lack of standardization of research in a systematic review of the literature in regard to LVA. Granzow et al. (2014) recently reported a literature review over the past ten years indicating that treatments have evolved to become more effective and less invasive; however, future studies are needed with larger sample sizes in order to determine best surgical practices in the prevention and treatment of BCRL.

Nodal status determination.

Breast cancer surgery has historically included nodal biopsy and removal in order to detect metastasis and aid in staging. With the advent of sentinel lymph node biopsy (SLNB), studies have changed surgical protocols in regard to the necessity of axillary lymph node dissection (ALND) and in decreasing the number of nodes necessary for ALND. The American College of Surgeons Oncology Group (ACOSOG) Z0011 trial (N = 891) reported no benefit to ALND in women who underwent lumpectomy and whole breast irradiation and had T1-T2 invasive breast cancer, 1-2 positive sentinel lymph nodes, and no palpable lymphadenopathy (Giuliano, Hunt, Ballman, & et al., 2011). There is also growing evidence in studies using diagnostics; for example, axillary reverse mapping (ARM) which helps surgeons spare arm-draining lymph nodes when performing sentinel lymph node biopsies (Khan, 2009). Most recently, Douek et al. (2014) reported findings from the SentiMAG Multi-Center Trial (N = 160) that demonstrated the feasibility of using superparamagnetic iron oxide contrast agent injected subcutaneously into the breast and detection of the sentinel node with a magnetometer. The technique was not inferior to the traditional SLNB procedure with an identification rate of 94.4% to

95% respectively. Contraindications for inclusion in the trial were patients with a hypersensitivity to iron or dextran compounds, magnetic tracers, or superparamagnetic iron oxide contrast agents, iron-overload disease, and patients with implantable devices or pacemakers on the chest wall.

Adjunct Therapies

Pneumatic compression therapy.

In addition to CDT as front-line treatment of BCRL, adjunct therapies are used for symptom management and risk reduction. Most of these include the use of pneumatics, aqua lymphatic therapy (ALT), complementary and alternative medicine (CAM), exercise, and low-level-laser therapy (LLLT). Intermittent pneumatic compression (IPC), consisting of a sleeve garment with chambers that apply pressure, simulating the work-and-release method of manual compression, is used in reducing edema (Feldman et al., 2012). Ridner et al. (2008) studied the use of pneumatic compression in comparison with self-administered manual lymphatic drainage for treatment of lymphedema. Although there were no statistically significant differences between the groups (N = 155), 95% of patients reported a self-perceived positive limb volume outcome with IPC in the home setting. In a pilot study to evaluate lymphatic response to pneumatic compression therapy in normal control and BCRL subjects (N = 9; control: 3 and BCRL subjects: 6) using near infrared (NIR) fluorescence imaging, Adams et al. (2010) reported greater lymphatic propulsion in 4 of 6 BCRL-affected arms after the use of IPC with a segmented sleeve with a calibrated gradient processor. NIR fluorescence imaging was used to measure lymphatic propulsion, velocity, and lymphatic vessel recruitment before, during, and after pneumatic compression therapy. The piloted use of NIR fluorescence imaging in this study allows for the use of microdosing, which decreases the potential for adverse reactions. Adams et al. (2010) also discussed the use of this image technology as a brighter or more easily visualized and improved sensitivity as compared to planar NIR devices.

Aqua lymphatic therapy.

Aqua lymphatic therapy is a method that uses the viscosity of water to provide resistance to body movement. Hydrostatic pressure is used to protect the arm from swelling and reduces edema. Groups of patients with BCRL (N = 48) attended 45-minute sessions in a pool and performed breathing and self-massage techniques in the water in sequence. An immediate mean arm volume reduction of 16% (53 mL) of the affected arm was reported after the first ALT session, and a reduction of 29% (98.2 mL) after the last ALT session (n = 16 ALT; n = 32 control) (Tidhar & Katz-Leurer, 2010).

Complementary and alternative medicine.

Complementary and alternative medicine (CAM) is used by as many as 75% of women with breast cancer as a means to cope with side effects from conventional treatment, find solace, and facilitate healing and cure (Wanchai, Armer, & Stewart, 2013). Wanchai et al. (2013) performed a systematic review of CAM use by women with breast cancer. Thirty-three articles identified natural products (e.g. herbs, minerals, vitamins, food), and mind/body medicine (e.g. meditation, prayer, humor) as the most frequently used types of CAM by women with breast cancer. Most of the studies were conducted in the US (52%), but included Canada (15%), China (9%), and Australia (6%). Body-based CAM (e.g. massage, energy work, acupuncture) is gaining more popularity, but can have adverse side effects. Massage therapy should not be applied to truncal borders and deep tissue massage is contraindicated for patients who are at risk for the development of BCRL due to the possibility of damaging the lymphatic structures (Wanchai et al., 2013). Wanchai et al. (2013) reported that communication and referral to CAM resources were found to be mainly through family and friends, rather than health care providers.

Low-level-laser therapy.

Low-level-laser therapy (LLLT) is another treatment modality that has been studied as an adjunct or alternative in reducing fluid volume and improving arm function in women who have BCRL; however, there are limitations to these studies in regard to sample sizes and differences in measuring objective outcomes (Kaviani, Fateh, Yousefi Nooraie, Alinagi-zadeh, & Ataie-Fashtami, 2006). In a systematic review of 41studies of which only 4 studies met eligibility and evidence point criteria, Lima, Lima, Andrade, & Bergman (2012) reported that all studies using LLLT showed favorable results in limb volume reduction; however, there were many methodological limitations. More recently results were reported of a pilot three-group RCT (N = 46) in which LLLT with compression bandaging demonstrated equal volume reduction in half the time as MLD. Advanced practice nurses (APNs) were trained to administer the treatment regimens in this pilot study which demonstrated that APNs could effectively treat lymphedema, decreasing time and burden on both, the patient and therapists (Ridner et al., 2013b). Ridner et al. (2013a) discuss the need to compare lymphedema therapy given by lymphedema trained therapists, RNs, occupational therapists with and without certification. It would seem feasible to train health care providers to deliver lymphedema therapy to accommodate the large number of patients with LE; however, there is currently no fee schedule for billing these services by healthcare providers (such as nurses and massage therapists) who are not covered under physiotherapy billing codes (Ridner et al., 2013b).

Regardless of the type of adjunct therapy, it is important patients communicate with health care providers to prevent possible adverse effects from combining therapies, prevent injury, and discuss resources that can most benefit patients.

Predisposing factors

There is more consistency needed in defining BCRL risk factors; however, the following are currently included in the literature: (a) obesity (BMI $\geq$ 30; (b) sedentary lifestyle; (c) breast cancer surgery; (d) radiation therapy (XRT); (e) post-surgical infection; (f) radiation skin reaction; (g) age; (h) comorbid conditions and medication usage; and (i) genetic predisposition (Armer et al., 2013; Dominick, Madlensky, Natarajan, & Pierce, 2012; National Lymphedema Network, 2013). Obesity has been reported as a risk factor for BCRL; however, is a modifiable risk factor with diet and exercise (Gho, Steele, Jones, & Munro, 2013). Ridner, Dietrich, Stewart, & Abbott (2013b) reported an approximate 3.6 times likelihood of developing BCRL at 6 months or greater after breast cancer diagnosis in women whose BMI was $\geq$ 30 at the time of breast cancer diagnosis than patients with a BMI<30.

Exercise.

There are many precautions in preventing BCRL that potentially lead to a sedentary lifestyle due to fear of developing lymphedema with strenuous activity. A systematic review of 19 studies by Kwan, Cohn, Armer, Stewart, & Cormier (2011) of which seven studies addressed resistance exercise, and five addressed other exercise modalities, reported findings that supported the safety of resistance exercise without an association with the development or exacerbation of BCRL. Schmitz et al. (2009) conducted a RCT of progressive weight lifting in women with BCRL (N=141). Women participated in a supervised program twice weekly over one year. Findings reported participants in the weight lifting group demonstrated increased strength and there was a decrease in lymphedema exacerbations and symptoms (Schmitz et al., 2009).

Breast cancer surgery and radiation therapy.

Breast cancer surgery, ALND, SLNB and radiation therapy are the main risk factors for the development of BCRL due to trauma to the lymphatic structures. Less invasive surgical procedures and the use of SLNB has helped to decrease the incidence of BCRL; however, there are still significant risks of developing BCRL with SLNB alone or no axillary surgery at all (Armer et al., 2004; Bernas, 2013; Dominick et al., 2012).

Comorbidities.

Cancer survivors are living longer, with an estimated 13,027,914 people currently living among all reported cancer sites in the United States. Based on 2004-2010 SEER data, 89.2% of breast cancer survivors are estimated to live at least 5 years (National Cancer Institute, 2014). Age is associated with decreased function and functional independence (Bellury et al., 2013). In addition, Bellury et al. (2013) found an interaction between symptom bother and comorbidities in 39% of older breast cancer survivors studied, [age $\geq$ 70 (N = 759)] and supported a gero-oncology survivorship paradigm to guide care-planning and delivery. Comorbidities associated with breast cancer survivors with BCRL (n = 74) compared with breast cancer survivors without BCRL (n = 75) were studied by Ridner and Dietrich (2008). Findings identified comorbidities such as obesity, orthopedic problems, hypertension, and arthritis as more prevalent in the lymphedema group (Ridner & Dietrich, 2008). Although determining causality has limitations due to pre-existing conditions, the findings suggested that further study was warranted in regard to the development of or consequences of lymphedema from being sedentary, compromised cardiovascular status, and inflammatory processes (Ridner & Dietrich, 2008). Co-association of medications ordered to manage these conditions may also be a factor in lymphedema development, progression, and management (Keeley, 2008; Ridner & Dietrich, 2008).

Genetic predisposition.

In addition to age, genetic predisposition is a non-modifiable risk factor that has gained increased attention. If patients can be identified as high risk for the development of BCRL from a genetic standpoint, it will help establish specialized monitoring and fast-track clinical management. Newman et al. (2012) identified two genetic loci and a third gene that possibly confer genetic predisposition to secondary lymphedema. More studies are necessary to determine genetic associations that will lead to more effective management strategies.

Risk-reduction strategies and preventive interventions

Physical means by which women with BCRL can perform risk-reduction measures include: (a) protection of skin (e.g. keeping skin clean and dry, avoiding punctures such as blood draws, injections, or intravenous infusions, observe for signs and symptoms of infection, and wearing gloves when gardening); (b) exercise; (c) avoiding extreme temperatures; (d) avoiding limb constriction; and (e) wearing well-fitted compression garments when prescribed (Armer et al., 2013; Bernas et al., 2010). Self-management is a responsibility of patients, which usually involves performing one or more interventions to control or prevent symptoms.

Self-management.

The ability to care for oneself by self-administration of a prescribed regimen to regulate symptoms and promote well-being encompasses self-management (Armer et al., 2011). Self-CDT or MLD is often performed by women with BCRL to facilitate lymph circulation of the affected extremity. A category of CAM, mind/body interventions, is used to promote relaxation and minimize stress. Although there is little to no evidence on the impact of mind/body interventions on outcome measures for BCRL, there has been increasing interest in more rigorous study in this area. Some of these interventions include tai chi, yoga, meditation, mindful-based stress reduction (MBSR), acupuncture or acupressure, and exercise. A quasi-experimental, pre- and post-test control group design was used to study MBSR with breast cancer survivors (N = 32) (Matchim, Armer, & Stewart, 2011b). The participants in the intervention group took an 8-week MBSR training course which, when compared to the control group, demonstrated a statistically significant decrease in systolic and diastolic blood pressure immediately following MBSR and at 1- month follow-up, although it did not remain statistically significant at completion. A state of mindfulness was statistically significant throughout the study. Morning and afternoon cortisol levels were also measured with all participants and, although not statistically significant in comparison at the completion of the study, a clinical significance was noted with the intervention group’s self-report of decreased stress (Matchim, Armer, & Stewart, 2011a). The stress of breast cancer is compounded by a diagnosis of BCRL and can often contribute to failure to perform self-care;

therefore, MSBR may be helpful in reducing risk and improving management of BCRL (Ridner, Bonner, Deng, & Sinclair, 2012a). As with most of the CAM studies reviewed, RCT with larger sample sizes are recommended to further evaluate effectiveness in treating and preventing BCRL.

Exercise and weight-lifting.

Exercise and weight-lifting have been reported as beneficial in women with BCRL, provided that training and conditioning are supervised. The Physical Activity and Lymphedema (PAL) Trial was a pivotal point for women with BCRL who were fearful of physical activity. The PAL Trial reported that progressive weight lifting demonstrated a decrease in exacerbation incidence, reduced symptoms, and increased strength with no significant effect on limb swelling (Schmitz et al., 2009). In addition, evidence suggests that resistance exercise is safe without an increase in BCRL risk for breast cancer patients (Kwan et al., 2011). In a prospective breast cancer morbidity trial, arm volume measures were performed preoperatively and at three month intervals post-surgery on 196 women of whom 43 developed lymphedema. For an upper arm volume increase $\geq$3%, women were prescribed a compression garment to wear daily for 4 weeks. Findings reported that the use of a compression garment was effective in treating subclinical arm volume (48 mL decrease; $p < 0.0001$) in a single-arm pilot (Stout Gergich et al., 2008); however, additional research studies with larger sample sizes and longer follow-up are necessary to establish compression garments as an evidence-based method of reducing BCRL risk.

Surgical prevention.

Surgical means for prevention of BCRL have been reported using the lymphatic microsurgical preventive healing approach (LYMPHA) technique during node dissection

(Boccardo et al., 2011). The LYMPHA approach is a technique by which the lymphatics are temporarily clipped in preparation for microsurgical anastomosis to one or two collateral branches of the axillary vein, without damage to lymphatic pathways (Boccardo et al., 2011). In a prospective study, Boccardo et al. (2011) randomized 46 women into two groups; one receiving the LYMPHA technique and a control group who had no preventive surgical approach. The patients underwent lymphoscintigraphy pre-operatively and at 18 months post-operatively and were followed with volumetry post-operatively at 1, 3, 6, 12, and 18 months. Lymphedema appeared in 1 patient in the treatment group at 6 months' follow-up compared to 7 patients in the control group. Arm volumes in the control group demonstrated a significant increase at every follow-up time point, while no statistically significant changes in volume were assessed in the treatment group. Reproducible results using the LYMPHA approach with larger sample sizes could change traditional approaches to node dissection, reducing the incidence of secondary lymphedema in breast cancer patients (Boccardo et al., 2011).

Psychological and psychosocial Symptoms

Psychological, and psychosocial symptoms contribute to poor adherence with self-management regimens to control BCRL symptoms (Fu et al., 2013; Ridner et al., 2011). Symptom distress results from the disruption in daily life, and women with BCRL are often faced with multiple symptoms that require complex self-management regimens (Fu & Rosedale, 2009; Norman et al., 2009). The burden of BCRL symptoms and self-management often elicit symptoms of anxiety, depression, emotional distress, diminished sexuality, and feelings of sadness (Fu & Rosedale, 2009; Norman et al., 2009). Rosedale and Fu (2010) reported a secondary analysis of phenomenologic data with breast cancer survivors (N = 13) in which temporal, attributive, and situational dimensions of symptom distress were identified. Also reported were lingering symptoms that are expected to disappear, unexpected identity issues in which the post-cancer self is viewed as inferior to the pre-cancer self, and unexpected situations such as those precipitated by symptoms associated with BCRL development. Fu et al. (2013) reported that factors associated with a negative psychosocial impact combined with psychological symptoms resulted in poorer social well-being in women breast cancer survivors with BCRL. Negative psychosocial impact was described by women with BCRL who had experienced unsupportive work environments, perceived social abandonment and social isolation, inability to participate in family leisure activities, marginalization, perceived diminished sexuality, public insensitivity, and financial burden (Fu & Kang, 2013; Fu et al., 2013; Radina, 2009). The lack of instruments that can accurately measure subjective data relevant to the negative impact of psychological and psychosocial issues in women with BCRL is challenging; however, health care providers can be a positive influence by providing a supportive-educative element to care, promoting self-management behaviors, and staying cognizant of internal and external resources to help alleviate symptom distress (Armer et al., 2009a; Sherman & Koelmeyer, 2013).

Impact on patients and families.

Literature suggests that the diagnosis of chronic disease has an impact on individuals and their families (Radina & Armer, 2001). Lymphedema has been reported to have an adverse effect on family functioning (Radina & Armer, 2001, 2004). Factors that determine how a family responds and copes with stressors are dependent on: (a) the relationship between the family members, especially immediate members; (b) functionality and flexibility of the family unit; (c) availability of resources (e.g. friends, community); and (d) the number of stressors (Radina & Armer, 2001, 2004). Radina and Armer (2001) performed interviews to determine issues that resulted from the impact of a lymphedema diagnosis in the context of family. The Family Adaptation and Adjustment Response model was used to interpret their findings as follows: (a) family adjustment to changes is a major factor with family functioning; (b) task modification with daily activities can be changed in the way they are done or someone else may be needed to help; (c) following risk reduction guidelines are important to achieve an understanding of self-management; (d) achieving effective coping strategies can be facilitated by identifying helpful resources; and (e) preventing risk of family functioning imbalance can be achieved by maintaining family routines. In addition, Radina (2009) performed interviews with women breast cancer survivors with BCRL (N = 27) in the context of family leisure and reported modifications to activities and refraining from dangerous or difficult activities as patterns of coping.

Supportive Care

Several studies in the literature focus on patient-education; however, few incorporate a supportive component. Education is important for patients and health care providers alike; however, education alone is not sufficient to provide the support that patients need (Armer et al., 2011). It is important to provide resources that address the psychological and psychosocial needs, as well with the availability of internal and external resources (e.g. lymphedema therapists, support groups, medical equipment, printed information and/or other media). Increasing the awareness and education of BCRL, risk factors for the development of BCRL, risk-reducing activities, and self-management, should be implemented early on after the diagnosis of breast cancer. Due to the increasing numbers of cancer survivors, supportive-educative programs will play a pivotal role in the quality of survivorship (Kwan et al., 2012).

Adherence to self-management of BCRL.

Self-care management can be complex and require education on several components. Motivational interviewing and interactive teaching strategies have been used to enhance the educational process. Armer et al. (2009a) described the use of motivational interviewing in helping breast cancer survivors become empowered in their own care. Solution-focused therapy was also helpful in motivating patients to set self-management goals (Armer et al., 2009a). Patient engagement is a key factor in reducing risk and symptom management of BCRL. Participatory learning methods such as interactive theatre have been used to engage patients in discussion regarding breast cancer issues (Khoury, Sabb, & Haidar, 2010). Further studies are needed to develop reliable and valid instruments that will determine the effectiveness of these innovative approaches.

Health care provider knowledge.

The importance of health care provider knowledge about BCRL is paramount to developing interdisciplinary programs of care. The numbers of patients who see cancer-related physicians are declining each year as patients move into the long-term survivorship phase of care (Pollack, Adamache, Ryerson, Eheman, & Richardson, 2009). Tam et al. (2012) reported results of a study of 887 oncologists, primary care physicians, and surgeons who took a web survey on knowledge of BCRL, education, and referral patterns. Oncologists and surgeons scored highest in knowledge and education categories.

Referrals were also highest in the oncologist and surgeon group, with only 36.2% of primary care physicians reported as ever having made a referral for BCRL. The response rate for this study was 35.9% and although referral information was not specific to time periods, the conclusions identified that educational programs, handouts, and emails were the preferred methods of staying current with BCRL information (Tam et al., 2012). With breast cancer survivors now living longer, oncologists and surgeons who typically follow patients long-term are beginning to feel comfortable with patients returning to their primary physicians for follow-up. This movement back to primary physicians is significant, especially if they are not informed about BCRL risks, treatment, and supportive care interventions (Kwan et al., 2012; Tam et al., 2012). The clinical implications of better-informed health care providers and patients in regard to managing BCRL are high priority because of the positive impact on patient outcomes; however, education does not stop with symptom management. There are cultural differences and similarities that need to be taken into account, due to the diversity of the population in the US; therefore, health care providers need to practice culturally-specific care (Wanchai, Stewart, & Armer, 2012). Patients who feel that their cultural beliefs have been included as part of their plan of care, tend to be more satisfied with care and are more apt to be compliant with treatment (Wanchai, Armer, & Stewart, 2012).

Palliative care.

Educative-supportive systems are also integral to providing palliative care. The World Health Organization (WHO) (2014) defines palliative care as that which integrates physical, psychological, and spiritual aspects of care with the goal of providing symptom relief and quality of life for both patients and their families. In a systematic review of the literature related to the effectiveness of cancer-related lymphedema management in the palliative care setting, eleven articles were selected. Beck, Wanchai, Stewart, Cormier, and Armer (2012) reported all studies were rated in the category of “effectiveness not established” and reported the need for larger, well-designed studies; however, closed-controlled subcutaneous drainage was deemed as potentially effective in patients with late stage cancer. A CDT program may be beneficial; however, treatment should be carefully evaluated by a trained therapist (Beck et al., 2012). The pathophysiology of late-stage cancer and accompanying comorbidities require adaptation and sometimes elimination of treatment components (Cheville, Andrews, Kollasch, Schmidt, & Basford, 2014).

Interdisciplinary Surveillance

An interdisciplinary approach to care and monitoring patients who have been diagnosed with breast cancer is a standard of the American College of Surgeons’ National Accreditation Program for Breast Centers (American College of Surgeons, 2013). With over 200,000 cases of breast cancer cases estimated in 2014 by the American Cancer Society, and up to 40% of 2.5 million breast cancer survivors in the United States who will develop BCRL (Adams et al., 2010; Armer et al., 2008; Paskett, Naughton, McCoy, Case, & Abbott, 2007), it is important to incorporate all disciplines involved in the care of patients in plans of care that emphasize early detection of BCRL, other comorbidities, and/or recurrence of disease. A seamless plan of care initiated pre-operatively gives health care providers the opportunity to detect BCRL symptoms early, when there is a greater chance to prevent progression in the subclinical stage (Stout

Gergich et al., 2008), and provides continuity of care from the inpatient to outpatient settings.

Measures for surveillance.

The most commonly used reliable and valid physical measures used to diagnose and monitor BCRL have been studied (Armer, 2005; Armer et al., 2013; Armer & Stewart, 2005; Bernas, 2013); however, there is little research that incorporates subjective measures relevant to quality of life with objective measures to determine a relationship with early detection of BCRL. Two reliable and valid instruments; the Lymphedema Breast Cancer Questionnaire (LBCQ) (Armer et al., 2003; Armer & Whitman, 2002) and the Functional Assessment of Cancer Therapy-Breast (FACT-B+4) have been used to monitor symptoms and evaluate health-related quality of life (HRQL) (Brady et al., 1997; Coster, Poole, & Fallowfield, 2001). There has been development of several valid and reliable tools to measure QOL issues, such as the 22-item Functional Living Index-Cancer (FLI-C) (Schipper, Clinch, McMurray, & Levitt, 1984). The LYMPQOL is another QOL measure specifically developed for patients with limb lymphedema that proven to be useful (Keeley et al., 2010).

Lymphedema breast cancer questionnaire (LBCQ).

The LBCQ is a 58-item semi-structured questionnaire designed to assess indicators of lymphedema, their frequency, and symptom management strategies (Armer et al., 2003; Armer & Stewart, 2005; Armer & Whitman, 2002; Bernas, 2013). The LBCQ has established reliability and validity using Kuder-Richardson-20 and the test-retest method, showing an acceptable measure of internal consistency (r =0.785). Test-retest reliability was reported high (r =0.98) using healthy women (N = 35) with a 2-hour test-retest interval and an acceptable internal consistency (Armer et al., 2003).

Functional assessment of cancer therapy (FACT-B+4).

The FACT-B is a 44 item self-report instrument for measuring multi-dimensional quality of life with patients who have breast cancer. It incorporates physical, functional, and emotional well-being. Brady et al. (1997) demonstrated test-retest reliability and validity of the FACT-B with two validation samples (alpha = 0.90 with subscale alpha coefficients ranging from 0.63 to 0.86). Coster, Poole, and Fallowfield (2001) designed and tested a supplement to the FACT-B; a 4-item arm subscale to assess the impact of arm morbidity following breast cancer surgery. The FACT-B+4 was validated on clinical trial participants (n = 279 women in a trial of sentinel node guided axillary therapy and n = 29 women attending a lymphedema clinic). Internal consistency was established (alpha coefficient = 0.62 to 0.88) and test-retest reliability (r = 0.97) and the sensitivity of the instrument over time was validated with a subset of 66 participants who completed three assessments (Coster et al., 2001).

Innovation in qualitative measures.

An online version of the LBCQ and FACT-B+4 is an innovative tool that has been developed at Ellis Fischel Cancer Center (EFCC) at the University of Missouri-Columbia, sponsored by the American Lymphedema Framework Project (ALFP) website. A prospective surveillance study using online LBCQ and FACT-B+4 instruments in conjunction with objective measures was initiated with an aim to demonstrate earlier detection of BCRL and improved QOL and functional outcomes compared to standard care (Table 2).

Table 3.2

Ellis Fishel Cancer Center Study Model: Early detection of BCRL with early intervention in the clinical setting

Aims	(1) To determine if rigorous surveillance with web-based questionnaires in conjunction with arm volume measures demonstrates earlier detection of BCRL compared to standard care. (2) To determine if earlier detection of BCRL using web-based HRQOL questionnaires in conjunction with arm volume measures improves QOL and functional outcomes. (3) To assess the cost and efficiency of nursing time in completing and evaluating questionnaires.
Methods	Longitudinal, prospective, mixed-method study which will recruit women with newly-diagnosed breast cancer to complete a comprehensive symptom and quality of life assessment (LBCQ) and undergo arm volume measures pre-operatively, post-operatively, and quarterly. Preoperatively and at 12-month follow-up, patients will complete the FACT-B+4 questionnaires. Descriptive statistics and correlations will be used to examine relationships between actual measured arm volumes and subjective web-based questionnaire responses to determine is early symptoms correlate with limb volume changes. This study has been approved by the University of Missouri Health Sciences Institutional Review Board.
Results	Currently recruiting; (n=25 currently have given informed, written consent; up to 100 will be recruited).
Conclusion	Early diagnosis and intervention for BCRL is reported to improve the patients' quality of life and functional outcomes. By utilizing a novel electronic tool developed in our institution (LBCQ) as a component of rigorous surveillance, we hope to show lymphedema is diagnosed earlier than with standard care, resulting in improved HRQL and functional outcomes for our patients.

Clinical Research

Breast cancer-related lymphedema incidence will continue to rise, despite less invasive surgical methods and the use of SLNB. Cancer survivors are living longer; increasing numbers of functional limitations and comorbidities, such as immobility and obesity, further increase the risk for the development of BCRL. There are no evidence-based methods of treatment, measurement, or consensus on guidelines for palliative care. There is a need for better methods for early detection of subclinical BCRL as well as improvement with adherence to self-management regimens. Currently, there are three clinical trials in progress administered by NCI-funded national oncology clinical trials (Table 3). There is a scarcity of rigorously conducted comparative research studies related to patients with breast cancer-related lymphedema, limiting the development of evidence-based assessment and treatment for hundreds of thousands of women who have or are at risk for the development of BCRL.

Table 3.3

Randomized clinical trials for lymphedema

Clinical Trial Organization	Clinical Trial Number	Name of Trial	Principal Investigator(s)
Alliance (CALGB)	70305	A randomized education/exercise intervention study to reduce risk of lymphedema in women treated for breast cancer	Electra Paskett, PhD, Jane Armer, RN, PhD, Lisa Yee, MD, Michele Naughton, et al.
Alliance (ACOSOG)	Z1070 Successor Trial	Axillary management of T0-T3 node positive breast cancer receiving neoadjuvant chemotherapy	Judy C. Boughey MD, Tom Buchholz MD, Bruce Haffty MD, Vera Suman PhD, Janice Cormier, MD, MPH, Jane Armer, RN, PhD
Gynecologic Oncology Group (GOG)		The Lymphedema and Gynecologic Cancer (LEG) Study: Incidence, Risk Factors, and Impact	Richard Barakat, MD, MSKCC, NCI R01 PI, Jane Armer, RN, PhD, Subcontract PI

Conclusion

A multidisciplinary approach to surveillance of BCRL should be instituted as a means of secondary prevention with all women diagnosed with breast cancer. A pre-operative history and physical, including bilateral arm volume measurements allows for baseline information that is reliable as a prognostic indicator with post-operative and future interval measurements. A baseline pre-operative measurement is more reliable because there is no surgical swelling to inhibit accuracy (Armer, 2005; National Lymphedema Network, 2013). Pre- and post-operative limb volume measures at regular intervals, such as quarterly for 12 months, semi-annually for 1-3 years, and then annually thereafter could identify LE at its earliest state, when there is a better chance for prevention of progression (Armer et al., 2013; Stout Gergich et al., 2008). In addition, education about predisposing factors for BCRL, risk-reduction activities, and resources should be made available pre-operatively (Sherman & Koelmeyer, 2011). Birkballe, Karlsmark, Noerregaard, and Gottrup (2012) conducted a clinical perspective analysis at a multidisciplinary lymphedema center at the Copenhagen Wound Healing Centre. Data were collected for the first 4-5 years after the center was established on 8,058 patient consultations. Birkballe et al. (2012) reported 31% of patients had never had any diagnostic testing or treatment for lymphedema prior to referral. In addition, 86% of the patients required multidisciplinary assessment (Birkballe et al., 2012). The center is staffed by two nurses who specialize in lymphedema with required training (research and clinical), two physicians 1 day a week (one resident with an interest in lymphedema and a dermatologist), and dedicated clinical physiologists for diagnostics and imaging services. Birkballe et al. (2012) reported that an organized and planned utilization of a multidisciplinary staff at their center improved management, knowledge, and awareness of lymphedema. This model is an example of a successful model that, with minor changes could be adapted to patients in the US as a supportive-educative program for the management of BCRL.

Prospective surveillance model.

International efforts have contributed to bringing lymphedema to the forefront of research and recognition. Multidisciplinary best practice templates and guidelines based on expert opinions have been developed in a number of organizations, such as the International Society of Lymphology (ISL) (International Society of Lymphology, 2013), International Lymphoedema Framework (ILF) (International Lymphoedema Framework, 2006), European Wound Management Association (EWMA) (European Wound Management Association, 2005), American Lymphedema Framework Project (ALFP) (e.g. (Armer et al., 2013; Beck et al., 2012; Bernas, 2013; Cormier et al., 2012; Feldman et al., 2012; Gho et al., 2013; Lasinski et al., 2012), and others. A prospective surveillance program for BCRL (PROSURV-BCRL) is proposed in Table 4. It is based on available recommendations by the above mentioned International organizations, as well as the National Lymphedema Network (National Lymphedema Network, 2013), Best Practice Guidelines (Armer et al., 2013), Stout et al. (Stout Gergich et al., 2008; Stout et al., 2012), Schmitz et al. (Schmitz et al., 2009), Birkballe et al. (Birkballe et al., 2012), and many experts in the field. Larger studies are needed to determine a greater advantage of the proposed program over the medical model currently used. The components are not necessarily different, except in terms of the time frame in which the program is initiated. Figure 1. illustrates a graphic abstract of the PROSURV Model.

Table 3.4

PROSURV-BCRL Model (Visits coordinated with MD appointments)

Pre-op assessment with every woman who will undergo breast cancer surgery and/or XRT.	H&P; height, weight, BMI, baseline bilateral limb (arm) volume measures with certified lymphedema therapist, functional assessment; provision of educational and resource information (predisposing factors, risk-reduction activities, signs and symptoms of early BCRL, support group information, team contact information; physical activity assessment and program information; nutritional information); introduction to team members and Q &A opportunities
Post-operative visit by team nurse and lymphedema therapist	Bilateral LV measure and assessment; supportive-educative visit; Ongoing: assess eligibility for clinical trials
Interval visits @ 1, 3, 6, 9, 12 months	Weight; BMI; bilateral LV measures; functional assessment; physical activity assessment; skin assessment. Ongoing: physical exercise program options, unless contraindicated; weight management program options; nutritional support and referral with dietician; support group information; virtual support group/blogs; contact with patient by team member monthly the first year post-breast cancer treatment; psychological /psychosocial assessment/Family assessment with a trained counselor.
Semi-Annual visits for 1-3 years	Same as above with team contact every 2 months to discuss status and evaluate need for resource referral.
Annual visits, if no BCRL is diagnosed	Team contact quarterly to discuss status and evaluate need for resource referral.
If BCRL is diagnosed:	Imaging: (lymphoscintigraphy/lymphangioscintigraphy, lymphography, MRI, ultrasound) to assess and/or rule out problems with lymphatic structures and flow and venous circulation, if indicated. Ongoing: Visits per treatment plan prescribed by lymphedema therapist for initial CDT. Ongoing: support of self-management: Team contact every month or more often initially if necessary, treatment information, clinical trial information if available, support group information/other media information, new product information, Online LBCQ/Fact 4 questionnaire q 3 months or per institution protocol
Ongoing throughout survivorship:	Celebration events at least annually

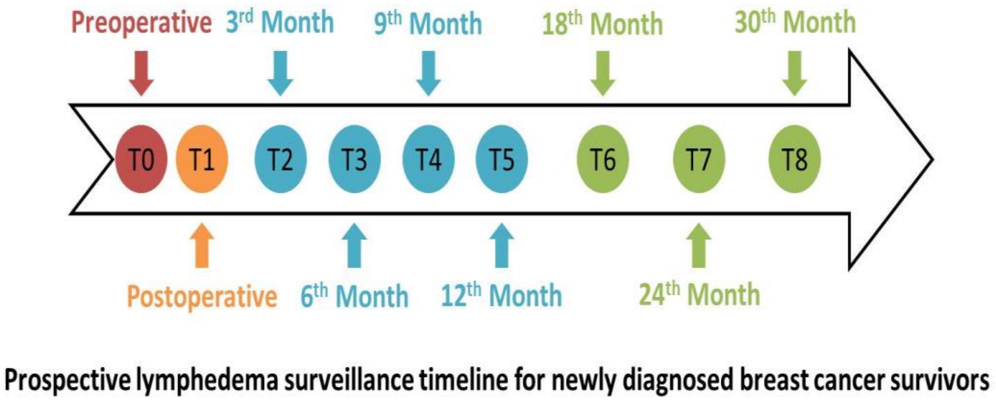

Figure 3.1: Graphical Abstract

Costs associated with traditional and prospective models.

Traditionally, medical models have been used that addressed lymphedema symptoms when patients reported them at provider follow-up visits or when visible swelling, pain, or decreased function causes the need for a problem-oriented visit. Stout et al. (2012) provided a detailed estimation of direct treatment costs of BCRL treatment with 100 women over a period of a year using extrapolated clinical scenarios. The costs were compared between a prospective surveillance model and a traditional model. A sensitivity analysis comparing varied incidence rates between the two models was also performed as well as an analysis of the affect that BCRL progression might have on their assumptions. Although direct cost data are lacking and further analysis is necessary, a reported potential decrease in direct costs of a prospective surveillance model was reported compared to the traditional model related to management of BCRL (Stout et al., 2012). Upfront costs of a prospective surveillance program and dedicated staffing would be significant and may be a deterrent; however, forward thinking past short-term gains and commitment to early detection and prevention of BCRL is predicted to result in significant long-term savings from a financial standpoint. Most importantly, patients may experience a higher quality of life.

Future research.

A commitment to high-level clinical research is needed to test treatment protocols in order to develop evidence-based guidelines. The achievement of standardization is a step that has to be taken in order to move forward in developing clinical trials with larger numbers of participants. Improved patient outcomes can only be quantified with valid and reliable measures. Minimum data sets (MDS) are currently under development and will be used by researchers as a repository for de-identified research data that will be available for outcome comparisons on national and international levels. Dr. Chi-Ren Shyu, Director of the University of Missouri Informatics Institute, and recipient of National Library of Medicine funding, has designed an internet-based system to collect and transfer data (Armer et al., 2013; Reneker, Armer, Stewart, & Shyu, 2011). Collecting, organizing, and analyzing data with findings that can be disseminated worldwide is a major achievement in our priority to facilitate global health. The increase in higher-level studies will enable us to shift the paradigm of care for breast cancer survivors with BCRL to a more user-friendly preventive approach.

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CHAPTER FOUR

Complexities of Adherence to Self-Management of Post-Cancer Lymphedema

Ostby, P. L., & Armer, J. M. (2015). Complexities of Adherence and Post-Cancer Lymphedema Management. *Journal of Personalized Medicine*, *5*(4), 370–388. http://doi.org/10.3390/jpm5040370

Of three million breast cancer survivors in the United States (American Cancer Society, 2015), up to 40% will develop breast cancer-related lymphedema (BCRL), a chronic, debilitating condition with a variety of causes that restricts the flow of lymphatic fluid (Armer et al., 2008; Khan, 2009). BCRL occurs more frequently in women who have undergone axillary lymph node dissection, sentinel lymph node biopsy, and/or radiation therapy for treatment of breast cancer (Armer et al., 2003). Lymphedema can occur soon after surgery or up to twenty years postoperatively in survivors. After emergence, it is a life-long condition that requires on-going management of symptoms with daily treatment regimens to prevent progression of serious symptoms that include swelling, loss of sensation, pain, reduced range of motion, and infection (Armer et al., 2008; Armer et al., 2003).

There is no standardized patient education for BCRL or universal standardized evidence-based treatment protocol to manage the symptoms of BCRL (Fu et al., 2010; Ridner et al., 2012c). The goal of BCRL treatment involves moving stagnating lymph fluid to an area where it can drain. Once diagnosed, intensive decongestive therapy is performed by a specialty-trained therapist followed by a prescribed self-management regimen (Lasinski et al., 2012). The ability to care for oneself by self-administration of a prescribed regimen to manage symptoms and promote well-being encompasses self-management (Armer et al., 2011). It is important to facilitate lymph circulation of the affected extremity; therefore, prescribed self-management regimens are often bundled and may number as many as twelve modalities of care, depending on the severity of the lymphedema, leading to significant patient burden (Brown et al., 2014). The aim of this contemporary literature review is three-fold: (a) to examine the complexities of BCRL self-management; (b) identify the adherence-focused studies relevant to BCRL; and (c) to summarize barriers to self-management of BCRL. Supporting studies relevant to complexities and barriers to treatment are discussed, followed by a review of eight interventional studies that met search criteria using adherence as an outcome measure.

Historically, the term “compliance” referred to a person’s conformity to clinical advice in regard to a prescribed dose, frequency, and time, without any autonomy or independent decision-making on the part of the patient (Haynes & Sackett, 1976; Lutfey & Wishner, 1999; Robinson, Callister, Berry, & Dearing, 2008). The term “adherence” places a focus on patient needs and the relationships between patients and health care providers, and suggests a broader interpretation on understanding the factors such as psychological, behavioral, and personality characteristics that affect a patient’s ability to follow treatment recommendations (Lutfey & Wishner, 1999; Robinson et al., 2008).

Although there are many variables that contribute to successful adherence, Vermeire, Hearnshaw, Van Royen, and Denekens (2001) reported that the strongest factor that correlates with adherence were patients' own beliefs based on their knowledge and experiences, as well as those of families and friends. Taking into consideration that both terms have been used interchangeably in the literature, both were used in this search to provide a more inclusive analysis of the complexities to self-care of BCRL. However, for ease in reading, the term, "adherence" is used throughout this review.

Adherence to prescribed self-management regimens is critical to preventing progression of BCRL. Complexities of adherence relevant to self-management of lymphedema symptoms encompass physiological, psychological, and psychosocial factors and have been correlated to low adherence to performing BCRL self-management regimens (Armer et al., 2013; Fu & Kang, 2013; Fu et al., 2013; Lasinski et al., 2012; Ridner et al., 2011). In addition, the belief in self-efficacy and the ability to control lymphedema are cognitive belief variables that have been correlated with adherence (Sherman & Koelmeyer, 2013). The complexities of BCRL self-management treatment are a barrier to adherence due to cumbersome and time-consuming treatment regimens. Over the past two decades, average self-management rates have remained sub-optimal, between 40% and 50% (Boris & Lasinski, 1994; Ridner et al., 2011). There is a need for additional research in the area of adherence to self-management of BCRL; however, this must be preceded by an understanding of the complexities that lead to poor adherence and inability to adhere to self-management regimens.

Methodology

A search of contemporary literature relative to BCRL treatment and adherence was independently assessed by the first author. Inclusion criteria for this review included: (1) studies pertaining to self-management of BCRL; (2) studies in which an intervention was used to improve symptom management through adherence or compliance to self-management of BCRL; (3) studies that included a specific outcome measure of adherence; (4) studies published in the English language; and (5) studies published between 2005-2015. The terms “breast cancer”, “lymphedema”, and “self-management” were applied to six electronic database indices, which included: Academic Search Complete, CINAHL, ERIC, MEDLINE, PsycARTICLES, and PubMed, from which 120 articles were retrieved. Fifty-nine studies unrelated to secondary lymphedema from breast cancer treatment and 39 studies that did not address BCRL self-management were excluded. Of the remaining 22 studies, eight studies met the inclusion criteria in which BCRL adherence was a primary outcome measure. Most studies identified barriers to adherence; however, most lacked information related to valid and reliable instruments used to measure adherence. A systematic literature review is a next step; however, this is not currently possible, given the limited number of studies with tested instruments, thus preventing a statistical comparison of results and preventing the establishment of meaningful levels of evidence in measuring BCRL adherence.

Complexities of BCRL Adherence

Successful self-management of BCRL is outcome-oriented and focuses on prevention of BCRL progression, decreased limb volume of the affected extremity, and an increase in range of motion and functionality (Stout et al., 2012). Complexities have been defined as a number of intricate variables that are interrelated and which serve as obstacles to successful self-management (Norman, 2010). The interrelated variables of BCRL management encompass every human dimension, with an emphasis on the patients’ perceptions of the condition and treatment (Ridgeway et al., 2014).

Psychological complexities.

Few studies have been published about the perceptions of women with BCRL performing daily self-managed treatment regimens (Fu & Rosedale, 2009), although a more recent systematic review commissioned by the American Lymphedema Framework Project (ALFP) reported that lymphedema has a negative impact on individuals who are affected by the condition (Fu et al., 2013). There are many factors that contribute to psychological distress which impact patients' abilities to cope with cancer and treatment for both the disease and subsequent treatment-related comorbidities (Fu & Rosedale, 2009; National Comprehensive Cancer Network (NCCN), 2015; Ridner & Dietrich, 2008). The National Comprehensive Cancer Network defines distress in cancer as:

> "…an unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment [which] extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis" (National Comprehensive Cancer Network (NCCN), 2015).

Distress can include symptoms of anxiety and depression and may cause insomnia, lack of appetite, and difficulty concentrating and carrying on normal activities. About one third of all cancer patients experience significant distress, with only 5% of those patients seeking psychological help (National Comprehensive Cancer Network (NCCN), 2015). In a qualitative study of women breast cancer survivors (N = 13), Rosedale and Fu conducted a secondary analysis of phenomenologic data, examining symptom distress in terms of temporal, situational, and attributive dimensions. Although more prospective studies are needed, common themes suggested a relationship between symptom distress and psychological distress (Rosedale & Fu, 2010).

Psychological and psychosocial factors have been correlated to low adherence in performing BCRL self-care management regimens (Armer et al., 2009a; Fu & Kang, 2013; Fu et al., 2013). In a systematic review of the literature between 2004-2011 (N = 23 articles), Fu et al. (2013) reported negative psychological and psychosocial impact in each of 12 qualitative studies, including negative self-identity, psychological distress, social isolation, public insensitivity, and perceived social abandonment. The extent of the relationships between negative psychological and psychosocial factors and BCRL has been documented as a cause of non-adherence to self-management, as well as diminution in quality of life (QOL) (McWayne & Heiney, 2005; Paskett & Stark, 2000; Ridner, 2005; Ridner et al., 2011; Ridner et al., 2012c). In a cross-sectional, mixed-methods QOL study with 128 breast cancer survivors (age-matched within 3 years), of whom 64 had BCRL and 64 did not, Ridner (2005) reported scores were significantly lower ($p<0.01$) on all QOL measures in the lymphedema group, including the functional assessment of cancer therapy (FACT-B) with the FACT-B Plus 4 subscale, the Upper Limb Lymphedema 27 (ULL-27), and the Wesley Clinic Lymphedema Scale (WCLS). It is necessary for health care providers to understand there is an overlap of psychological and physiological sequelae, which has a significant impact on adherence to self-management of chronic conditions, such as BCRL.

Education.

Education about lymphedema, treatment, and risk-reduction is an important factor in promoting adherence to self-management; however, knowledge by itself is not a predictor of adherence to risk-reduction behaviors (Sherman & Koelmeyer, 2011, 2013). In addition, several studies focus on patient education; however, few incorporate a supportive component. Education by itself is not sufficient to provide the support that patients need. Tsuchiya, Horn, and Ingham (2012) reported information provision about lymphedema alone may not lead to improved adherence or help-seeking behaviors. In addition, it was suggested that patients' perceptions of illness, consistent with Leventhal's Common Sense Model (CSM), should be considered as necessary in facilitating effective symptom management (Leventhal et al., 1980a; Tsuchiya, Horn, & Ingham, 2012). Leventhal's CSM of Self-Regulation concepts include: (a) representation of illness; (b) coping; and (c) appraisal (Leventhal et al., 1980a). The adaptability of the CSM is one of its main benefits and it can be used with a variety of patients who struggle with chronic disease. Leventhal and colleagues describe five components of illness representations: (1) identity: the label or name given to the condition and the symptoms that 'appear' to go with it; (2) cause: the patient's own ideas about the perceived cause of the condition, which may or may not be medically accurate; representations are based on personal experience, opinions of significant others, health care professionals, and media sources which may reflect adverse issues such as stress; (3) time-line: the predictive belief about how long the condition might last; (4) consequences: the individual beliefs about the consequences of the condition and how it will affect them both physically and socially; and (5) curability/controllability: the beliefs about the degree to which a patient believes they can demonstrate self-efficacy and self-regulation in controlling or managing the condition (Lau & Hartman, 1983; Leventhal, Safer, Cleary, & Gutmann, 1980b). The appraisal process and choosing effective coping strategies are the basis of improved perceptions of self-efficacy and self-regulation. Leventhal's CSM of illness representations suggests that patients' perceptions should be considered in order to facilitate effective symptom management and better adjustment (Leventhal et al., 2011; Leventhal, Leventhal, & Cameron, 2001).

Patients' perceptions of self-efficacy are also contributing factors to adherence to self-management of BCRL. In a study of women (N = 98) who were scheduled for breast and lymph node surgery, Sherman and Koelmeyer (2013) reported that data from questionnaires completed pre- and 3-months post-surgery demonstrated greater adherence to BCRL risk-reduction behaviors with participants who had greater beliefs of self-efficacy and self-regulatory abilities to control lymphedema. Findings suggest that while inclusion of education is important, it should have a motivational component to facilitate long-term adherence (Sherman & Koelmeyer, 2013). Another study was conducted by Sherman et al. (2015) with women who had undergone breast and lymphatic surgery (N = 103). The participants completed questionnaires to measure perceived lymphedema risk, beliefs and expectancies, self-regulatory ability, distress, knowledge, and adherence to BCRL risk-reduction behaviors. The women were then given printed information from the American Cancer Society about breast cancer. Cognitive and affective variables were reassessed at 6- and 12- months post-baseline (N = 62). The findings of the study reinforced the importance of education about lymphedema risk and self-management of BCRL as a factor associated with adherence; however, in addition to knowledge, adherence levels were higher in women with lower lymphedema-related distress and increased perception of self-regulation in managing distress (Sherman et al., 2015). Deng et al. (2013) conducted one of the first studies to examine sources of educational materials about lymphedema and knowledge levels of patients with primary (n = 517) and secondary lymphedema (n = 1025). Between 2006 and 2010, data were collected from participants with the completion of an online survey. Overall, participants reported that a variety of sources were used for obtaining information; however, 76% of the patients favored dedicated websites. Physician/primary health care providers were favored by 55.5%, followed by internet support groups (33.6%) and friends and family (32.1%). Participants with primary lymphedema reported lower knowledge levels about lymphedema, treatment approaches, and complications than participants with secondary lymphedema. Nurses were more often reported to be responsible for providing educational materials to participants with secondary lymphedema, with the internet being the main source for participants with primary lymphedema. Opportunities exist for health care providers to expand and utilize additional formats for providing accurate and understandable information (Deng et al., 2013). In addition, patient-centered strategies should include education to increase awareness with attention to patients’ responses to their perceived health threat responses on both cognitive and affective levels (Sherman et al., 2015).

Treatment burden.

The lifelong requirements of BCRL self-care are associated with patient burden, reduced quality of life (QOL), and poor adherence (Armer et al., 2008; Cormier et al., 2009; Fu et al., 2010; Fu & Kang, 2013; Fu et al., 2013; Fu & Rosedale, 2009; Paskett, Dean, Oliveri, & Harrop, 2012; Ridner et al., 2011; Ridner et al., 2012c; Rosedale & Fu, 2010; Sherman & Koelmeyer, 2013). The components of self-management regimens can be simple to complex; however, these often culminate in significant treatment burden. Shippee et al. (2012) developed a framework of cumulative complexity, which defined treatment burden as an imbalance between patient "workload," which includes day-to-day demands and responsibilities, including treatment and self-care; and patient "capacity," which concerns the patient's abilities to address the demands. It is critical to understand the factors that create imbalance between the demands of self-care and the capacity to cope in order to prevent higher perceived treatment burden and poor patient outcomes, such as non-adherence (Ridgeway et al., 2014).

Self-management of BCRL can only be effective if it is performed; therefore, it is necessary to better understand the complexities that directly affect women with BCRL. The components of a BCRL self-management regimen may include manual lymphatic drainage (MLD), compression garments, bandaging, skin care, and exercise (Lasinski, 2013; Lasinski et al., 2012). MLD is a hands-on, light lymphatic massage that stimulates superficial lymphatic vessels to move lymph fluid from the extremity to an area where the lymphatics can drain properly (Lasinski, 2013; National Lymphedema Network, 2015). Compression bandaging includes several layers of short stretch bandages that cover the entire limb and create an effective gradient compression to move lymph fluid out of congested areas (Lasinski, 2013). Compression garments are personal garments that are properly fit by a trained specialist and are worn on the affected extremity to maintain or prevent progression of swelling. These garments are worn long-term. Some women with BCRL have a garment for day wear and one with a stronger compression gradient to wear during sleep as an alternative to bandaging (Deng et al., 2013). Exercise is prescribed depending on the severity of BCRL symptoms and level of conditioning. Remedial exercises are prescribed initially when the goal is to reduce swelling in the extremity. Aerobic, strengthening, and flexibility exercises are prescribed in the self-management phase (National Lymphedema Network, 2015; Stout Gergich et al., 2008). Skin care is essential for lymphedema management and includes meticulous hygiene and ongoing observation for breaks in the skin (Deng et al., 2013; National Cancer Institute, 2015; National Lymphedema Network, 2015). Education about risk-reduction measures to avoid exacerbation of BCRL should be included in patient teaching (Armer et al., 2011; Armer et al., 2013; National Lymphedema Network, 2015). Low-level-laser therapy has been studied as a modality in reducing fluid volume and improving arm function in women who have BCRL; however, there are limitations to these studies in regard to sample sizes and differences in measuring objective outcomes (Kaviani et al., 2006; Omar, Shaheen, & Zafar, 2012). The complexity of self-management regimens can be overwhelming and contribute to the everyday demands of patients with BCRL.

Psychosocial impact.

The examination of psychosocial adjustment and its impact on women with BCRL has been difficult to quantify due to lack of accurate measures and an operational definition (Fu et al., 2013; Heppner et al., 2009). In a systematic review, of which 19 of 23 studies were related to BCRL, Fu et al. (2013) examined psychosocial impact using a combination of psychological and social impact domains that directly affect an individual with lymphedema and its treatment. Operational domains for psychological impact included negative self-identity, emotional disturbance, and psychological distress. Social impact domains included marginalization by health care providers, financial burden, social isolation, perceived diminished sexuality, and public insensitivity. In addition, of 11 quantitative studies, poorer social well-being was statistically significant in persons with lymphedema compared to persons without lymphedema. Of 12 qualitative studies reviewed, all described negative psychological and social impact related to lymphedema (Fu et al., 2013). Consistent findings of a negative impact on physical and mental QOL were described by Paskett, Dean, Oliveri, and Harrop (2012) in a literature review of articles published since 1990 (N = 726 references), of which 60 studies met inclusion criteria examining the evidence for causes, risk, prevention, diagnosis, treatment, and impact of BCRL. Most studies reviewed were relevant to BCRL with conclusions as follows: (1) the need for more studies in patients with other types of cancers; (2) the need for consensus on definitions and measures; (3) increased awareness of lymphedema signs and symptoms by both patients and health care providers; and (4) the need for prompt access to care and treatment that includes psychosocial support. Armer et al. (2004) reported specific contributors to psychological distress which included altered body image, imposed lifestyle changes and occupational role changes, and negative impact on interpersonal and family relationships. Dominick, Natarajan, Pierce, Madanat, and Madlensky (2014) examined the impact of lymphedema-related stress on psychosocial functioning (i.e. QOL and depressive symptoms). Psychosocial outcomes were measured using a data set from a cross-section of participants in the Women's Healthy Eating and Living (WHEL) study (N = 2431 of which 692 self-reported ever having lymphedema). Findings indicated that breast cancer survivors with lymphedema-related distress had worse physical health and mental health outcomes than women who were not distressed with lymphedema and breast cancer survivors without lymphedema. The evidence of a relationship between BCRL and its negative impact on psychosocial functioning demonstrates the need for further research in developing conceptual and operational definitions, as well as measures that are more specific to psychosocial functioning.

Physiological complexities.

Poor adherence to BCRL self-care modalities is associated with a wide range of physical symptoms in which severity is measured by a grading system (International Society of Lymphology, 2013). Three levels of objective criteria include: Grade I, which may present with pitting of the skin with the application of pressure and reversible edema of an extremity with elevation; Grade II, in which elevation rarely relieves edema and pitting is manifest, then later may or not demonstrate pitting due to excess fat or fibrotic skin changes; and Grade III, worsening swelling and severe thickening of the skin with the development of huge skin folds (International Society of Lymphology, 2013). BCRL mainly affects areas of the arm, hand, breast, and trunk; however, symptoms can be present that are unable to be detected by routine clinical evaluations (Armer et al., 2004; Cormier et al., 2009).

Symptom burden.

In addition to objective symptoms, studies have confirmed the importance of subjective symptoms, as well. Listening to patients for self-reported subjective symptoms is important in detecting BCRL at a subclinical level, if possible (Armer & Stewart, 2010; Hulett et al., 2015; Ostby et al., 2014; Stout Gergich et al., 2008). In earlier studies, self-reported symptoms of heaviness and/or swelling were identified as the most common predictors of BCRL (Armer et al., 2004; Armer et al., 2003; Armer et al., 2009a; Armer

& Whitman, 2002). In a National Lymphedema Network online survey of patients with upper extremity lymphedema (n =729) and lower extremity lymphedema (n= 1114) between March 2006 through January 2010, Ridner et al. (2012c) reported symptoms experienced most frequently among individuals with upper extremity lymphedema were swelling (96.8%), a feeling of extremity heaviness (76.2%), current pain (67.3%), stiffness (65.8%), numbness (63.9%), and decreased range of motion (48.0%). Symptom burden is a barrier to self-management of BCRL, which is critical to prevent progression. Life-long self-management requires a plan to guide patients throughout survivorship.

Comorbidities.

There are an estimated 14 million cancer survivors among all reported cancer sites in the United States (American Cancer Society, 2015). In 2015, there were an estimated 3 million women living with breast cancer in the United States (American Cancer Society, 2015). Based on 2005-2011 Surveillance, Epidemiology, and End Results (SEER) program sponsored by the National Cancer Institute data, 89% of all patients diagnosed with breast cancer have lived 5 years or more. The majority of breast cancer survivors are 65 years of age or older (Howlader et al., 2015), and although chronological age alone is not the only factor to consider when classifying older adults, it has been reported that they are three times more likely to develop BCRL than younger people (Nazarko, 2006) and are at risk for delayed diagnosis due to the coexistence of other forms of edema and comorbidities (Armer et al., 2012). Bellury et al. (2013) found an interaction between symptom burden and comorbidities in 39% of older breast cancer survivors studied, [age > 70 (N = 759) and supported a gero-oncology survivorship paradigm to guide care. In a study of breast cancer survivors with BCRL (n = 74) compared with breast cancer survivors without BCRL (n = 75), Ridner and Dietrich (2008) reported more orthopedic problems, hypertension, obesity (BMI > 30), and arthritis in the lymphedema group. Although pre-existing conditions present some limitations in determining causality, the findings suggested that being sedentary, compromised cardiovascular status and the relationship of inflammatory and infectious processes with BCRL warrant further investigation (Ridner & Dietrich, 2008). In addition, co-association of medications ordered to manage comorbid conditions could also be a factor in lymphedema emergence, progression, and management (Keeley, 2008; Ridner & Dietrich, 2008). The barriers to self-management of BCRL are exacerbated due to comorbidities, decreased function, lack of support, and cognitive inconsistencies and require more innovative strategies to help improve adherence to self-management of symptoms.

Through a secondary review of the qualitative studies included in this review by the first author, the most common barriers to BCRL self-management have been summarized in Table 1.

Table 4.1

Categories of factors related to decreased adherence to BCRL Self-Management

Psychological Distress	Psychosocial Factors	Physiological Factors	Treatment Burden	Education	Comorbidities
Symptom distress	Social isolation	Heaviness of extremity	Imbalance between patient burden of treatment and their capacity to cope	Education about BCRL and self-management is not always provided	Loss of function/ROM (i.e. arthritis)
Anxiety	Lack of support	Numbness	Reduced QOL	Need exists for expanding the variety of formats for BCRL education	Age
Depression	Spiritual crisis	Swelling	Decreased time for family, leisure activities due to time spent for BCRL treatment	Patient-centered strategies are needed to address both cognitive and affective levels	Cognitive changes (i.e. stroke, dementia)
Emotional disturbance (i.e. sadness)	Perceived diminished sexuality	Skin changes			Co-association of medications
Fear	Marginalization by health care providers	Stiffness			Sedentary lifestyle (cardiovascular implications)
Decreased perceptions of self-efficacy	Financial burden	Pain			
Stress					

Results

Ridner et al. (2014) suggested BCRL self-management adherence rates of less than 50% from previous study participants and patients’ perceptions that they lacked results from self-care (i.e. arm volume measurements) and feelings of decreased self-efficacy were reasons for poor self-care adherence (Ridner et al., 2014). Ridner et al. (2014) conducted a pilot study using bioelectrical impedance in a home measurement program (n = 11 women with BCRL and n = 11 women without BCRL). It was theorized that a home measurement system would provide the ability to set self-care goals, reinforce care with measureable results, allow informed decision-making, and experience satisfaction with outcome information. Although compliance rates were not calculated, an adjustment in the number of times for self-measurement was made based on participant feedback. Overall, feasibility of the home measurement system was demonstrated and it was accepted by the participants and captured limb volume change. It may be able to lend support with monitoring BCRL treatment and clinical trials are warranted (Ridner et al., 2014).

Armer et al. (2009a) conducted a prospective surveillance study in which 27 participants were enrolled. The participants were assessed for symptoms of BCRL pre- and post-operatively and every 6 months for 18 months. Based on feedback from the parent study which indicated that patients were not performing the self-care task of manual lymphatic drainage as they had been instructed, it became clear that an enhancement to the current intervention was needed. Motivational interviewing and solution-focused therapy were interactive activities that were implemented by the study nurses. Through interactive strategies, non-compliance was addressed, allowing for rapport building between the patients and the nurses, a clinical assessment, and discussion to summarize and identify advantages and disadvantages to care. Solution-focused therapy was achieved through dialogue with the nurses who empowered and motivated patients to become engaged in the self-care goal-setting process. The addition of motivational interviewing and solution-focused therapy enabled the study staff to identify strengths and weaknesses in the participants' abilities to develop self-care agency or the power to engage in self-care.

A third study conducted by Brown et al. (2014) specifically profiled prescription and adherence with 141 breast cancer survivors with BCRL who had been in a previous physical and activity trial (PAL) using a 12-month randomized weightlifting trial. A questionnaire developed to assess adherence to self-care modalities was administered at baseline, 3-, 6-, and 12-month intervals. Adherence was defined as the percentage of time that self-care modalities were completed at the frequency recommended by the lymphedema therapist. At 12 months, overall adherence to all self-care modalities was not optimal with the majority of the participants (69%) reporting an adherence rate of less than 75%. The study concluded there was a need for an infrastructure for BCRL education and support, such as that which exists for patients with Type I diabetes (Brown et al., 2014).

Forner-Cordero et al. (2010) studied adherence to bandaging during combined decongestive therapy (CDT) with 171 patients with BCRL. The endpoint of the study was the percentage of limb volume reduction at the end of the CDT period. Adherence to bandaging was acknowledged daily by the physician. Bandages were removed each session and adherence to reapplying the bandages at home per protocol and arriving the next day with the bandages in place constituted adherence. Percentages were assigned as a measure of adherence; “good” adherence was when the patient maintained the bandages 90% of the time of treatment, “fair” between 60% and 89%, and “bad” with less than 60% of the time. Adherence to bandaging during CDT was predictive of better limb volume reduction (Forner-Cordero et al., 2010).

Tidar and Katz-Leurer (2010) used treatment diaries as a measure of adherence with an aqua lymphatic therapy (ALT) intervention. ALT was the intervention in a study to examine whether there were differences in adherence, limb volume, and QOL between women who performed only self-management treatment for BCRL and women who performed self-management for BCRL and ALT. ALT is a method that uses the viscosity of water to provide resistance to body movement. Hydrostatic pressure is used to protect the arm from swelling and reduces edema. Groups of patients with BCRL attended 45-minute sessions in a pool and performed breathing and self-massage techniques in the water in sequence. An immediate mean arm volume reduction of 16% (53 mL) of the affected arm was reported after the first ALT session, and a reduction of 29% (98.2 mL) after the last ALT session (n = 16 ALT; n = 32 control). Adherence to therapy was the main outcome in this study; therefore, calculation of an adequate sample size was based on the assumption of an approximate 50% adherence rate in the control group, as compared to 85% in the study group (based on earlier studies by Boris and Lasinski) (Tidhar & Katz-Leurer, 2010). Additionally, Letellier, Shimony, and Tidhar (2014) conducted a second study with ALT to compare weekly ALT and home-based exercise to home-based exercise alone (n = 13 ALT and n = 12 control) for 12 weeks. Home-based exercises were performed using an instructional DVD. Diaries were used to measure adherence with a 52% return rate (n = 13 from both groups), which prohibited the ability to look at an association of adherence with self-management practices and outcome measures; however, ALT demonstrated a significant difference over home-based exercise alone with a reduction in pain intensity scores, arm disability and an increase in QOL.

Studies that are conducted to understand factors that influence and lead to initiation and maintenance of self-management strategies are limited; however, psychological and psychosocial factors have begun to emerge as indicators of adherence (Dominick et al., 2014; Fu & Kang, 2013; Fu et al., 2013; Sherman & Koelmeyer, 2011, 2013; Sherman et al., 2015). In addition, there are a growing number of studies in the area of patient knowledge of BCRL self-care practices and its influence on adherence. Sherman and Koelmeyer (2011) conducted a study of 106 women diagnosed with breast cancer and at risk for BCRL in an effort to assess the role of educational resources and objective risk status on knowledge and BCRL risk-minimization behaviors. A survey questionnaire was administered at the time of surgery and 3-months post-operatively to measure demographics, lymphedema knowledge, lymphedema information sources used, and adherence to risk-minimization recommendations. Adherence to risk-minimization behaviors was addressed with 12 self-report items which were based on national recommendation guidelines for lymphedema. For each recommendation practice, a score of 1 was given, with a score total summed out of 12. High internal consistency with this scale was demonstrated with a Cronbach alpha of 0.86. The mean total adherence was 9.53 (SD = 2.95; range 0–12), with 32 women performing every recommendation and 2 performing none. The highest level of non-adherence, reported in 28% of the participants, was in seeking medical assistance with the emergence of BCRL symptoms, wearing gloves for housework or gardening, and using an electric razor when shaving the axillae. Other outcomes measures demonstrated that knowledge was high and increased over time and receiving information from nursing staff three months post-operatively was significant in predicting risk-minimization behaviors (Sherman & Koelmeyer, 2011).

Sherman et al. (2015) have recently published a study (N = 103) which expands on their previous research and investigates psycho-educational factors associated with BCRL risk. Adherence to BCRL risk-minimization behaviors is again assessed using a 12-item self-report scale. Psycho-educational factors were measured at baseline and then again at 6- and 12-months after giving participants an American Cancer Society publication entitled, "Lymphedema: What Every Woman with Breast Cancer Should Know." Findings demonstrated an increase in knowledge over time, lower distress, and higher self-efficacy and self-regulatory abilities to manage stress; and an association with increased adherence (Sherman et al., 2015). Table 2 is a summary of the studies selected for this review.

Table 4.2

Summary of adherence studies

Study	Topic/Sample	Outcome Measure	Findings
Ridner S, Bonner CM, Doersam JK, et al. Bioelectrical impedance self-measurement protocol development and daily variation between healthy volunteers and breast cancer survivors with lymphedema. Lymphatic Research and Biology. 2014;12(1):2-9.	Home measurement program using bioelectrical impedance to establish feasibility and acceptability by patients with and without BCRL. (n = 11 with and n = 11 without BCRL)	Participant feedback used to adjust number of home measures. Participants were involved in determining feasibility of using home measures to monitor BCRL and were able to see limb volume changes.	Goal setting, informed decision-making, and experience satisfaction with outcome information relevant to limb volume measures were achieved. Ridner et al. suggests patients' perception of a lack of results in self-care and subsequent feelings of decreased self-efficacy lead to poor adherence.
Armer J, Shook RP, Schneider MK, et al. Enhancing supportive-educative nursing systems to reduce risk of post-breast cancer lymphedema. Self Care Dependent Care Nurs. 2009; 17(1):6-15.	Prospective surveillance study to assess for BCRL with self-care using manual lymphatic drainage (MLD). (N = 27)	Motivational interviewing and solution-focused therapy	When participants were found to be non-adherent to the MLD intervention, motivational interviewing and solution-focused therapy enabled staff to identify strengths and weaknesses associated with non-adherence.
Brown J, Cheville A, Tchou JC, Harris SR, Schmitz KH. Prescription and adherence to lymphedema self-care modalities among women with breast cancer-related lymphedema. Supportive Care in Cancer. 2014; 22(1):135-43.	Adherence to BCRL self-care modalities at 3-, 6-, and 12-month intervals. (N = 141)	A questionnaire developed to assess adherence to self-care modalities. Adherence = percentage of time that self-care modalities were completed at the frequency recommended by the lymphedema therapist. Adherence ≥ 75%.	At 12 months, adherence was sub-optimal at 69%. Results identified a need for an infrastructure of support and education.
Forner-Cordero I, Muñoz-Langa J, Forner-Cordero A, DeMiguel-Jimeno J. Predictive factors of response to decongestive therapy in patients with breast-cancer-related lymphedema. Annals of Surgical Oncology. 2010;17(3):744-51.	Adherence to bandaging during combined decongestive therapy (CDT). (N = 171)	Bandaging of the extremity at home and arriving for therapy each day with bandages in place constituted adherence. Adherence was assigned percentages as follows: 90% = Good 60% - 89% = Fair >60% = Bad	Adherence to bandaging during CDT was predictive of better treatment outcomes.

Study	Topic/Sample	Outcome Measure	Findings
Tidhar D, Katz-Leurer M. Aqua lymphatic therapy in women who suffer from breast cancer treatment-related lymphedema: a randomized controlled study. Support Care Cancer. 2010;18(3):383-92.	Comparison of adherence, limb volume, and QOL in women who perform only self-management treatment for BCRL and those who perform self-management treatment for BCRL and aqua lymphatic therapy (ALT). (n = 16 study group; n = 32 control group).	Adherence diary based on attendance based on an assumption of 50% adherence in the control group and 85% in the ALT group. Limb volume measures and QOL questionnaires were also used.	The mean adherence rate to self-management for both groups was lower than 30% at entry time and during the study period. The adherence for ALT was 79%. Eighty-six percent of the women adhered to more than 75% of the ALT sessions. This was significantly higher compared with self-management therapy and each of its components ($p<0.05$).
Letellier ME, Towers A, Shimony A, Tidhar D. Breast cancer-related lymphedema: a randomized controlled pilot and feasibility study Am J Phys Med Rehabilitation. 2014;93(9):751-59; quiz 60-61	Comparison of home-based exercise to home-based exercise and weekly aqua lymphatic therapy (ALT). (ALT group n = 13; control group n = 12)	Diaries used to measure adherence. Arm disability, pain intensity scores, and QOL were also examined.	The ALT group demonstrated a significant difference over the home exercise alone group (control) with a reduction in pain intensity scores, arm disability, and increased QOL. Association of adherence with self-management practices and outcome measures were prohibited due to a 52% return rate of diaries.
Sherman K, Koelmeyer L. The Role of Information Sources and Objective Risk Status on Lymphedema Risk-Minimization Behaviors in Women Recently Diagnosed with Breast Cancer. Oncology Nursing Forum. 2011; 38(1): E27-36.	A measure of demographics, lymphedema knowledge, lymphedema information sources used, and adherence to risk – minimization recommendations in women recently diagnosed with breast cancer. (N=106)	A survey questionnaire of 12 self-report items was administered at the time of surgery and 3-months post-operatively. For each recommendation practice, a score of 1 was given, with a total score summed out of 12.	Women breast cancer survivors at risk for BCRL scored high on performing most BCRL risk-reduction activities. Mean total adherence was 9.53, with 32 women performing every recommendation and 2 performing none. The scale demonstrated a high internal consistency with a Cronbach alpha of 0.86.
Sherman K, Miller S, Roussi P, Taylor A. Factors predicting adherence to risk management behavior of women at increased risk for developing lymphedema. Supportive Care in Cancer. 2015; 23(1):	Adherence to risk minimization behaviors and psycho-educational factors was assessed. (N = 103)	Adherence was measured using a 12-item self-report yes/no dichotomous items based on the ACS lymphedema risk management guidelines. The survey questionnaire was administered at baseline, 6-, and 12-months after	Women breast cancer survivors who understand BCRL risk and feel confident in managing it are more likely to adhere to recommended strategies. The study demonstrated an increase in knowledge over time, lower distress, and higher

Study	**Topic/Sample**	**Outcome Measure**	**Findings**
61-9.		giving printed information about breast cancer.	self-efficacy and self-regulation abilities.

Discussion

There are few studies in the literature that utilize a valid and reliable measure of patient adherence to self-management of BCRL. Adherence is used in the medical sense as a definition of success in the form of a treatment response or physical change, most often referring to limb volume. A positive treatment response of a 50% decrease in limb volume assumes that a patient has chosen to adhere to the study activities. This may or may not be the case and it is necessary to differentiate between physical responses and behavioral responses, especially when dealing with chronic conditions requiring life-long maintenance. Behavioral self-monitoring, a method of self-observation, evaluation, and recording of one's behavior, is used by 80% of cognitive and behavioral therapists to help people to make behavioral changes (Olson, Schmidt, Winkler, & Wipfli, 2011). Similar to Leventhal's Common Sense Model, adherence to self-management of BCRL requires women to perform self-observation, adopt risk-reduction and symptom management activities on a regular basis, and, in some fashion, record their behavior for later reappraisal of outcomes (Leventhal et al., 1980a). There are many theoretical frameworks that can be applied to behavior change relevant to self-care; however, there is a lack of reliable and valid measures that can be used to evaluate the concept of adherence.

Conclusion

BCRL research has grown significantly in understanding the barriers and facilitators to self-management. Recent studies have reported that psychological and psychosocial factors are contributors to poor adherence to BCRL risk-minimization behaviors and treatment regimens. Further research is needed to advance the body of knowledge in the area of instrument development to measure outcomes to behavioral change relevant to adherence and successful management of chronic diseases and conditions, such as BCRL. Health care providers have a responsibility to provide resources to help patients learn about their health and how best to manage it. An understanding of patient care on a multi-dimensional level is necessary to build rapport and anticipate and provide adequate resources. Patient engagement in taking an active role in understanding their health and plan of care may help to increase BCRL adherence with meaningful measures of successful outcomes.

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CHAPTER FIVE

Methodology

Specific Aims

Better strategies are needed to improve suboptimal adherence rates to BCRL self-management regimens. There are currently no published studies that measure adherence to BCRL self-management regimens following the use of interactive theatre (IT). There is also a scarcity of studies that examine the perceptions of women with BCRL who perform daily self-managed treatment regimens (Fu & Rosedale, 2009). The lifelong requirements of BCRL self-care are associated with patient burden, reduced quality of life, and poor adherence (Armer et al., 2009a; Armer et al., 2009b; International Society of Lymphology, 2013; Ridner et al., 2011; Sherman & Koelmeyer, 2013; Stout et al., 2012). The components of self-management regimens can be simple to complex and often times result in treatment burden.

Currently, the standard of care most commonly used in providing BCRL education consists of providing printed information to women who have undergone breast cancer treatment. Although accurate lymphedema information and knowledge may increase patients' involvement in self-management of BCRL and possibly decrease symptom burden and distress, information provision about lymphedema alone may not lead to improved adherence or help-seeking behaviors (Deng et al., 2013; Tsuchiya et al., 2012). It has been reported that an educative program alone is not sufficient to maintain ongoing self-management of BCRL (Armer et al., 2009a).

A supportive component of care is needed that allows for ongoing facilitation of patient engagement. This study will compare the most commonly used standard of care in providing patient education (printed information) to a bundled intervention, consisting of printed information about BCRL and attendance at an interactive theatre (IT) program and will be guided by the following specific aims:

Specific Aim 1. Test an IT intervention bundled with printed information about BCRL that aims to improve patient adherence and symptom management to self-management regimens for BCRL;

Specific Aim 2. Determine the impact of an IT intervention bundled with printed information about BCRL on patient perceptions of self-efficacy and self-regulation in managing BCRL compared to printed information alone.

The hypotheses of this study are: (1) A bundled intervention of an IT program combined with printed information about BCRL is more efficacious in improving adherence and self-management rates of BCRL than the current standard of providing printed information about BCRL alone; and (2) A bundled intervention of an IT program and printed information about BCRL is more efficacious than printed information about BCRL alone in improving perceptions of self-efficacy and self-regulation.

Variables include: demographics, BCRL self-management, adherence, self-efficacy, and self-regulation. The ability to care for oneself by self-administration of a prescribed regimen to regulate symptoms and promote well-being encompasses **self-management** (Armer et al., 2011). Self-management will be measured in terms of whether action was taken to manage symptoms now or in the past year using a yes/no format adopted from the Lymphedema Breast Cancer Questionnaire (LBCQ) (Armer et al., 2003). The term **adherence** places a focus on patient needs and the relationships between patients and health care providers, and suggests a broader interpretation on understanding the factors, such as psychological, behavioral, and personality characteristics that affect a patient's ability to follow treatment recommendations (Robinson et al., 2008). Comparison of percentages from pre- and post-intervention treatment diaries will be used to measure adherence to each participant's prescribed self-management regimen. **Self-efficacy** is one's belief that he/she can affect a situation or condition and **self-regulation** is the ability to control emotion, behavior, and distractions that may interfere with pre-set goals to control what is perceived as a health threat (Leventhal et al., 2011). Valid and reliable questionnaires will be used to measure self-efficacy and self-regulation using a Likert-scale format.

Research Engagement Plan

This study has been approved by the MU Health Sciences Institutional Review Board (IRB). Breast cancer survivors with BCRL were invited to participate in this study. Study invitation flyers, social media, and online newsletter and internet sites, such as the National Lymphedema Network (NLN) and the American Lymphedema Framework Project (ALFP) were used for recruitment efforts concentrated in the Mid-Missouri and Greater St. Louis areas; however, potential participants were not excluded if they lived outside of Missouri. The PI has made face-to-face visits with health care providers, orthotists (garment fitters), physicians, lymphedema therapists, and nurses who have been educated on the purpose of the study and have agreed to help in the recruitment of eligible potential participants. Presentations to breast cancer and lymphedema support groups have been given in St. Louis, Jefferson City, Osage Beach, and Columbia, Missouri. In addition, approximately 350 breast cancer survivors who are currently participating in survivorship studies at the University of Missouri Sinclair

School of Nursing (MUSSON) lymphedema research laboratory who have agreed to be contacted about future studies were invited to participate if they met eligibility criteria. IRB-approved computer searches using the MU University Health i2b2 database system was used as well. A summary of the recruitment strategies used for this study are described in Table 1 and Table 2. At the completion of all data collection, an IT performance will be offered to all participants, focus group participants, and guests.

Table 5.1

Recruitment with Health Care Providers

Hospitals	Nurses/ NP	Lymphedema Therapists	PCPs	Surgeons	Oncologists	Radiation Therapy
Mercy St. Louis (Pratt & Clarkson locations)	XX	XX	XX	XX- Mercy XX- BJC XX- SSM	XX	XX
Cap Regional, St. Mary's Health Center, (Jefferson City)	XX (JCMG)	XX (Sam Cook Healthplex)			XX	XX Goldschmidt Cancer Center
Boone Hospital Columbia		XX		XX	XX	
MU/ EFCC Columbia	XX	XX		XX	XX	XX
Barnes Siteman Cancer Center St. Louis/ St. Peters locations	XX	XX	XX	XX	XX	XX
Saint Louis University Hospital	XX					
Lake Regional Hospital Osage Beach	XX	XX			XX	
KUMC/ Truman Kansas City (KS & MO)	XX	XX		XX	XX	
Koenig Cancer Center Lake Saint Louis (SSM)	XX	XX			XX	XX

Table 5.2

Presentations/Organizations/Events

Organizations/Events/Presentations	National	Greater St. Louis	Warren/ Lincoln Counties	Boone County	Jefferson City
Komen Race for the Cure/Boards		XX		XX	
American Cancer Society (ACS)		XX		XX	
ACS Relay for Life		XX	XX	XX	
ACS Sister Strut		XX			
EFCC Breast Cancer Awareness events - flyers				XX	
Survivorship Events		XX		XX	
American Lymphedema Framework Project Webpage (ALFP)	XX				
National Lymphedema Network Webpage (NLN)	XX				
Breast Cancer Coalition Webpage	XX	XX	XX	XX	
Lymphedema Guru Webpage	XX				
Mercy Lymphedema Support Group		XX			
Inspirations Cancer Support Group			XX		
ETC Support Group – Cap Regional					XX
JCMG Support Group					XX
Mid-Missouri Breast Cancer Support Group				XX	
Church (flyers and bulletin inclusion)		XX (4)			
Koenig CC Support Group Presentation		XX			
Article submitted-St. Charles Women’s Journal		XX			
Article published in Lake Saint Louis Magazine		XX			

Study design.

This mixed-method, randomized study tested outcomes of a bundled IT intervention (printed information about lymphedema and attending an IT performance) compared with printed information about BCRL alone on improving adherence to BCRL self-management regimens, symptom management, and perceptions of self-efficacy and self-regulation. Participants were recruited to the study followed by a face-to-face visit at which written informed consent was given. Baseline physical measures were taken, including height, weight, and arm circumferential and perometric arm measures. Questionnaires were completed relevant to demographics and health characteristics, symptom management, and perceptions of self-efficacy and self-regulation. Participants were also given a pre-intervention three-week treatment diary to complete. Using computer-generated randomization, participants were randomized to a control group which received printed information about BCRL or the intervention group which received printed information about BCRL and attended an IT intervention about BCRL. All participants received post-intervention packets (mailed to control group) which included printed information about BCRL, symptom management and self-efficacy questionnaires, and a three-week post-intervention treatment diary to be completed and returned by mail. Study participants received a $20 gift card in appreciation of their participation. Figure 1 illustrates a participant flow chart, which includes preliminary work that led up to this study.

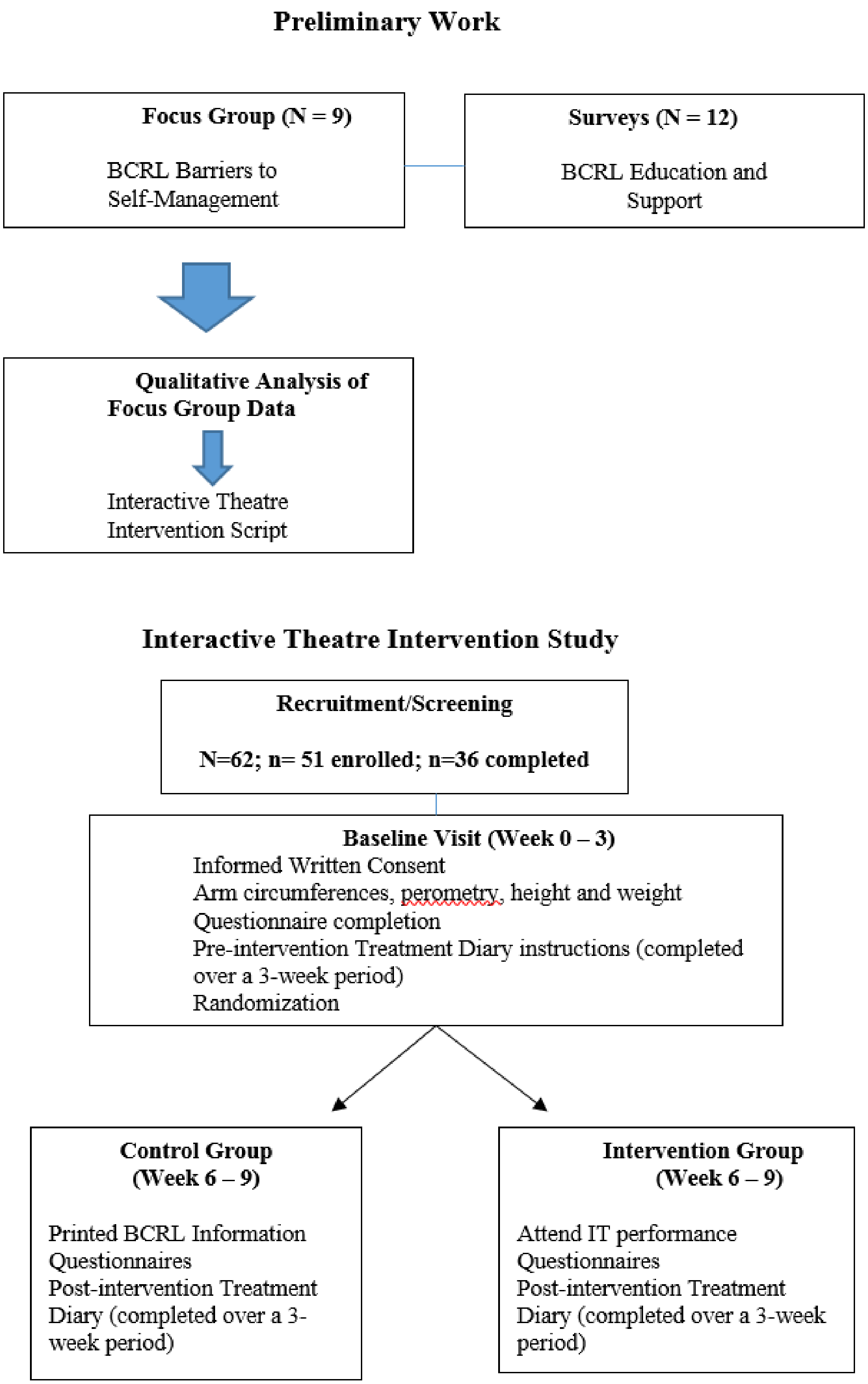

Figure 5.1: Participant Flow Chart

Patient population.

The incidence of newly diagnosed invasive breast cancer by age is estimated for 2015 as: 11,330 cases in women under the age of 40; 50,430 cases in women between 40-50 years of age; 81,970 cases in women between 50- 64 years of age; and 98,080 cases in women 65+ years of age (American Cancer Society, 2015). An effort was made to include women of diverse ethnicities to the extent that is consistent with minority representation reported by the US Census Bureau. The latest figures from the US Census Bureau (2010) for the number of minority females reported: 20% minorities in Boone County; 10% in Jefferson County; 32.3% in St. Louis County; and 1.9% in Osage County. In addition, fifty percent of the Mid-Missouri participants resided in rural areas (Armer & Stewart, 2010). The most recent definition of rural is based on the US Census 2000 definition of designated places that have less than 2,500 residents (Hall, Kaufman, & Ricketts, 2006).

Sampling plan.

Non-probability purposive sampling was used to enroll breast cancer survivors with BCRL to the study. The recruitment goal was sixty-two participants, of which 51 have been enrolled and 36 have completed the study. Inclusion criteria for participants were female breast cancer survivors who: (a) had surgical and/or radiation therapy for breast cancer; (b) were medically-diagnosed with BCRL (self-report) who have been prescribed a self-management regimen by a trained therapist; and (c) had no history of lymphedema prior to breast cancer diagnosis. Potential participants were excluded if they were unable to attend a baseline visit at the MU Lymphedema Laboratory or unable to complete study activities due to illness.

Sample size and power.

The recruitment goal was to achieve a sample size of 62 participants, with 31 participants in each study group. The primary outcome measure in this study was the BCRL self-management adherence rate, with the goal of having sufficient power to reject the null hypothesis of no difference in adherence rates when the true difference was large enough to be of practical importance. The procedure used to obtain an adherence rate was similar to that used by Brown et al. (2014) and it was assumed that the distribution of rates that we would’ve seen would be similar to theirs. Specifically, based on the proportion of subjects reported by Brown et al, to have adherence rates in intervals 0-25%, 25-50%, 50-75%, and 75-100%, it was estimated that the mean and standard deviation of the adherence rates based on the treatment diaries in this study would be about 0.56 and 0.255 (Brown et al., 2014). If the responses were modeled using a beta distribution (whose values were constrained to the interval (0, 1), a good match would be found to the proportions reported by Brown et al. (2014). A simulation study (with 1000 trials) was done to generate beta distributed data with a mean of 0.56 for the control group and various values for the mean for the treatment group. This was done using the software SAS v9 (SAS Institute Inc., Cary, NC, USA). The analysis of the simulated data was done using the GLIMMIX procedure modeling responses using a Beta distribution with a logit link function. Descriptive summary statistics were used to measure each outcome at the 0.05 significance level (two-sided) with a 95% confidence interval. A power of 90% was estimated based on 62 participants (n = 31 in each group) with a two-sided alternative hypothesis and a 0.05 level of significance when the mean for the treatment group was 0.75. The power would be about 80% when the treatment group mean was 0.73. A difference of 0.56 for one group and 0.73 for the other would be clinically important. Findings from this study were expected to contribute information about what effect size exists for this type of intervention. Intentional oversampling was used to allow for a 10% dropout rate. The participant sample of 36 was underpowered; however, recruitment was projected to continue until a sample of 62 participants was accrued, at which time the aforementioned power analysis would be used.

Setting.

The research team has a dedicated, environmentally-controlled laboratory and office (two suites for a total of seven rooms) at the University of Missouri (MU) Mizzou North campus. Additional space dedicated to one-on-one teaching and demonstration of self-care risk-reduction procedures is located in a room near the research laboratory where there is privacy without risk of interruption. The Lymphedema Laboratory is equipped with state-of-the-art limb volume measurement devices. The research study staff was current with Collaborative Institutional Training Initiative (CITI) certification.

Procedure.

Baseline Visit

Interested participants were screened with the guidance of a telephone script to determine eligibility and then scheduled for a face-to-face visit at the MU Lymphedema Laboratory. Once written consent was given, participants were oriented to the study. Computer-generated randomization was used to determine the participant’s study group; a control group that received printed information about BCRL or the intervention group, which received printed information about BCRL and attended an IT intervention. Physical measures were taken at the baseline visit, including arm circumferences and perometry to document lymphedema status and height and weight to document each participant’s Body Measurement Index (BMI). Three valid and reliable questionnaires were administered by the PI to identify important factors regarding coping strategies, symptom management behaviors, and cognitive perceptions of self-efficacy and self-regulation. At the end of the baseline visit, participants were given a pre-intervention self-management treatment diary to take home accompanied by a pre-addressed stamped envelope. Instructions were given on how to complete the diary. Participants documented BCRL self-management activities in their diaries daily for three weeks and mailed the completed diary back to the PI in the provided envelope. Daily reminders to complete daily diary entries were made to all participants, depending on the participants’ preference: via SMS/text, email, or telephone call. The baseline visit lasted approximately 1.5-2 hours.

Control Group

Following completion of pre-intervention data and at least a 2-week break period, participants in the printed information-only control group were mailed intervention packets. Each packet contained the following intervention materials: (a) printed information about BCRL; (b) a second set of symptom management, self-efficacy, and self-regulation questionnaires; (c) a post-intervention self-management treatment diary; (d) a stamped pre-addressed envelope; and (e) instructions for completion of packet materials. Participants were contacted by phone and notified when the packets were mailed. Participants were reminded daily to complete their self-management treatment diary entries. Upon receipt of the completed intervention questionnaires and post-intervention self-management treatment diary, participants were sent a personalized thank you letter and a $20 gift card.

Interactive Theatre Intervention Group

As recruitment progressed, an IT performance was scheduled when at least six participants in the intervention group had completed their pre-intervention self-management treatment diaries. The IT performances were held in the MU Corner Playhouse Theatre. Light refreshments were served during a 30-minute discussion and update for participants prior to the IT performance. Also, at this time, participants were asked to self-address a postcard and answer the preprinted question on the postcard that asked, “What goal(s) do I hope to achieve in the next three weeks in regard to managing my BCRL and my abilities to cope with it?” The post cards were collected by the PI and sent to each participant mid-way through the completion of the post-intervention treatment diary period. The post cards served as an intervention “boost” for participants to recall and re-examine their IT experience and allowed for a sense of ownership in setting goals for their BCRL self-management. Participants were given post-intervention packets to take home with the same contents as were given the control group participants containing: (a) printed information about BCRL; (b) a second set of symptom management, self-efficacy, and self-regulation questionnaires; (c) a post-intervention self-management treatment diary; (d) a stamped pre-addressed envelope; and (e) instructions for completion of packet materials. Upon receipt of the completed self-management treatment diary and questionnaires, each participant received a $20 gift card for participation.

Measures

Demographic form.

Participants were asked to complete a demographic form including: (a) date of birth; (b) race; (c) highest grade of school completed; (d) stated height and weight; (e) breast cancer diagnosis date; (f) breast cancer treatment(s); (g) nodal status; and (h) complications of treatment (if applicable).

Circumferential arm measurements.

Circumferential arm measurements were performed on all participants. Arm circumferential measurements using a non-stretch tape measure is the most common means to measure limb volume (Bernas et al., 2010). A circumferential difference of 2cm or greater between the affected and non-affected arm may indicate the presence of BCRL (Armer & Stewart, 2005). Both arms were measured at the hand and from the wrist to the axilla at 4cm intervals. Circumferential arm measurements were performed by the PI and a study staff member, who are specialty-trained and undergo monthly inter-rater reliability testing by performing circumference measures on the same person as a quality control measure. A standard deviation of 0.5 cm or less is used between measures.

Perometry.

Perometric limb volume assessments were performed on all participants. The opto-electric infra-red laser Perometer 350S (Juzo USA, Cuyahoga Falls, Ohio) assesses limb volume and shape and records data over time. Perometric measurements have been shown to reliably match water displacement limb volume (Armer & Stewart, 2005). A change of 10% limb volume in the affected extremity as compared to baseline (pre-surgery) or in comparison with the contralateral limb is used to demonstrate the presence of Stage II BCRL (Armer & Stewart, 2005).

Lymphedema breast cancer questionnaire (LBCQ).

The LBCQ is a valid, reliable, semi-structured interview tool designed to assess lymphedema indicators, their frequency, and symptom management strategies (Armer et al., 2003). The development of the LBCQ was based on the symptom experiences of 25 women diagnosed with lymphedema through individual interviews and observations, followed by thematic analysis. Reported findings identified 28 symptoms associated with lymphedema, which were subsequently used to develop the LBCQ (Armer et al., 2003).

The LBCQ has established reliability and validity. Kuder-Richardson-20 showed acceptable internal consistency (r =.785). Test-retest reliability was reported high (r =.98) using healthy women (n = 35) with a 2-hour test-retest interval (Armer et al., 2003). Fifteen items were used to elicit responses relevant to symptoms and actions taken to alleviate symptoms, with subsequent calculation of a pre- and post-intervention symptom management action score for each participant.

Self-efficacy/self-regulation questionnaire.

The self-efficacy/self-regulation questionnaire is a valid, reliable instrument used for measuring self-efficacy and self-regulation perceptions of women at risk for BCRL. The questionnaire was developed for use with breast cancer survivors at risk for BCRL (Sherman & Koelmeyer, 2013). Cronbach’s alpha coefficients for internal consistency of subscales were: ($\alpha = 0.81$) for perceived risk of lymphedema; ($\alpha = 0.82$) for perceived control of lymphedema; and ($\alpha = 0.68$) for perceived consequences of lymphedema. Items which had significantly higher positive correlations with adherence were cognitive variables: self-efficacy and self-regulation. The questionnaire was adapted with permission for use with breast cancer survivors with BCRL. Participants answered eight questions to the extent that they agree (1 = not at all; 2 = a little bit; 3 = somewhat; 4 = quite a bit; and 5 = very much) at baseline and post-intervention regarding perceptions of how well they perceived their ability to manage BCRL. Self-efficacy/self-regulation questionnaire scores were calculated as one of the outcome measures.

Breast cancer survivor self-efficacy scale (BCSES).

The BCSES was developed by Champion (2013) with eleven items tested with mailed and telephone responses (N = 1,127). Research variables included demographics, symptom bother, communication with healthcare provider, attention function, fear of recurrence, depression, marital satisfaction, fatigue, sexual functioning, trait and state anxiety, and overall well-being. The BCSES demonstrated reliability with an alpha coefficient of 0.89, inter-item correlations ranging from 0.3-0.6, and item total correlation coefficients ranging from 0.5-0.73. The scale was determined to be unidimensional with predictive validity, high internal consistency, reliability, and excellent content and construct (Champion et al., 2013). Participants answered questions 11 questions (1 = strongly disagree; 2 = disagree; 3 = neutral; 4 = agree; and 5 = strongly agree) at pre- and post-intervention, with subsequent calculation of a self-efficacy score as an outcome measure.

Self-management treatment diary.

The self-management treatment diary was used by participants to record BCRL self-management activities pre- and post-intervention. The PI developed the self-management treatment diary with subsequent review of the content by two additional researchers. The diary was then piloted with female breast cancer survivors diagnosed with BCRL (N = 7) prior to use in this study. Based on participant feedback, the diary was refined by expanding the exercise section and cutting each week to fit on one page.

Study participants were instructed to make diary entries for three weeks pre- and post-intervention to document BCRL self-management activities. Total adherence percentage scores were calculated as the primary outcome of the study.

Height and weight.

Although height and weight were not a focused outcome measure, a calibrated Health-O-Meter vertical scale was used to measure height and weight. Participants were instructed that if bilateral limbs increase as weight increases, limb change may not be BCRL-related.

Data Collection

The qualitative data for this study included demographic and health characteristic data and symptom management information. Quantitative data for this study includes: (a) arm circumference measurements; (b) perometry measurements; (c) self-efficacy and self-regulation questionnaire data; (d) symptom-management scores; (e) self-management treatment diary scores; and (f) height and weight measures. All demographic and pre-intervention questionnaire data were collected by the PI by interview in a private setting without risk of interruption. All post-intervention data were mailed to the PI upon completion. Post-intervention questionnaires required approximately 1 hour of the participants’ time and three weeks for completion of the post-intervention self-management treatment diaries. The participant baseline visit lasted approximately 1.5-2 hours. The IT performance for the intervention group lasted approximately 1.5-2 hours. Data was de-identified and entered into a password-protected database by trained research assistants. Pre- and post-intervention self-management treatment diary data was entered by the PI into a password protected computer database.

Data Management

Study data were only accessible by the PI and designated study staff. All participants were de-identified by code assignment upon enrollment into the study. This code was used with all data. Identifiers collected during the study included names, email and home addresses, and telephone numbers. All identifiers were stored separately from other data in a secured cabinet accessible only by the PI. A copy of all computerized records were kept on a separate safe medium. All study materials will be retained for three years per University policy.

The risks for participating in this study were minimal; however, a protocol for dealing with distress was incorporated into the data management safety (DSM) plan to include identifying, reviewing, and reporting unanticipated problems (involving risks to study participants or others), adverse events, or serious events. Although this study posed minimal risks, it was possible that participants could have experienced emotional distress when completing the surveys or when participating in the interactive theatre intervention. Emotional distress can occur because of the nature of the information and a recollection of distressing events. Every attempt was made to protect subjects from emotional distress. Participants were made aware that they could discuss feelings or issues of any nature with the PI and information and referrals to community resources would be provided, as necessary. Participants were reminded of their right to refuse participation at any time, including withdrawal from the study without penalty. The PI was also cognizant of study instrument names or references that might cause participants to identify with a disorder or disturbance.

If a participant became emotionally distressed during the course of the study, the PI was prepared to determine the severity of the situation with therapeutic communication techniques. Permission from the participant via written informed consent would be obtained to contact the participant’s oncologist or health care provider. If indicated, a referral would be made to a mental health care provider. If the participant refused, a list of support resources would be given. Every effort was made to provide resources that were in the participant’s geographic location and at low or no cost to participants. If the participant demonstrated suicidal ideations or intent to do harm, 911 would have been called and, if necessary, security personnel. Participants requiring care and/or resource referral would be contacted to provide any additional resources and opportunities for questions.

Adverse events and unanticipated problems were not expected, the following protocol was in place to be used in the case of an adverse event (AE), a serious adverse event (SAE), and unanticipated problems. Study staff were to report all adverse events (AEs) to the PI immediately. Each AE would be reviewed by the PI, utilizing any supporting information available, to determine severity and relationship to study procedures. The PI would make a determination of the association with the study (not associated, potentially associated, possibly associated or definitely associated to the study, and whether the event met criteria for an unanticipated problem). Adverse Event reporting to the IRB, institutional officials, and the Department or Agency Head would be carried out, following the University of

Missouri Health Sciences Institutional Review Board's protocol, as outlined here. Any adverse event would be reported to the IRB in writing within 5 working days. Any Serious Adverse Event (an event that is life-threatening regardless if associated with the study) would be reported immediately to the IRB. All adverse events, serious and non-serious, would be fully documented on the appropriate report form(s). The research team members would report all potential adverse events to the PI. Members of study staff that are MU students would also communicate events to their advisor. For each adverse event, the PI would provide the onset, duration, intensity, treatment required, outcome and action taken.

It was not anticipated that there would be adverse events in this study that would cause a halt in accrual. Unanticipated problems were reviewed for consideration of substantive changes in the research protocol or informed consent process/document or other corrective actions in order to protect the safety, welfare, or rights of subjects. The participants were monitored on an on-going basis for any changes or signs of distress.

Data Analysis

Descriptive statistics were used to analyze the demographic data. Mean and standard deviation were computed for continuous variables. Frequency and relative frequency were computed for categorical values. Groups were compared relative to demographic variables; however, group differences relative to demographic variables were not expected due to the fact that subjects were randomized to the groups. Comparisons were done using Chi-square tests (or Fisher's Exact test) for categorical variables and either Student’s t-tests or Wilcoxon Rank Sum tests for ordinal or numeric variables.

For Aim 1., self-management adherence scores were based on self-management treatment diaries that contained BCRL self-management modalities from which participants identified their prescribed regimens. A check-off system was used daily in which participants would check each modality they completed as part of their self-management regimen. Diary entries were used as the primary analysis to compare the groups relative to adherence rate, by calculating an adherence percentage of compliance for each component and an overall adherence percentage for all components against the prescribed regimen. Data for three weeks was collected on the self-management treatment diaries; however, the first week of data was set aside and adherence rates were calculated using the latter two weeks of data. Covariates included number of BCRL symptoms, comorbidities, barriers to self-care identified in the preliminary work for this study, and time since diagnosis. Should a significant difference be found for any variable, the relationship between that variable and the outcome of adherence rate was examined. If a relationship was found, then that variable was included in the primary analysis as a covariate. The primary analysis compared both groups relative to adherence rate.

The second outcome of interest used 15 symptom management items from the LBCQ to examine self-management responses that identified how participants took action to alleviate or treat a BCRL symptom. A comparison of pre- and post-intervention responses to the 15 items was made and scores were calculated by counting the number of positive changes (no action to action) compared to the number of negative changes (action to no action), resulting in a net score. The self-management rate was analyzed by using beta regression with group as a predictor and with the baseline self-management rate used as a covariate.

For Aim 2., an overall percentage and percentage by each item response was calculated to determine scores for self-efficacy and self-regulation. A Wilcoxon Rank Sum test was used to compare groups for statistical significance.

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CHAPTER SIX

The Effectiveness of an Interactive Theatre Intervention on Improving Patient Adherence to Self-Management Regimens for Breast Cancer-related Lymphedema

> *These dissertation findings will be submitted for publication. Results in this chapter contain preliminary results from the first 36 study participants who have completed the study. Prior to publication, additional data will be collected until a total number of 62 participants have completed the study.*

Abstract

Purpose: The purpose of this study was to determine the effectiveness of an interactive theatre (IT) intervention bundled with printed information to printed information alone in improving adherence to self-management of breast cancer-related lymphedema (BCRL) and perceptions of self-efficacy. The research questions included: (1) What is the effectiveness of an IT intervention bundled with printed information about BCRL on adherence to self-management regimens among breast cancer survivors with BCRL compared to printed information about BCRL alone? and (2) What is the effectiveness of an IT intervention bundled with printed information about BCRL on improving patient perceptions of self-efficacy and self-regulation compared to printed information alone?

Methods: Thirty-six female breast cancer survivors with BCRL were randomized into one of two study groups: a group that received printed information about BCRL [hereafter, control group] (n = 19), and an intervention group that received printed information and attended an IT performance (n = 17). Circumferential and perometric measures were taken at a baseline visit to document BCRL status and valid, reliable questionnaires relevant to symptom management, self-efficacy, and self-regulation were administered pre- and post-intervention.

Results: The analysis comparing outcome measures of both groups in this study did not reach statistical significance; however, there were positive indications that the intervention group did slightly better in respect to perceptions of self-efficacy/self-regulation and with taking action for managing the same symptoms pre- and post-intervention. Statistical significance was achieved ($p = 0.0169$) with an analysis of both groups in regard to taking action to manage all symptoms, regardless of the time period in which they occurred.

Conclusions: The findings of this study suggest that an interactive format, such as IT, may positively influence symptom management. A limitation of this study was the small sample size; however, continued study with a larger sample size is warranted to further examine the outcome measures in this study population using IT.

Keywords: Breast cancer-related lymphedema, patient education, adherence, self-efficacy

From 1989 to 2012, breast cancer death rates declined by 36% due to improvements in early detection and treatment (American Cancer Society, 2015). There are currently an estimated 3 million breast cancer survivors in the US (Howlader et al., 2015), of whom at least 40% will develop BCRL (Armer & Stewart, 2010).

BCRL is a chronic condition, which can be debilitating and disfiguring. It is typically caused by disruption to the lymphatics due to axillary lymph node dissection, sentinel lymph node biopsy, and/or radiation therapy for treatment of breast cancer

(Armer et al., 2003; Shaitelman et al., 2015). Once symptoms emerge, BCRL requires life-long symptom management. The ‘gold standard’ for treatment of BCRL is combined decongestive therapy (CDT) which includes: manual lymphatic drainage (MLD); compression bandaging and/or garments; exercise; skin care; and sequential pumps, in which one or more components are initiated as intensive treatment by a specialty-trained therapist, followed by instruction on self-management activities that are individually prescribed (Armer et al., 2013; Lasinski, 2013).

Adherence to BCRL self-management is critical to preventing BCRL progression and complications, such as infection; however, self-management rates over the past two decades have remained between 40-50% (Bonnie Lasinski, personal communication, July 19, 2015) (Boris & Lasinski, 1994). In a study conducted with 141 women with BCRL who were prescribed an average of 3.6 ± 2.1 BCRL self-care modalities, sub-optimal BCRL self-management rates were reported, including: 13% of participants reported an average adherence rate of <25%; 24% reported 25-49% adherence; 32% reported 50-74% adherence; and 31% reported ≥ 75% (Brown et al., 2014).

Physiological, psychological, and psychosocial barriers negatively affect adherence (Alcorso, Sherman, Koelmeyer, Mackie, & Boyages, 2016; Armer et al., 2011; Armer et al., 2008; Fu et al., 2013; Ridner et al., 2011; Shaitelman et al., 2015). Consistent with contemporary literature and preliminary work for this study, women are voicing concerns about the lack of education received about BCRL and the lack of support in managing it (Alcorso et al., 2016; Ridner et al., 2016). A preliminary survey study (N = 12) reported 81% of the participants preferred an interactive approach to education and 77% of participants preferred interaction with others as the best way to provide support (Ostby, Armer, Smith, & Stewart, 2016). [Manuscript submitted for publication]. Currently, printed information is the most commonly used format for providing patient education and support (Deng et al., 2013).

Method

Study design.

This was a mixed-method randomized design used to examine pre- and post-intervention outcomes relevant to adherence to self-management regimens; symptom management; and perceptions of self-efficacy and self-regulation, by comparing printed information about BCRL to printed information about BCRL and attendance at an IT performance (N = 36 participants; 19/17). Baseline measurements of circumferences and perometry were taken to document BCRL status and valid, reliable questionnaires were administered pre- and post-intervention. A treatment diary was used to determine adherence to self-management regimens both pre- and post-intervention for three-week intervals. It was hypothesized that an IT intervention bundled with printed information would be more effective in improving adherence and perceptions of self-efficacy and self-regulation than printed information alone. This study was approved by the University of Missouri (MU) Institutional Review Board.

Study population.

An analysis was performed from pre- and post-intervention data on 36 participants. Non-probability purposive sampling was used to enroll breast cancer survivors diagnosed with BCRL between January 2015 and January 2016 who met the following inclusion criteria: (a) were over 18 years of age; (b) had surgical and/or radiation therapy for treatment of breast cancer; (c) were medically diagnosed with

BCRL (self-report) and who had been prescribed a self-management regimen by a trained therapist; and (d) had no history of lymphedema prior to breast cancer diagnosis. Participants who could not attend a baseline visit at the MU Lymphedema Laboratory or complete study activities due to illness were excluded. Participants were recruited from a study pool of breast cancer survivors who had agreed to be contacted for future studies and through community advertisement, such as flyers, online and print articles, media, face-to-face group presentations, and an IRB-approved health system database search of lymphedema-related ICD-9 codes.

Interactive theatre intervention.

Prior to initiating this study, a focus group was conducted with female breast cancer survivors with BCRL (N = 9) to identify barriers to BCRL self-management. A qualitative analysis of the focus group data was conducted, with findings contributing to script development for an IT intervention through collaboration with the MU Department of Theatre. The script was integrated in this study as the basis for the IT intervention performance by actors in the MU Interactive Theatre Troupe.

Printed information.

The printed information used for this study was actual patient education materials about BCRL and services that are routinely given to newly-diagnosed breast cancer patients at an academic health sciences center.

Data Collection

After written informed consent was given, participants completed a demographic form. Documentation of lymphedema status was recorded using arm circumferential measures and perometric limb volume assessments on all participants. Circumferential measures were taken on both arms at 4cm intervals using a non-stretch tape measure. The opto-electric infra-red laser Perometer 350S (Juzo USA, Cuyahoga Falls, Ohio) assesses limb volume and shape and maps a 3-dimensional image and calculation of limb volume on the affected and non-affected arms. Height and weight measures were also taken. Following physical measures, three valid and reliable questionnaires relevant to self-efficacy and self-regulation, and symptom management were administered. A treatment diary was then given to each participant with instructions for completion. Upon receipt of the pre-intervention treatment diary and after an average of two to three-week break period, a post-intervention packet of the same questionnaires and a post-intervention treatment diary were mailed to the control group participants. Each participant in the intervention group received a post-intervention packet on the night of the IT performance.

Results

Of over 350 female breast cancer survivors screened, fifty-one participants who met inclusion criteria have been recruited to the study. Data from thirty-six participants who completed this study have been analyzed. The attrition rate for this study was 15%. Reasons for not completing the study were death (1), moved out of area (2), illness and hospitalizations (4), and caring for a terminally ill family member (1).

Prior to data analysis, demographic, questionnaire, and circumference and perometric data were double-entered by two research team members into a password-protected computer using Windows 7OS Excel. Synkronizer version 11.0 (Switzerland) Excel comparison software was used to detect discrepancies. Discrepancies were corrected by comparing hard copy data to the entered data, which was then corrected and re-entered. Reports were run continuously until there was a verified match between both spreadsheets. The pre- and post-intervention self-management treatment diary data were entered by the first author. A nurse research assistant corroborated the coding by auditing 20% of the participant charts (n = 7). Agreement was achieved for both sets of coding.

All statistical tests were conducted at the 0.05 significance level (two-sided) and 95% confidence intervals (CI) were provided for estimates. The desired number of participants (N = 62) was not achieved for this analysis; therefore, the power of the study did not reach the projected 90%. The data analysis was accomplished using the following steps: (1) looking at summary data for each measure; (2) comparing groups at baseline; (3) calculating post- minus pre-intervention differences between the two groups; and (4) comparing the differences between the two groups. SASv9 software (SAS Institute Inc., Cary, NC, USA) was used for analysis.

Participant demographics.

Participants were asked to complete a demographic form including: (a) date of birth; (b) race; (c) highest grade of school completed; (d) stated height and weight; (e) breast cancer diagnosis date; (f) breast cancer treatment(s); (g) nodal status; and (h) complications of treatment (if applicable).

Descriptive statistics were used to analyze demographic data for participants who had completed the study (N = 36). Mean and standard deviation were computed for continuous variables and frequency and relative frequency were computed for categorical variables. In terms of race, 33 (92%) of the participants were Caucasian and 3 (8%) were African American. The mean age of participants for the combined groups (N = 36) was 67.1 years. The mean level of education was 15 years. The mean stated weight of the participants was 165.5 and height 63.2 inches. Wilcoxon rank-sum test was used to compare the groups, with no significant differences found. Demographic summary results for each group and the combined groups are shown in Tables 1, 2, and 3, respectively. The following breakdown of definitive treatment for breast cancer was reported as: mastectomy with lymph node removal (n = 20); lumpectomy with radiation and lymph node removal (n = 13); lumpectomy with no report of lymph node removal (n = 2); and mastectomy with no report of lymph node removal (n = 1).

Table 6.1

Demographic Summary Statistics (Intervention Group)

Variable	N	Mean	Median	SD
Age	17	66.9	65.1	12.5
Education (Years)	17	15.8	16.0	2.8
Height (inches)*	17	62.3	61.0	3.1
Weight (lbs.) *	17	167.9	160.5	36.5

Race	Frequency	Percent
African-American	1	5.9
Caucasian	16	94.1

Table 6.2

Demographic Summary Statistics (Control Group)

Variable	N	Mean	Median	SD
Age	19	67.3	66.9	12.2
Education (Years)	19	14.9	16.0	2.1
Height (inches)*	19	64.0	63.5	2.7
Weight (lbs.) *	19	164.8	158.0	20.6

Race	Frequency	Percent
African-American	2	10.5
Caucasian	17	89.5

Table 6.3

Demographic Summary Statistics (Combined Groups)

Variable	N	Mean	Median	SD
Age	36	67.1	66.0	12.2
Education (Years)	36	15.3	16.0	2.5
Height (inches)*	36	63.1	64.0	3.0
Weight (lbs.) *	34	166.0	166.0	29.5

Race	Frequency	Percent
African-American	3	8.3
Caucasian	33	91.7

* Height and weight as reported

Outcome Measures.

Self-efficacy/Self-regulation.

The pre-intervention IT group mean was 31.8 and 31.0 for the control group. A Wilcoxon Rank-Sum test was used which showed no significant differences in the groups at baseline (p = 0.68). Table 4 provides details of pre-intervention and post-intervention means for each group, with a positive direction indicating an improvement in perceptions of self-efficacy/self-regulation. A boxplot graph illustrated a slight increase from pre-intervention to post-intervention for the intervention group with a mean increase of +0.29 (Figure 1). A slight decrease was seen in the control group of -0.57. However, the difference in the groups was not shown to be statistically significant (Wilcoxon Rank Sum test; p = 0.62) (Table 4).

Table 6.4

Self-efficacy/Self-regulation Summary Statistics

Comparison of each group at baseline (pre-intervention)

Group	N	Mean	Median	SD
(Post) Intervention	17	32.1	33.0	2.81
(Pre) Intervention	17	31.8	31.0	4.02
(Post) Control	19	30.3	30.0	5.1
(Pre) Control	19	31.0	33.0	4.59

Wilcoxon Rank Sum Test for differences between both groups at baseline (pre-intervention): no significant differences; p = 0.68.

Comparison for differences between pre- and post-intervention of each group

Group	N	Mean	Median	SD.
Intervention	17	0.29	0.00	3.29
Control	19	-0.57	-1.00	4.84

Wilcoxon Rank Sum Test for differences between pre- and post-intervention for each group: no significant differences; p = 0.62.

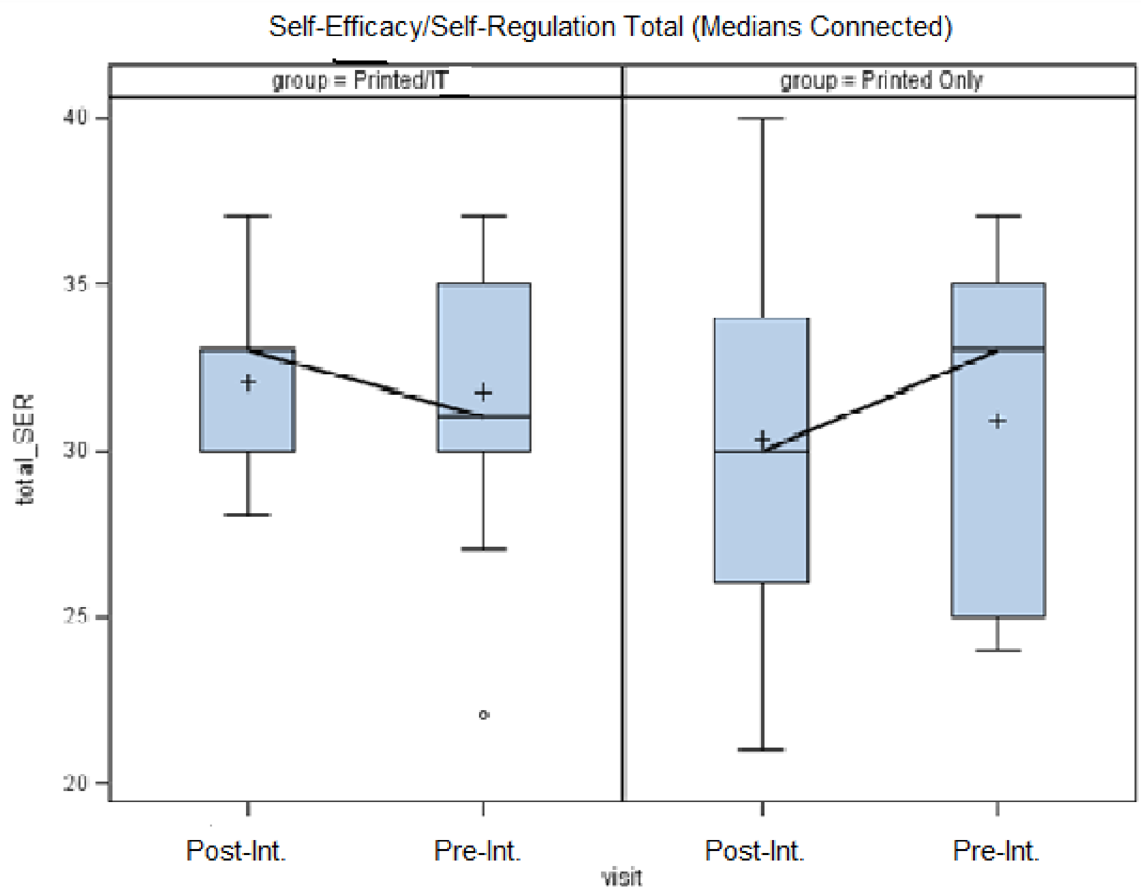

Figure 6.1: Self-efficacy/Self-regulation Total Medians (boxplots)

Self-management treatment diary.

Self-management treatment diaries were used pre- and post-intervention by both groups as the primary measure of adherence. The diary was developed by the first author, with content review by two additional researchers. The diary was also piloted with breast cancer survivors with BCRL (N = 7), at which time changes were made to categorize the exercise section and fit each week’s activities on one page prior to use in this study. Participants were asked to add daily entries to the diary that corresponded with their BCRL self-management activities for three weeks at pre- and post-intervention time periods. There were three weeks of pre-intervention values and three weeks of post-intervention values. Descriptive statistics for each time period, comparison of groups at baseline (pre-intervention), and the post- minus pre-intervention differences for each group are shown in Table 5.

There were no group differences for any of the three weeks at baseline (pre-intervention). Wilcoxon Rank-Sum test was used, with a p-value range of 0.56 to 0.66. As planned for this study, the first week of pre- and post-intervention treatment diary data was dropped with the remaining two weeks used for the overall adherence score. A very slight gain in the adherence score (+0.01) for the control group and a slight loss (-0.04) for the intervention group was observed on post- minus pre-intervention comparisons of the two groups. A Wilcoxon Rank-Sum test showed no significant differences (p = 0.58).

An additional analysis of the self-management treatment diary data was performed to examine whether there was an increase in risk-reduction activities with either group. Risk-reduction activities were defined as hygiene, observation of the arm for signs of progression or infection, application of moisturizer, and exercise. Descriptive statistics for adherence were used for the four risk-reduction items. Groups differences were compared showing a negative median difference (-0.03) in the control group compared to a median difference of 0.00 for the intervention group. Although there was a slight decrease in the control, a Wilcoxon Rank Sum test analysis detected no significant differences between the two groups (p = 0.19).

Table 6.5

Summary Statistics of Self-Management Treatment Diary Adherence
Outcome Descriptive statistics for Adherence (complete data for all weeks)

Analysis Variable: Total Adherence

group	visit	N	Mean	Median	SD
Intervention					
	Post-Intervention Week 1	17	0.85	0.92	0.15
	Post-Intervention Week 2	17	0.83	0.86	0.14
	Post-Intervention Week 3	17	0.83	0.86	0.19
	Pre-Intervention Week 1	17	0.84	0.86	0.10
	Pre-Intervention Week 2	17	0.87	0.88	0.11
	Pre-Intervention Week 3	17	0.87	0.86	0.10
Control					
	Post-Intervention Week 1	19	0.88	0.93	0.14
	Post-Intervention Week 2	19	0.86	0.91	0.15
	Post-Intervention Week 3	19	0.80	0.93	0.22
	Pre-Intervention Week 1	19	0.84	0.88	0.13
	Pre-Intervention Week 2	19	0.84	0.88	0.13
	Pre-Intervention Week 3	19	0.81	0.88	0.17

Comparison of groups at baseline: no significant differences

Time period	Variable	P value
Pre-Int. Week 1	Total adherence	0.66
Pre-Int. Week 2	Total adherence	0.60
Pre-Int. Week 3	Total adherence	0.56

Descriptive Statistics based on 2 weeks of data: Post- minus pre-intervention for both groups; no significant difference; p = 0.58.

Group	N	Mean	Median	SD
Intervention	17	-0.04	-0.02	0.14
Control	19	0.01	0.00	0.11

Breast cancer survivor self-efficacy scale.

Descriptive statistics revealed no significant difference between groups at baseline (pre-intervention); (p = 0.21). Summary statistics are shown in Table 6, which indicated no significant difference in post- minus pre-intervention comparisons (p = 0.28). Figure 2 provides comparison of total BCSES data using a boxplot graph which illustrates a lower post- than pre-intervention median in the intervention group and a higher post- than pre-intervention median in the control group.

Table 6.6

Summary statistics for BCSES (Comparison between groups at pre-and post-intervention)

BCSES baseline (pre-intervention) Wilcoxon Rank-Sum Test – no significant differences (p = 0.21)

Group		N	Mean	Median	SD
Intervention	Pre-Int.	17	49.6	52.0	6.51
	Post-Int.	17	49.2	49.0	4.25
Control	Pre-Int.	19	47.1	46.0	6.67
	Post-Int.	19	47.3	49.0	7.43

BCSES post- minus pre-intervention comparisons (total data): Wilcoxon Rank Sum Test: no significant differences (p = 0.28)

Group	N	Mean	Median	SD
Intervention	17	-0.41	-1.00	4.82
Control	19	0.21	0.00	5.65

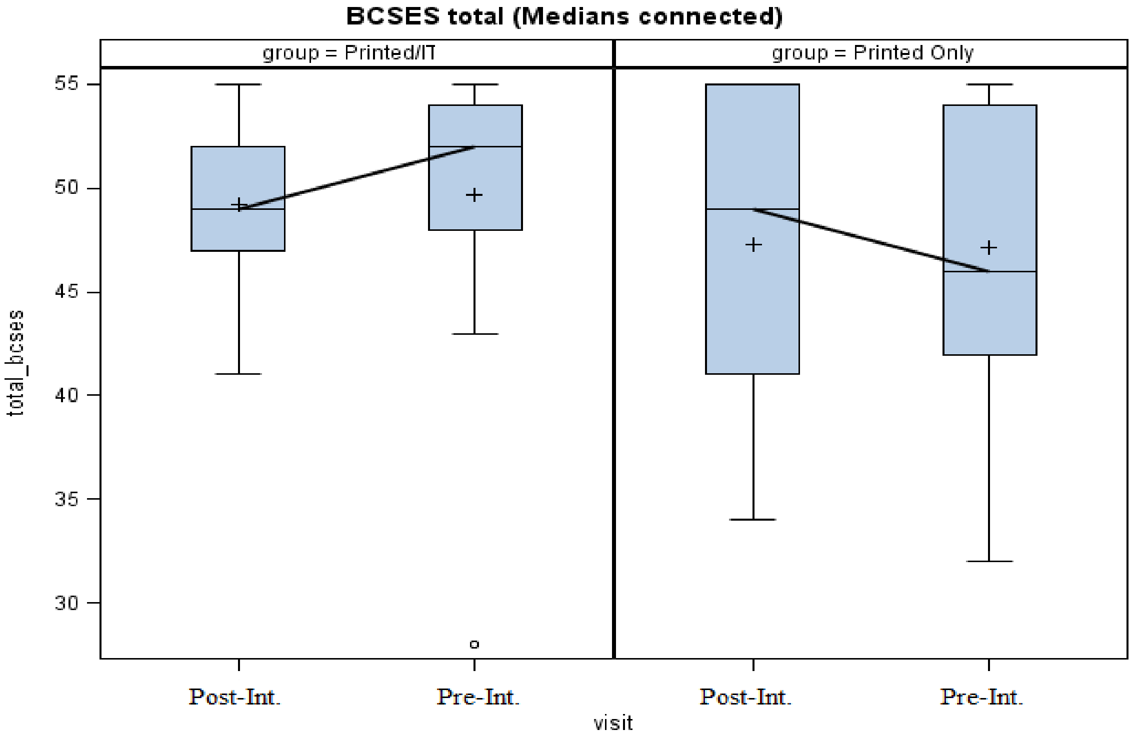

Figure 6.2: BCSES boxplot graph (Total medians connected)

Lymphedema Breast Cancer Questionnaire (LBCQ).

The Lymphedema Breast Cancer Questionnaire (LBCQ) is a valid, reliable tool that was used to identify lymphedema symptoms, their frequency, and strategies for symptom management (Armer et al., 2003). The LBCQ has established reliability and validity. Kuder-Richardson-20 showed acceptable internal consistency (r =.785). Test-retest reliability was reported high (r =.98) using healthy women (n = 35) with a 2-hour test-retest interval (Armer et al., 2003).

Fifteen items from the LBCQ were used to assess symptoms and symptom management strategies. The questions addressed two time periods, during the last month and during the past year; however, scores were used only for “during the past month” which were relevant to the study period. The data were paired if participants reported the same symptom at both pre- and post-intervention time periods, followed by determining a net score. The variable, “SAME” was used to compare how many of the same symptoms were present at both times (pre- and post-intervention) for each individual. There were two participants who had no symptoms in common at both pre- and post-intervention; therefore, they did not enter into the analysis.

The net score represented the net change in number of positive actions take post-intervention as compared to pre-intervention. For example, if a participant reported having 6 symptoms at pre- and post-intervention, and took action to manage all of the symptoms at pre-intervention, but took action to manage only 5 of the symptoms at post-intervention, the net score would be [5 – 6 = -1]. Another participant who reported having 6 symptoms at pre- and post-intervention, and took action to manage 3 of the symptoms at pre-intervention, but took action to manage 5 of the symptoms at post-intervention would have a net score of [5 - 3 = +2].

The proportional change was calculated by dividing the net score by the number of common symptoms (SAME variable). A positive value corresponded to more actions taken post- than pre-intervention. The mean score was slightly positive for the intervention group (+0.06) and slightly negative for the control group (-0.05). A Wilcoxon Rank Sum test was performed and the difference was not statistically significant (p = 0.27). Table 7 provides detail of the LBCQ statistical analysis.

Table 6.7

LBCQ Analyses

Participant frequency and number of common symptoms pre- and post-intervention

```
                                   Cumulative    Cumulative
same    Frequency      Percent     Frequency     Percent
-----------------------------------------------------------
  0         2            5.6           2            5.6
  1         7           19.4           9           25.0
  2         7           19.4          16           44.4
  3         7           19.4          23           63.9
  4         2            5.6          25           69.4
  5         3            8.3          28           77.8
  6         4           11.1          32           88.9
  7         1            2.8          33           91.7
  9         2            5.6          35           97.2
 11         1            2.8          36          100.0
```

Net Score = Scores indicating ‘Action to No Action’ in managing a particular symptom

```
                                 Cumulative    Cumulative
net    Frequency      Percent    Frequency     Percent
---------------------------------------------------------
 -4        1            2.8            1          2.8
 -3        1            2.8            2          5.6
 -1        3            8.3            5         13.9
  0       23           63.9           28         77.8
  1        8           22.2           36        100.0
```

Variable Net with Proportional Change Averages by Group

Group	Variable	N	Sum	Mean	Median	SD
Intervention	SAME	17	44.00	2.59	2.00	2.27
	net	17	3.00	0.18	0.00	0.53
	prop. chg.	15	0.87	0.06	0.00	0.23
Control	SAME	19	81.00	4.26	4.00	2.79
	net	19	-5.00	-0.26	0.00	1.28
	prop.chg.	19	-1.08	-0.05	0.00	0.22

Wilcoxon Rank Sum Test: no significant differences; p = 0.27

A second analysis of the LBCQ symptom data was performed to further examine the proportion of actions taken to manage symptoms. In the first analysis, only symptoms and associated actions occurring in both pre- and post-intervention time periods were analyzed, which was reasonable for comparison of matching sets of symptoms. An alternative analysis was performed to look at the rate for all symptoms, even if those symptoms did not occur in both time periods (pre- and post-intervention). The rate = actions taken/number of symptoms and represents the proportion of symptoms for which action was taken. Using logistic regression, the proportion of actions taken in the post-intervention period was used as the dependent variable with the proportion of actions taken in the pre-intervention period and group as predictor variables.

The median rate for the intervention group increased (0.88 to 1.0) and the median rate for the control group decreased (0.90 to 0.88). Statistical significance was achieved ($p = 0.02$), suggesting there may be some improvement in the intervention group in terms of taking action in managing symptoms (Table 8). However, the groups may differ in terms of the symptoms that were experienced. There were different rates of action for symptoms experienced, for example, actions were taken 90% of the time for “limited movement in shoulder” and “swelling”, whereas, actions were taken only 55% of the time for “increased temperature of arm” and 56% of the time for “numbness of the arm.” Therefore, consideration of the symptom experienced and the availability of remedy interventions must be given. Taking action to manage a symptom may be dependent on the ‘severity’ of the symptom and, consequently, when comparing groups, the differences in likelihood of addressing the symptom through taking action was not ignored. The primary analysis did not ignore the difference in symptoms experienced. The proportion of all actions with medians connected are shown in Figure 3. The four most common symptoms reported also had the highest percentage of actions taken to remedy the symptom. These included swelling, limited shoulder movement, firmness/tightness, and achiness. Table 9. provides details of the proportion of actions for specific symptoms. The use of the median instead of the mean was due to skewness of the data, which mathematically is related to the fact that many women took a relatively high number of actions and a few took a relatively small number of actions. Therefore, the median was more representative of the groups' values than the mean.

Table 6.8

LBCQ Total Symptom/Action Analysis

Group	Variable	N	Mean	Median
Intervention	Actions Taken (Pre-Int.)	17	3.82	4.00
	Actions Taken (Post-Int.)	17	3.64	2.00
	Symptoms (Pre-Int.)	17	4.88	5.00
	Symptoms (Post-Int.)	17	4.00	3.00
	Rate (Pre-Int.)	17	0.75	0.88
	Rate (Post-Int.)	17	0.88	1.00
Control	Actions Taken (Pre-Int.)	19	5.05	5.00
	Actions Taken (Post-Int.)	19	4.73	4.00
	Symptoms (Pre-Int.)	19	6.32	7.00
	Symptoms (Post-Int.)	19	6.00	5.00
	Rate (Pre-Int.)	19	0.81	0.90
	Rate (Post-Int.)	19	0.79	0.88

Using logistic regression, the proportion of actions taken in the post-intervention period was used as the dependent variable with the proportion of actions taken in the pre-intervention period and group as predictor variables. Statistical significance was achieved (p = 0.02)

Proportion = Actions/symptoms and is the proportion of symptoms for which action was taken (or the rate at which actions were taken). The proportion (Pre-Int.) is used as a covariate in order to adjust for possible baseline differences.

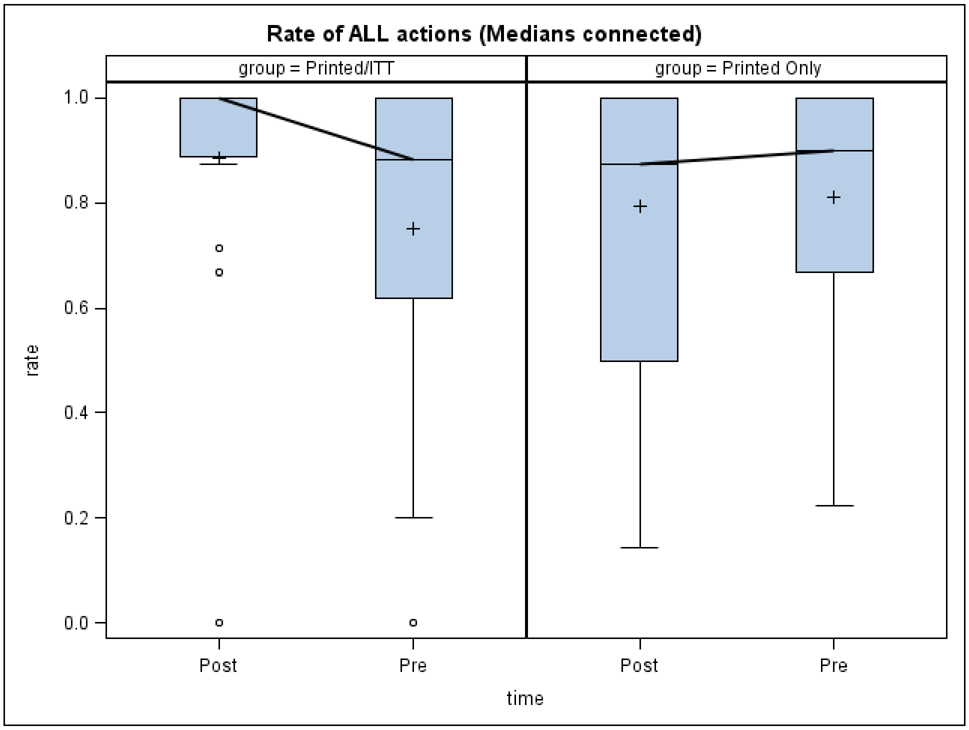

Figure 6.3: LBCQ – Proportion (or rate) of ALL Actions (Medians Connected)

Table 6.9

Proportion of Actions for Specific Symptoms Reported in order of frequency

Symptom	Total Reported	Total Action	%/Action rate
Swelling	61	59	97%/0.967
Firmness/tightness	48	41	85%/0.854
Aching	36	32	89%/0.888
Heaviness	35	24	69%/0.685
Numbness	30	17	57%/0.566
Limited Shoulder Movement	30	28	93%/0.933
Stiffness	27	24	89%/0.888
Development of pockets of fluid	22	18	82%/0.818
Swelling with pitting	22	15	68%/0.681
Increased temperature of arm	18	10	56%/0.555
Chest wall swelling	17	13	76%/0.764
Other	17	15	88%/0.882
Redness	15	12	80%/0.800
Breast swelling	6	4	67%/0.666
Blistering	1	1	100%/1.00

Discussion

The purpose of this study was to compare a bundled interactive theatre intervention about lymphedema to printed information alone. Preliminary work for this study supported an intervention study that focused on delivering an interactive educative-supportive program that would positively influence adherence to BCRL self-management and perceptions of self-efficacy and self-regulation.

Research by Sherman and colleagues (2015) reported that there is an association with improved risk-reduction adherence activities with breast cancer survivors who are at high-risk for BCRL and in women who also have increased knowledge about lymphedema. This study provided information on these associations with breast cancer survivors who have BCRL and is the first study to examine an interactive format in providing education and support using interactive theatre.

With one exception, the analysis of outcome measures comparing both groups in this study did not reach statistical significance; however, statistical results showed positive trends for the intervention group in regard to improvement with perceptions of self-efficacy and self-regulation and with taking action to manage symptoms. Statistical significance was achieved ($p = 0.02$) with the intervention group in regard to taking action to manage all symptoms, regardless of the time period in which they occurred. This suggests that an interactive format, such as interactive theatre, may positively influence symptom management with women diagnosed with BCRL. Consistent with reported associations of improved self-management in women who feel more confident in their ability to manage BCRL risk-reduction activities successfully (Alcorso et al., 2016; Deng et al., 2013; Ridner et al., 2016; Sherman & Koelmeyer, 2013), this study suggested an increase in perceptions of self-efficacy and self-regulation over the control group post-intervention, although it did not reach statistical significance.

Study Strengths

Strengths of this study included: (1) participants represented a wide cross-section of Missouri from rural, suburban, and urban settings; (2) quantitative measures were used to document the diagnosis of lymphedema, in addition to self-report; (3) provided instrument development and testing of a diary tool for measuring adherence to BCRL self-management regimens; and (4) provided the first randomized interdisciplinary study with women diagnosed with BCRL to measure outcomes of adherence, self-efficacy, and self-regulation using interactive theatre; and (5) demonstrated the feasibility of an IT intervention.

Study Limitations

The main limitations of this study were the small sample size and inadequate power to allow for statistically meaningful results for most of the outcomes measured. Although the focus of the study was not for generalizability, the participants were very similar in regard to age, race, and educational preparation. Although every attempt was made to reduce deviations from the evidence-based script and pre-performance workshops with the actors were led by the lead researcher to discuss possible 'talk-back' responses, there was innate variability among the actors (and thus, the performances) due to the very nature of interactive theatre and the dynamic interactions between and among actors and audience participants (the latter who varied performance to performance).

In addition, the self-management treatment diary tool was difficult to decipher at times, due to hand-written entries, requiring telephone contact with some of the participants for clarification. Refinement of the tool to make it more coder-friendly through further testing is warranted.

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CHAPTER SEVEN

Conclusion

This study has led to ongoing development of stakeholder engagement skills and identification of stakeholder groups, including breast cancer survivors, lay individuals, breast cancer and lymphedema support groups, health care providers, and interdisciplinary collaborators that were helpful in making this study possible. Breast cancer survivors with BCRL have contributed to the research design of this study through focus group interviews and surveys by identifying outcomes that matter in regard to learning about lymphedema, maintaining adherence to treatment, the meaning of support, and identifying barriers to self-management of BCRL. Participants have embraced IT as an interactive option that facilitates education, communication, and, in this particular study, possible improvement in symptom management.

Adherence to self-management in this population is sub-optimal (Lasinski et al., 2012; Ridner et al., 2012c), even with knowledge that non-adherence may result in progression, infection, and loss of function (Armer et al., 2011; Feldman & Semel, 2011; Stout Gergich et al., 2008); therefore, evidence-based research is necessary to improve patient education standards and plans of care that continue support with self-management throughout survivorship. The distribution of educational materials is beneficial, but does not address psychological and psychosocial parameters, such as perceptions of self-efficacy and self-regulation (Champion et al., 2013; Sherman & Koelmeyer, 2013)

Most importantly, breast cancer survivors with BCRL in this study have voiced their interest in interactive methods from which to learn and meet support needs throughout survivorship. This use of IT in bringing women together to discuss issues of self-management, share ideas, and support one another warrants further study, and this was an added advantage of the study.

Implications for Future Practice, Education, and Research

It is hoped that nurses will take the lead in implementing practice changes that encompass physiological, psychological, and social parameters to facilitate patients' abilities to engage in successfully self-management of BCRL and other chronic conditions. The involvement of nurses, patients and community organizations in advisory board capacities would ensure continued development of future IT programs that meet patients' needs. This patient-centered approach to implementing new concepts is also envisioned as a way to share ideas that will increase patient accessibility.

There are many implications for continued research using interactive formats for educative-supportive programs for patients who manage chronic diseases and conditions. The continuation of this dissertation will lend more information to the use of IT. A goal for further research using IT includes the exploration of multidisciplinary applicability and methods of outcome measurement based on theoretical frameworks, such as transformational learning and the CSM of self-regulation. The inclusion of family members that share the issues of chronic disease and other patient populations present many opportunities for further study.

Future implications also include the use of interactive technology both for patients and in the classroom. Use of virtual reality headsets and gaming, to include IT and health-oriented platforms is also a future goal for interactive learning and support.

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APPENDICES

Appendix A: Focus Group IRB Approval

Appendix B: Focus Group Telephone Script

Appendix C: Focus Group Interview Guide

Appendix D: Survey IRB Approval

Appendix E: Survey

Appendix F: Survey Cover Letter

Appendix G: Randomized Study IRB Approval

Appendix H: Consent

Appendix I: HIPPA Waiver for i2b2 Database Query

Appendix J: Recruitment Flyer

Appendix K: i2b2 Recruitment Letter

Appendix L: Therapist Letter

Appendix M: Gift Card Approval

Appendix N: LBCQ Symptom Instrument

Appendix O: Self-Efficacy/Self-Regulation (SER) Instrument

Appendix P: Permission for SER

Appendix Q: Breast Cancer Self-Efficacy Scale (BCSES) Instrument

Appendix R: Permission for BCSES

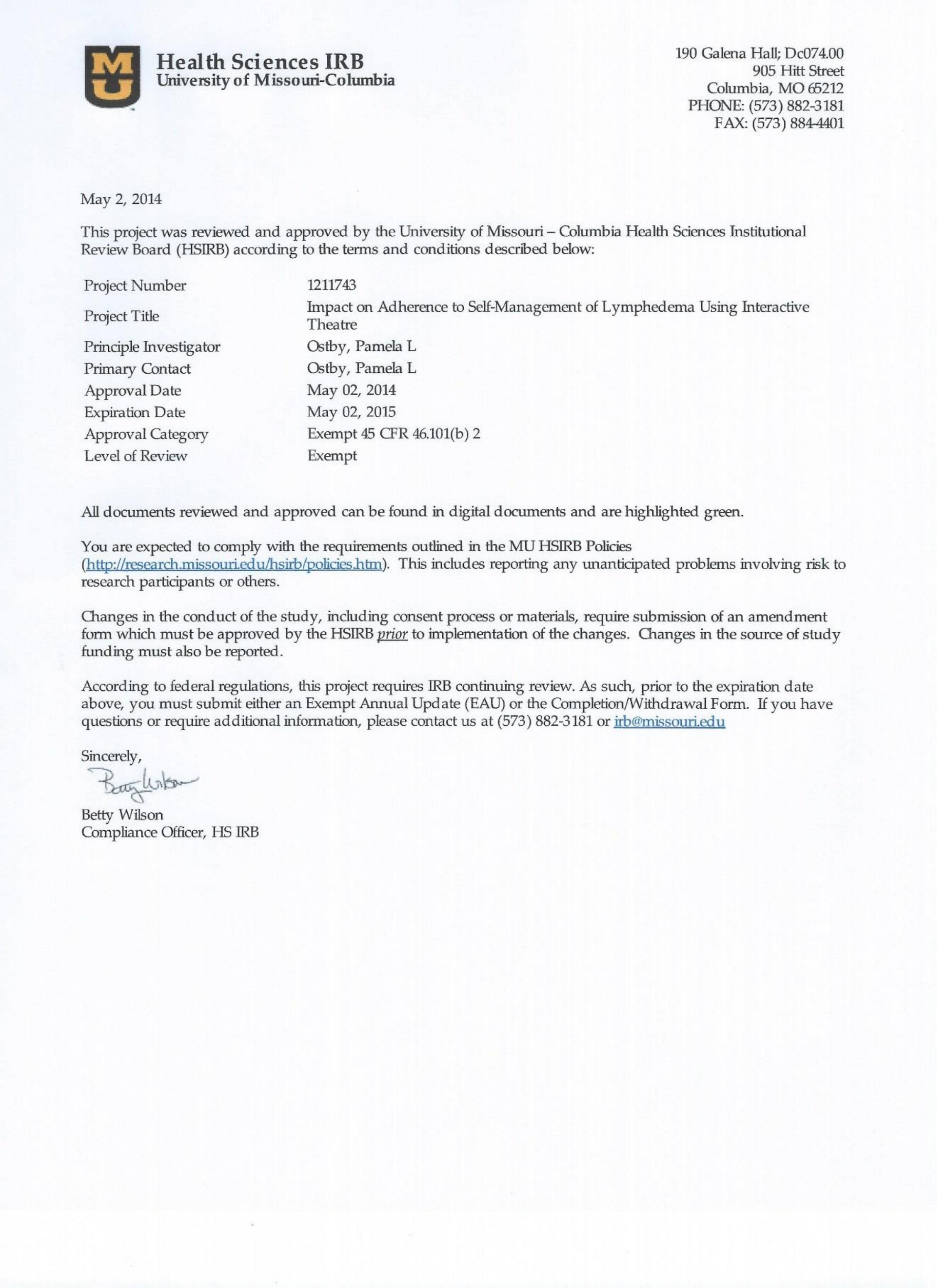
Appendix S: Self-Management Treatment Diary Instrument

Appendix T: Interactive Theatre Script

Appendix U: Printed Information

Appendix A

Focus Group IRB Approval



Health Sciences IRB
University of Missouri-Columbia

190 Galena Hall; Dc074.00
905 Hitt Street
Columbia, MO 65212
PHONE: (573) 882-3181
FAX: (573) 884-4401

May 2, 2014

This project was reviewed and approved by the University of Missouri – Columbia Health Sciences Institutional Review Board (HSIRB) according to the terms and conditions described below:

Project Number	1211743
Project Title	Impact on Adherence to Self-Management of Lymphedema Using Interactive Theatre
Principle Investigator	Ostby, Pamela L
Primary Contact	Ostby, Pamela L
Approval Date	May 02, 2014
Expiration Date	May 02, 2015
Approval Category	Exempt 45 CFR 46.101(b) 2
Level of Review	Exempt

All documents reviewed and approved can be found in digital documents and are highlighted green.

You are expected to comply with the requirements outlined in the MU HSIRB Policies (http://research.missouri.edu/hsirb/policies.htm). This includes reporting any unanticipated problems involving risk to research participants or others.

Changes in the conduct of the study, including consent process or materials, require submission of an amendment form which must be approved by the HSIRB *prior* to implementation of the changes. Changes in the source of study funding must also be reported.

According to federal regulations, this project requires IRB continuing review. As such, prior to the expiration date above, you must submit either an Exempt Annual Update (EAU) or the Completion/Withdrawal Form. If you have questions or require additional information, please contact us at (573) 882-3181 or irb@missouri.edu

Sincerely,

Betty Wilson

Betty Wilson
Compliance Officer, HS IRB

Appendix B

Focus Group Telephone Script (1211743)

Hello. I am Pam Ostby, a doctoral nursing student working with Dr. Jane Armer at the MU Lymphedema Laboratory. Since you have indicated your interest in future lymphedema studies, I wanted to let you know about my research study. I am recruiting breast cancer survivors who have been diagnosed with lymphedema to participate in a focus group.

The focus group will be approximately 10 women. Dr. Armer and I will guide the group discussion, but the purpose of the group is to hear stories, listen to your experiences, and better understand the barriers that women face in managing breast cancer-related lymphedema (BCRL).

It will last about 1-1.5 hours and is a one-time visit. We will use the recorded focus group data and notes to write an interactive theatre script that will be performed in the second phase of this study for breast cancer survivors with lymphedema. We want to see if interactive programs along with printed information improve adherence to self-management of BCRL over printed information alone. You will not be identified as a participant in the group and you can choose to not participate at any time during the group.

Light refreshments will be served and a $20 gift card will be given as a thank you for your participation. The focus group is next Wednesday at 5PM at Mizzou North Campus. I will follow-up with a reminder of the group early next week. My contact information in case you have questions is: 314-255-6677. Thank you.

Appendix C

Interview Guide and Permission

Interview Guide Probes – Focus Group

12. What can you tell me about your lymphedema diagnosis?
    a. Feelings

13. What do you think caused your lymphedema?

14. Were you told that you might develop lymphedema?
    a. When? (Pre-op, Post-op, Not at all, Not until you were diagnosed?)

15. Do you think you would have reacted differently if you were told? If you were told at a different time during your diagnosis and treatment of breast cancer?
    a. What do you have to do to control symptoms?
    b. Feelings

16. How long before you noticed your lymphedema?
    a. What did you do?
    b. Did you know what it was?
    c. Did you know who to call?
    d. Did you ignore it?

17. Tell me what you have done to decrease your symptoms?

18. Do you feel like you are controlling the symptoms?

19. What do you consider a barrier in controlling your symptoms?
    a. Time
    b. Pain
    c. Expense
    d. Unable to do it? Why?
    e. Don't think you can do it?
    f. Don't think it will help?

20. How does lymphedema affect your daily life?

21. Psychological impact? Clothes? Social? Decrease in family time? Support? What kind? Do you need it? What kind of support do you want?

22. If you have had BCRL for a long time, do you take care of it differently now that when you were first diagnosed? Are you as careful? Why or why

not?

12. How did you know that you had lymphedema?

13. What was it like when you first learned you had lymphedema?

14. How have other people commented on your lymphedema/or sleeve?
    c. At work?
    d. In personal life?

15. How does having lymphedema make you think about what activities you do?

16. How does having lymphedema make you think about what you wear?

17. What challenges do you feel have been the most difficult to overcome?

18. Has anyone surprised you with a reaction to your having lymphedema?

*Adapted with permission from Fu M. Managing lymphedema in breast cancer survivors [dissertation]. Columbia: University of Missouri; 2003

Mei R Fu <mf67@nyu.edu>
Ostby, Pamela L. (MU-Student);02/11/16
Cancer Nursing
You replied on 02/11/16 18:22.

Dear Pam,

It is my pleasure to grant you the permission to use the Interview Questions that I developed for my prior qualitative research. It is wonderful to see you doing a great work to advance our understanding of lymphedema from patients'perspective.

Best Wishes to your research endeavor!

mei

Mei R. Fu, PhD, RN, FAAN
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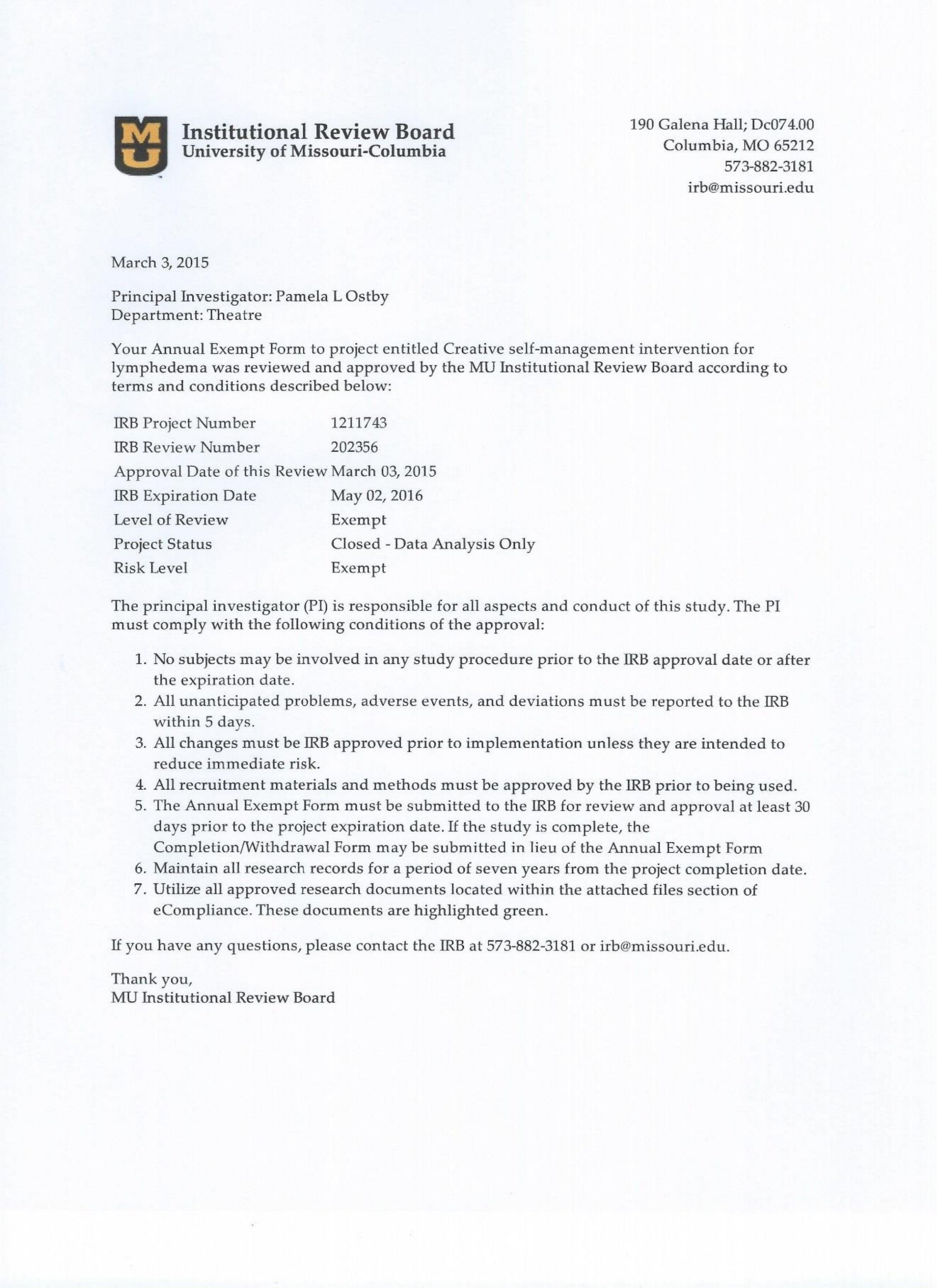
Appendix D – Survey IRB Approval



Institutional Review Board
University of Missouri-Columbia

190 Galena Hall; Dc074.00
Columbia, MO 65212
573-882-3181
irb@missouri.edu

March 3, 2015

Principal Investigator: Pamela L Ostby
Department: Theatre

Your Annual Exempt Form to project entitled Creative self-management intervention for lymphedema was reviewed and approved by the MU Institutional Review Board according to terms and conditions described below:

IRB Project Number	1211743
IRB Review Number	202356
Approval Date of this Review	March 03, 2015
IRB Expiration Date	May 02, 2016
Level of Review	Exempt
Project Status	Closed - Data Analysis Only
Risk Level	Exempt

The principal investigator (PI) is responsible for all aspects and conduct of this study. The PI must comply with the following conditions of the approval:

1. No subjects may be involved in any study procedure prior to the IRB approval date or after the expiration date.
2. All unanticipated problems, adverse events, and deviations must be reported to the IRB within 5 days.
3. All changes must be IRB approved prior to implementation unless they are intended to reduce immediate risk.
4. All recruitment materials and methods must be approved by the IRB prior to being used.
5. The Annual Exempt Form must be submitted to the IRB for review and approval at least 30 days prior to the project expiration date. If the study is complete, the Completion/Withdrawal Form may be submitted in lieu of the Annual Exempt Form
6. Maintain all research records for a period of seven years from the project completion date.
7. Utilize all approved research documents located within the attached files section of eCompliance. These documents are highlighted green.

If you have any questions, please contact the IRB at 573-882-3181 or irb@missouri.edu.

Thank you,
MU Institutional Review Board

Appendix E

Survey Questions and Permission

Lymphedema Survey

This is a survey about lymphedema (swelling which may occur after cancer treatment). You are being asked to participate in a research study because you have identified you have lymphedema. This research is being conducted to understand barriers to self-management of lymphedema and to learn what types of education and support that patients need and want. Completion of this survey is <u>voluntary</u>. You may choose not to participate without penalty. All surveys are anonymous and confidential.

1. How were you told that you might develop lymphedema?
    - d. When were you told? (for example: when you were diagnosed with breast cancer; when you were diagnosed with lymphedema; not at all)
    - e. By whom?

2. In what ways were you provided with information about lymphedema?
    - d. From whom?
    - e. How effective do you feel the information was in providing education in learning about lymphedema and reducing risks or treating symptoms already present?
    - f. How helpful was the education you received in supporting you to maintain your self-management regimen?

3. In what ways were you provided with resources and support?
    - a. How has support continued throughout your survivorship?

4. What do you do to manage your lymphedema symptoms?

5. In what ways is your self-management regimen for lymphedema hard to maintain?

6. What do you think is the best way to provide education about lymphedema?

7. What do you think is the best way to provide support in helping you to maintain your regimen?

8. How do you think you need support?
    - a. Do you want support?
    - b. When?
    - c. What kind?
    - d. From whom?

9. What do you think are barriers to your management of your lymphedema?

10. How well do you think you are managing your lymphedema symptoms?

11. How do you think lymphedema affects quality of life?
    a. How do you think quality of life is different with people who have lymphedema than those who don't?
    b. Why?

*Adapted with permission from Fu M. Managing lymphedema in breast cancer survivors [dissertation]. Columbia: University of Missouri; 2003

Mei R Fu <mf67@nyu.edu>
Ostby, Pamela L. (MU-Student);02/11/16
Cancer Nursing
You replied on 02/11/16 18:22.

Dear Pam,

It is my pleasure to grant you the permission to use the Interview Questions that I developed for my prior qualitative research. It is wonderful to see you doing a great work to advance our understanding of lymphedema from patients'perspective.

Best Wishes to your research endeavor!

mei

Mei R. Fu, PhD, RN, FAAN
Associate Professor
College of Nursing
New York University
433 First Avenue, 4th Floor, Room 424
New York, NY 10010
Telephone: 212-998-5314
Cell: 973-986-1758
Fax: 212-995-3143
Email: mf67@nyu.edu

Appendix F

Survey cover letter

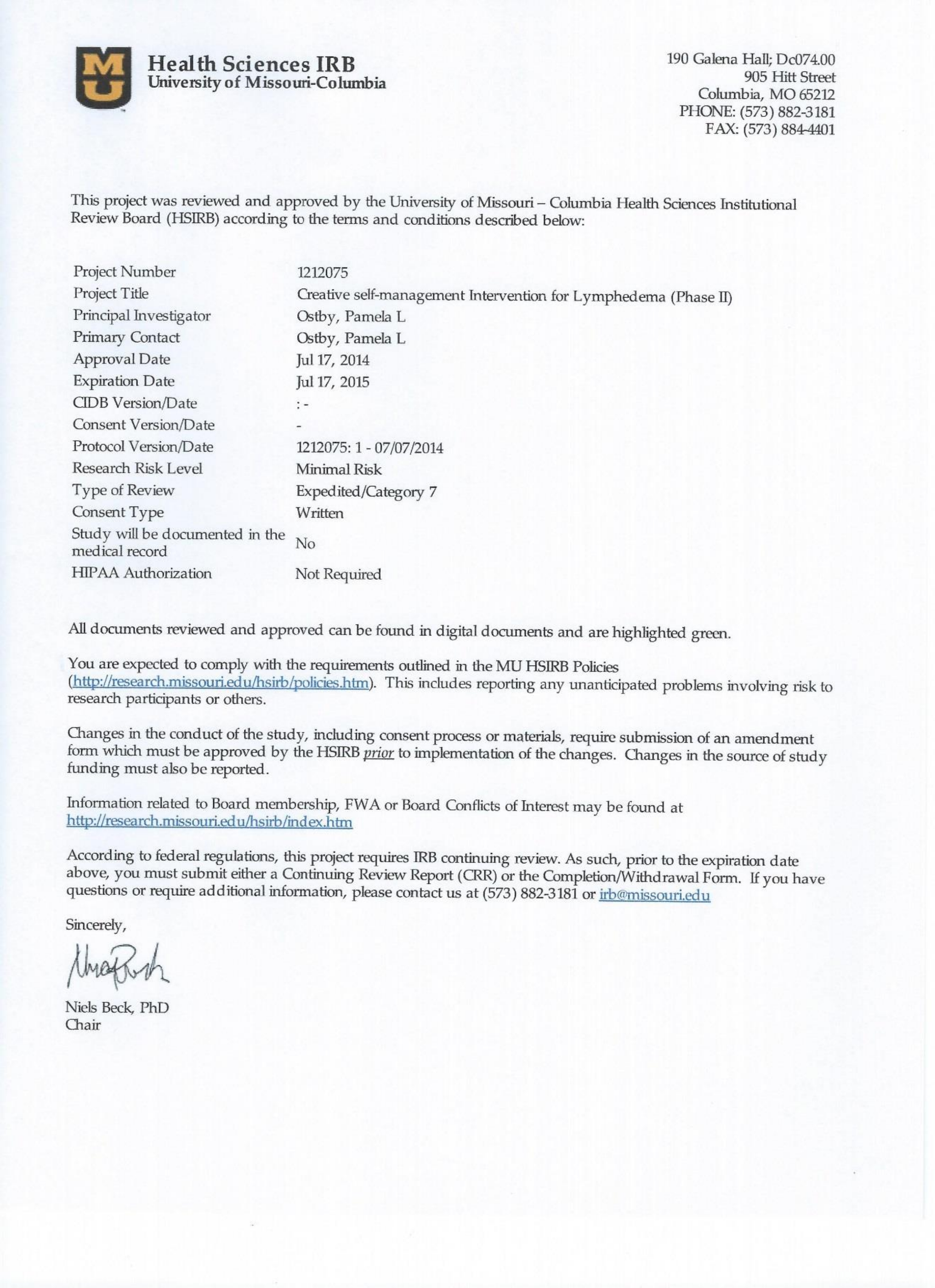
Dear Participant,

I have developed this questionnaire to add to our study in an effort to get more information about methods of education and support for breast cancer survivors with lymphedema. Completion of this questionnaire is voluntary. You may choose not to participate without penalty. All surveys are anonymous and confidential. If you choose to participate, please complete the questionnaire and return it back to me in the provided self-addressed stamped envelope.

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this study, you may contact the University of Missouri Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181. Thank you.

Pam Ostby, PhD(c), RN, OCN®
University of Missouri-Columbia
Sinclair School of Nursing
314/255-6677
Plo7c9@mail.missouri.edu

Appendix G – Randomized Study Approval



Health Sciences IRB
University of Missouri-Columbia

190 Galena Hall; Dc074.00
905 Hitt Street
Columbia, MO 65212
PHONE: (573) 882-3181
FAX: (573) 884-4401

This project was reviewed and approved by the University of Missouri – Columbia Health Sciences Institutional Review Board (HSIRB) according to the terms and conditions described below:

Project Number	1212075
Project Title	Creative self-management Intervention for Lymphedema (Phase II)
Principal Investigator	Ostby, Pamela L
Primary Contact	Ostby, Pamela L
Approval Date	Jul 17, 2014
Expiration Date	Jul 17, 2015
CIDB Version/Date	: -
Consent Version/Date	-
Protocol Version/Date	1212075: 1 - 07/07/2014
Research Risk Level	Minimal Risk
Type of Review	Expedited/Category 7
Consent Type	Written
Study will be documented in the medical record	No
HIPAA Authorization	Not Required

All documents reviewed and approved can be found in digital documents and are highlighted green.

You are expected to comply with the requirements outlined in the MU HSIRB Policies (http://research.missouri.edu/hsirb/policies.htm). This includes reporting any unanticipated problems involving risk to research participants or others.

Changes in the conduct of the study, including consent process or materials, require submission of an amendment form which must be approved by the HSIRB *prior* to implementation of the changes. Changes in the source of study funding must also be reported.

Information related to Board membership, FWA or Board Conflicts of Interest may be found at http://research.missouri.edu/hsirb/index.htm

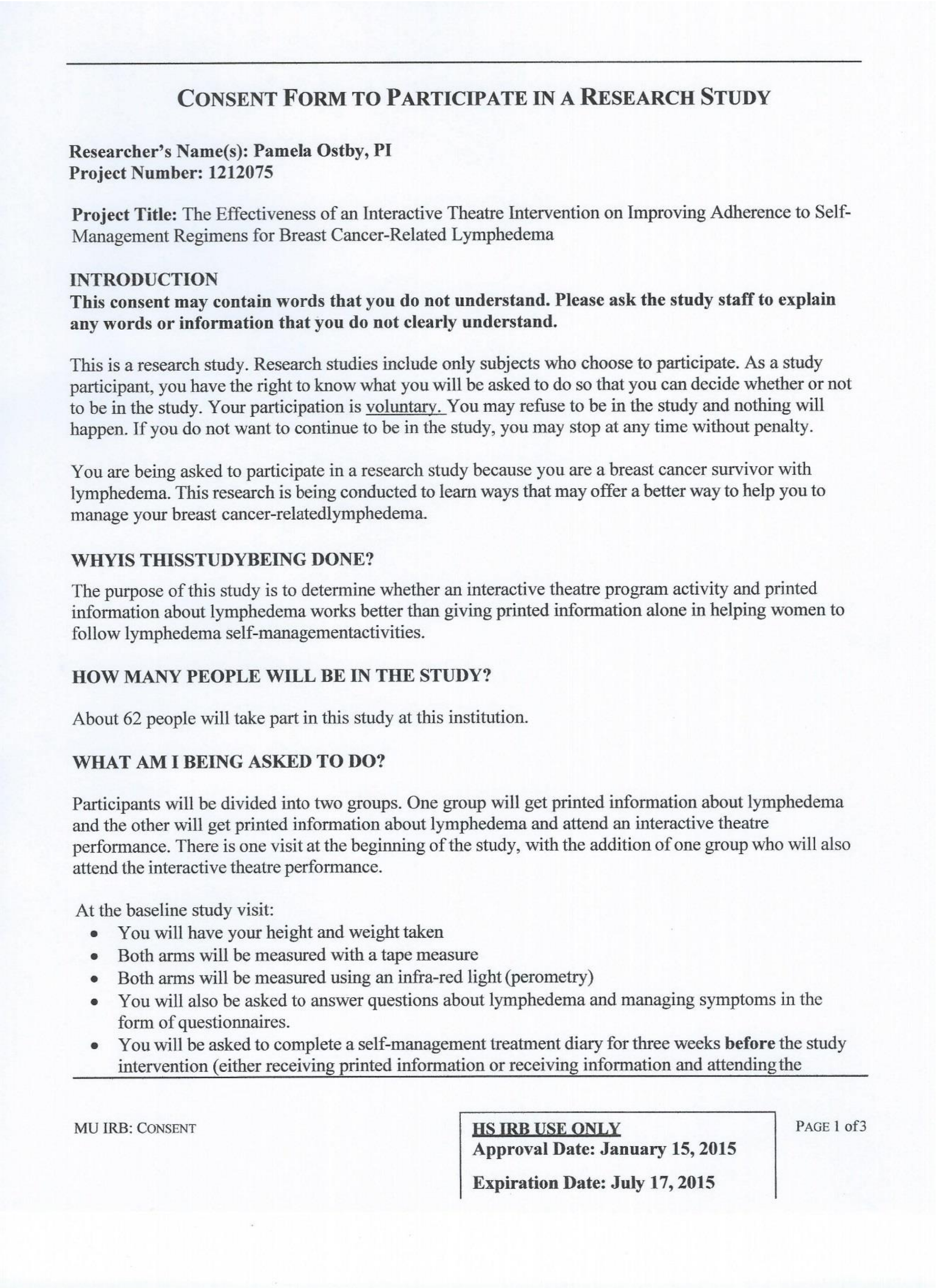
According to federal regulations, this project requires IRB continuing review. As such, prior to the expiration date above, you must submit either a Continuing Review Report (CRR) or the Completion/Withdrawal Form. If you have questions or require additional information, please contact us at (573) 882-3181 or irb@missouri.edu

Sincerely,

Niels Beck, PhD
Chair

Appendix H

Consent



CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Researcher's Name(s): Pamela Ostby, PI
Project Number: 1212075

Project Title: The Effectiveness of an Interactive Theatre Intervention on Improving Adherence to Self-Management Regimens for Breast Cancer-Related Lymphedema

INTRODUCTION

This consent may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

This is a research study. Research studies include only subjects who choose to participate. As a study participant, you have the right to know what you will be asked to do so that you can decide whether or not to be in the study. Your participation is voluntary. You may refuse to be in the study and nothing will happen. If you do not want to continue to be in the study, you may stop at any time without penalty.

You are being asked to participate in a research study because you are a breast cancer survivor with lymphedema. This research is being conducted to learn ways that may offer a better way to help you to manage your breast cancer-relatedlymphedema.

WHYIS THISSTUDYBEING DONE?

The purpose of this study is to determine whether an interactive theatre program activity and printed information about lymphedema works better than giving printed information alone in helping women to follow lymphedema self-managementactivities.

HOW MANY PEOPLE WILL BE IN THE STUDY?

About 62 people will take part in this study at this institution.

WHAT AM I BEING ASKED TO DO?

Participants will be divided into two groups. One group will get printed information about lymphedema and the other will get printed information about lymphedema and attend an interactive theatre performance. There is one visit at the beginning of the study, with the addition of one group who will also attend the interactive theatre performance.

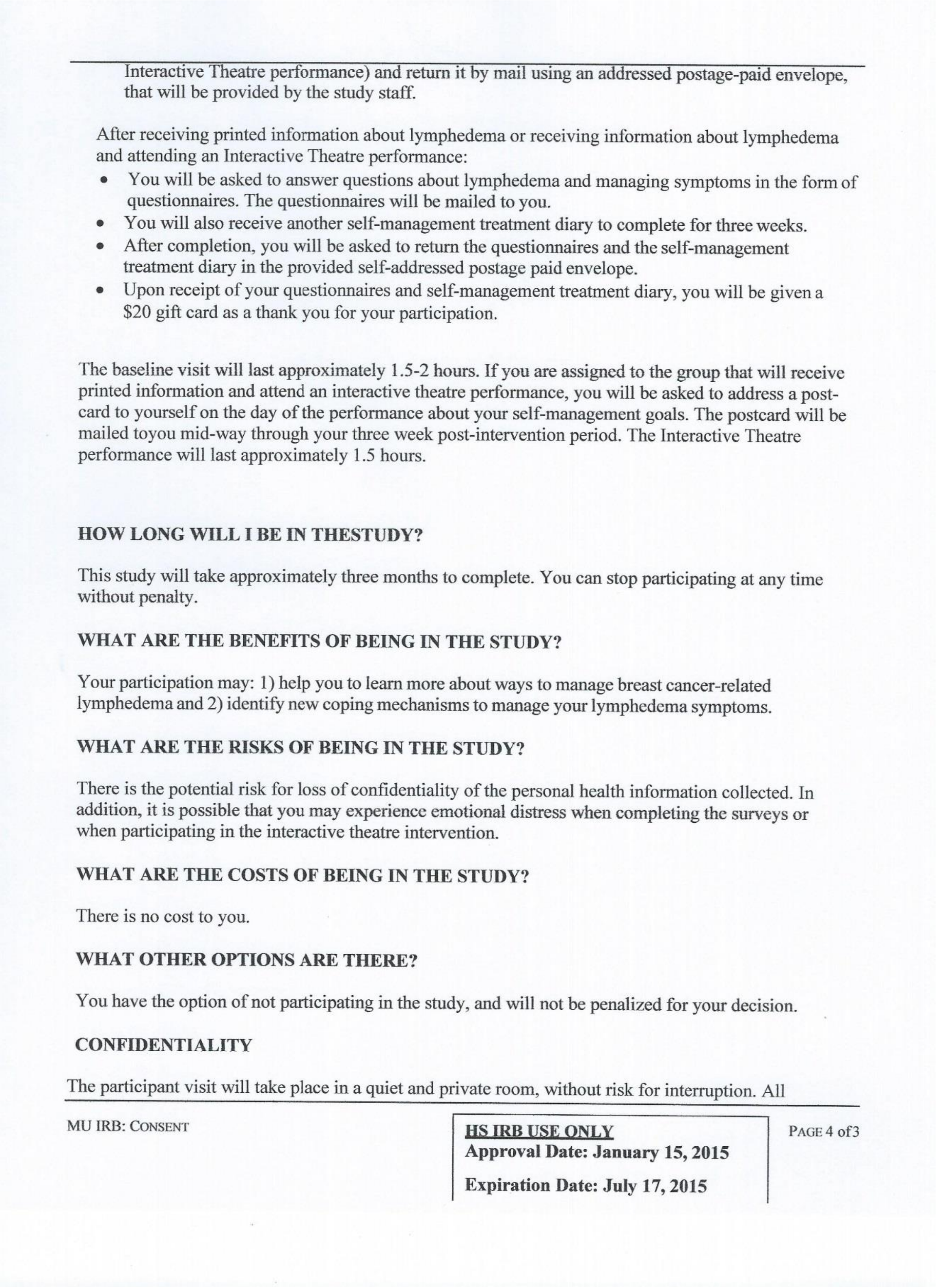
At the baseline study visit:

- You will have your height and weight taken
- Both arms will be measured with a tape measure
- Both arms will be measured using an infra-red light (perometry)
- You will also be asked to answer questions about lymphedema and managing symptoms in the form of questionnaires.
- You will be asked to complete a self-management treatment diary for three weeks **before** the study intervention (either receiving printed information or receiving information and attending the

MU IRB: CONSENT

HS IRB USE ONLY
Approval Date: January 15, 2015
Expiration Date: July 17, 2015

PAGE 1 of3



Interactive Theatre performance) and return it by mail using an addressed postage-paid envelope, that will be provided by the study staff.

After receiving printed information about lymphedema or receiving information about lymphedema and attending an Interactive Theatre performance:

- You will be asked to answer questions about lymphedema and managing symptoms in the form of questionnaires. The questionnaires will be mailed to you.
- You will also receive another self-management treatment diary to complete for three weeks.
- After completion, you will be asked to return the questionnaires and the self-management treatment diary in the provided self-addressed postage paid envelope.
- Upon receipt of your questionnaires and self-management treatment diary, you will be given a $20 gift card as a thank you for your participation.

The baseline visit will last approximately 1.5-2 hours. If you are assigned to the group that will receive printed information and attend an interactive theatre performance, you will be asked to address a post-card to yourself on the day of the performance about your self-management goals. The postcard will be mailed toyou mid-way through your three week post-intervention period. The Interactive Theatre performance will last approximately 1.5 hours.

HOW LONG WILL I BE IN THESTUDY?

This study will take approximately three months to complete. You can stop participating at any time without penalty.

WHAT ARE THE BENEFITS OF BEING IN THE STUDY?

Your participation may: 1) help you to learn more about ways to manage breast cancer-related lymphedema and 2) identify new coping mechanisms to manage your lymphedema symptoms.

WHAT ARE THE RISKS OF BEING IN THE STUDY?

There is the potential risk for loss of confidentiality of the personal health information collected. In addition, it is possible that you may experience emotional distress when completing the surveys or when participating in the interactive theatre intervention.

WHAT ARE THE COSTS OF BEING IN THE STUDY?

There is no cost to you.

WHAT OTHER OPTIONS ARE THERE?

You have the option of not participating in the study, and will not be penalized for your decision.

CONFIDENTIALITY

The participant visit will take place in a quiet and private room, without risk for interruption. All

HS IRB USE ONLY
Approval Date: January 15, 2015
Expiration Date: July 17, 2015

information produced by this study will be stored in the investigator's file and identified by a code number. The code key connecting your name to specific information about you will be kept in a separate, secure location. Information contained in your records may not be given to anyone unaffiliated with the study in a form that could identify you without your written consent, except as required by law.

WILL I BE COMPENSATED FOR PARTICIPATING IN THE STUDY?

You will be compensated with a $20 gift card at the completion of study upon receipt of your post-intervention questionnaires and self-management treatment diary.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Participation in this study is voluntary. You do not have to participate in this study.

You will also be informed of any new information discovered during the course of this study that might influence your health, welfare, or willingness to be in thisstudy.

WHO DO I CONTACT IF I HAVE QUESTIONS, CONCERNS, OR COMPLAINTS?

Please contact the PI, Pamela Ostby if you have questions about the research. Additionally, you may ask questions, voice concerns or complaints to the research team.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this study, you may contact the University of Missouri Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181.

You may ask more questions about the study at any time. For questions about the study, contact Pamela Ostby or Jane M. Armer at 314-255-6677 or 573-884-3249.

A copy of this Informed Consent will be given to you before you begin participation in this study.

SIGNATURES

I have read this consent form and my questions have been answered. My signature below means that I do want to be in the study. I know that I can remove myself from the study at any time without any problems.

Subject	Date
Legal Guardian/Advocate/Witness (ifrequired)	Date
Additional Signature (if required) (identify relationship to subject)	Date

HS IRB USE ONLY
Approval Date: January 15, 2015
Expiration Date: July 17, 2015

Appendix I

HIPPA Waiver for i2b2 database search for recruitment

UNIVERSITY OF MISSOURI – COLUMBIA
INSTITUTIONAL REVIEW BOARD

Waiver or Alteration of Health Information Portability and Accountability Act (HIPAA) Authorization for the Use and/or Disclosure of Protected Health Information (PHI) Resulting from Participation in a Research Study

PRINCIPAL INVESTIGATOR NAME: Pamela Ostby
PROJECT #: 1212075

PROJECT TITLE: The Effectiveness of an Interactive Theatre Intervention on Improving Adherence to Self-Management Regimens for Breast Cancer-Related Lymphedema. (Phase II)
Please provide a brief description of this project.

This randomized study will recruit 62 participants with one group receiving printed information about breast cancer-related lymphedema and the other group receiving printed information and attending an interactive theatre performance about lymphedema. The aims that guide this study are to test the effectiveness of printed information and an interactive theatre program intervention about lymphedema compared to printed information alone.

To obtain approval for a waiver or alteration of Health Information Portability and Accountability Act (HIPAA) authorization for the use and/or disclosure of Protected Health Information (PHI) resulting from participation in a research study, the project must meet the criteria listed below. Please explain how your study meets these criteria.

1. Describe the protected health information (PHI) to be collected and the source(s) of PHI.

Name, address, phone number, and email addresses will be collected from the MUHC i2b2 database to inform potential participants about this study.

2. Provide a brief explanation of why the research activity to be permitted by this waiver or alteration involves no more than minimal risk to the subjects.

To inform potential participants about this study only.

3. Explain why this waiver or alteration will not adversely affect the privacy rights and welfare of the subjects.

I do not have a treating relationship with participants.

4. Demonstrate that the research involves no more than minimal risk to the privacy of subjects by describing the plans requested below.

a. Describe the plan to protect the identifiers from improper use and disclosure; and indicate where the PHI will be stored and who will have access to this information.

Information will be kept in a password protected computer database located in a locked location.

b. Describe the plan to destroy the identifiers at the earliest opportunity consistent with the conduct of the research (how and when identifiers will be destroyed). If there is a health or research justification for retaining the identifiers or such retention is otherwise required by law, provide the reason to retain identifiers.

All information will be deleted for those potential participants who choose not to participate. Those who enroll will be de-identified with a number code. Identifying information will be kept separate from study information in a password protected database in a locked location.

5**.** Explain why this research could not practicably be conducted without the waiver or alteration [indicate why it is very difficult to obtain authorization from the participants (inconvenience, time, resources are not acceptable criteria)].

I do not have a treating relationship with potential participants and information is obtained retrospectively from a database.

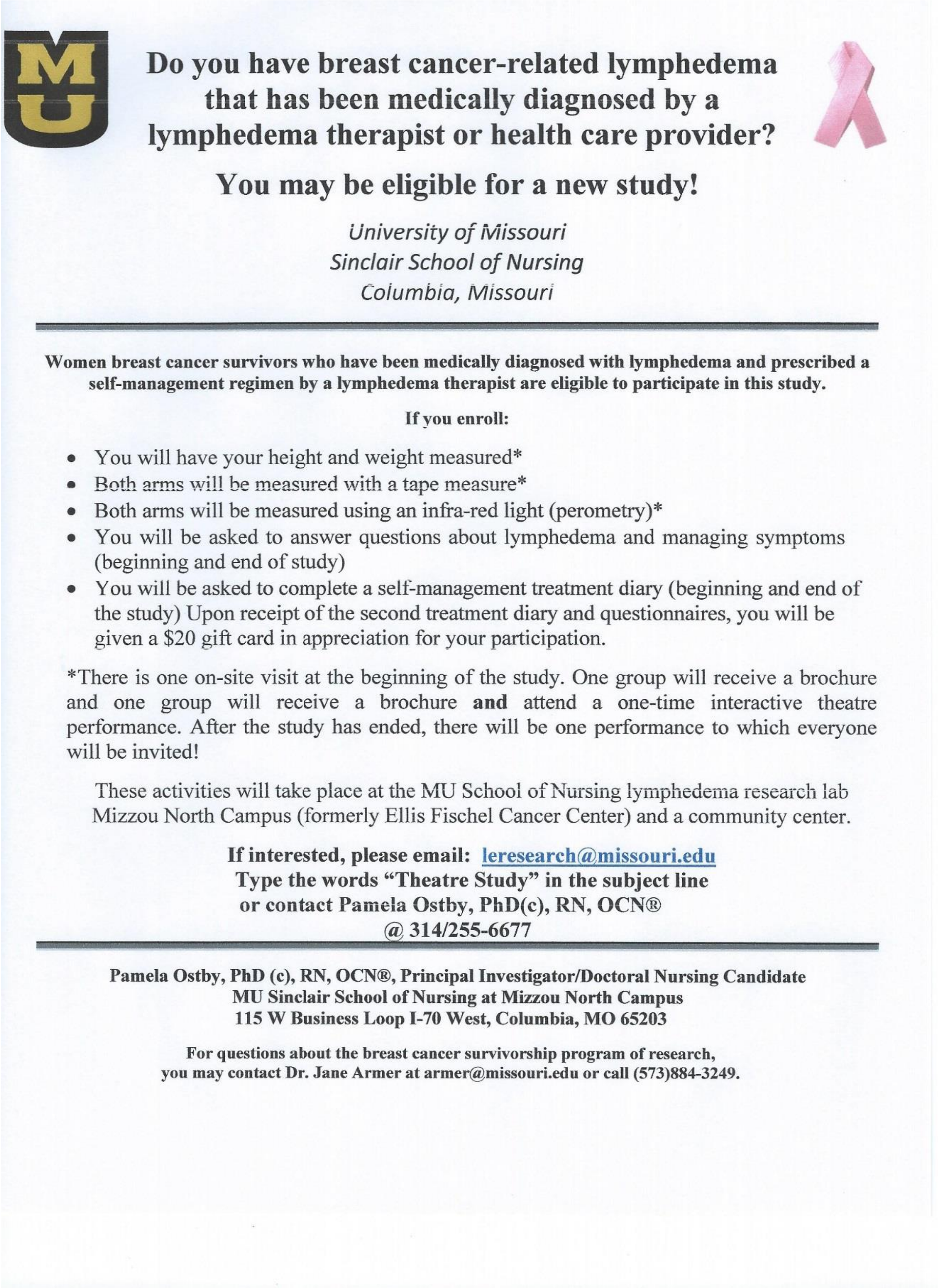
6**.** Indicate why the research could not practicably be conducted without access to and use of PHI.

This recruitment strategy could not be implemented without access to PHI.

I assure the HS IRB that the information that I have provided in this application is accurate and complete; that the PHI that I am requesting is the minimum amount of identifiable private information necessary for my research project; and that the PHI will not be reused or disclosed to any other person or entity, except (a) as required by law, (b) for authorized oversight of the research study, or (c) for other permitted uses or disclosures according to federal regulations.

Pamela Ostby___________________________________
9/23/2015___________________________
PI Signature Date

Appendix J – Recruitment Flyer



Do you have breast cancer-related lymphedema that has been medically diagnosed by a lymphedema therapist or health care provider?

You may be eligible for a new study!

University of Missouri
Sinclair School of Nursing
Columbia, Missouri

Women breast cancer survivors who have been medically diagnosed with lymphedema and prescribed a self-management regimen by a lymphedema therapist are eligible to participate in this study.

If you enroll:

- You will have your height and weight measured*
- Both arms will be measured with a tape measure*
- Both arms will be measured using an infra-red light (perometry)*
- You will be asked to answer questions about lymphedema and managing symptoms (beginning and end of study)
- You will be asked to complete a self-management treatment diary (beginning and end of the study) Upon receipt of the second treatment diary and questionnaires, you will be given a $20 gift card in appreciation for your participation.

*There is one on-site visit at the beginning of the study. One group will receive a brochure and one group will receive a brochure **and** attend a one-time interactive theatre performance. After the study has ended, there will be one performance to which everyone will be invited!

These activities will take place at the MU School of Nursing lymphedema research lab Mizzou North Campus (formerly Ellis Fischel Cancer Center) and a community center.

If interested, please email: leresearch@missouri.edu
Type the words "Theatre Study" in the subject line
or contact Pamela Ostby, PhD(c), RN, OCN®
@ 314/255-6677

Pamela Ostby, PhD (c), RN, OCN®, Principal Investigator/Doctoral Nursing Candidate
MU Sinclair School of Nursing at Mizzou North Campus
115 W Business Loop I-70 West, Columbia, MO 65203

For questions about the breast cancer survivorship program of research, you may contact Dr. Jane Armer at armer@missouri.edu or call (573)884-3249.

Appendix K – i2b2 Recruitment Letter

November 2015

Dear Potential Participant,

My name is Pamela Ostby, PhD, RN, OCN®, a doctoral nursing student working with Dr. Jane Armer at the University of Missouri-Columbia Lymphedema Laboratory. I have received approval to seek patients who have been treated for breast cancer-related lymphedema in our institutional database in order to inform patients of a new study for breast cancer survivors with lymphedema. It is strictly confidential, with no access to your medical records.

I am recruiting breast cancer survivors who have been diagnosed with lymphedema to participate in a study to see if an interactive program works better than giving printed information alone in helping women to stick to their self-management regimen to control lymphedema symptoms. The study will divide participants into two groups. One group will get printed information about lymphedema and the other will get printed information **AND** attend an interactive theatre performance about lymphedema. There is a baseline on-site visit at the beginning of the study, with the addition of one group also attending the interactive theatre performance. Other than the baseline visit and the theatre performance, the study is conducted by mail.

The baseline study visit takes place in Columbia at the University of Missouri-Columbia Lymphedema Laboratory. During your baseline visit:

- You will have your height and weight taken
- Both arms will be measured with a tape measure
- Both arms will be measured using an infra-red light (perometry)
- You will also be asked to answer questions about lymphedema and managing symptoms in the form of questionnaires.
- You will be asked to complete a self-management treatment diary for three weeks **before** the study intervention (either receiving printed information **or** receiving information and attending the Interactive Theatre performance) and return it by mail using a stamped self-addressed envelope provided by the study staff.

After your intervention (printed information only or printed information and attending an Interactive Theatre performance about lymphedema):

- You will be asked to complete the answer questions about lymphedema and managing symptoms in the form of questionnaires and mail them back to the study site using the provided self-addressed postage paid envelope.
- You will be asked to complete a **second** self-management treatment diary for three weeks and mail it back in the provided envelope.

- Once your questionnaires and self-management treatment diary are received, you will be given a $20 gift card as a thank you for your participation.

If you would like to discuss the study further and/or make a study appointment, please contact me at
314/255-6677 or you can email leresearch@missouri.edu. Please know that you are not under any obligation to participate and I appreciate your consideration of taking part in this study. The findings from this study may help us to learn better ways to provide education and support to women who struggle every day with lymphedema.

Sincerely,

Pamela Ostby, PhD(c), RN, OCN®
MU Sinclair School of Nursing

Appendix L – Therapist Letter

Dear Lymphedema Therapist,

I am writing to ask for your help in recruiting participants for my dissertation research study, entitled, “The Effectiveness of an Interactive Theatre Intervention on Improving Adherence to Self-Management Regimens for Breast Cancer-Related Lymphedema.” My study will use an Interactive Theatre intervention to determine if it is effective in improving adherence to self-management of breast cancer-related lymphedema (BCRL) vs. printed information. A second aim of this study is to see if there is an improvement in perceptions of self-efficacy and self-regulation post-intervention. This is a multidisciplinary study in which the role of lymphedema therapists is crucial. Eligibility for the study is as follows:

- Female breast cancer survivors over the age of 18
- Have medically diagnosed breast cancer-related lymphedema
- Have been prescribed a BCRL self-management regimen by a trained lymphedema therapist
- Must have no prior history of lymphedema

As you know, the treatment for BCRL can occur within days or up to decades postoperatively in breast cancer survivors, which makes follow-up difficult due to delayed development. Regardless of varying BCRL incidence rates, there are hundreds of thousands of women worldwide that struggle on a day-to-day basis with BCRL symptoms and millions who live in fear of developing it. The barriers to self-management of BCRL and symptom distress contribute to sub-optimal adherence rates. This study hopes to lay a foundation for participatory research using interactive theatre to improve adherence to self-management. Participants will be randomized into two groups; one who will receive printed information about BCRL, and the other who will receive printed information and attend an interactive theatre intervention.

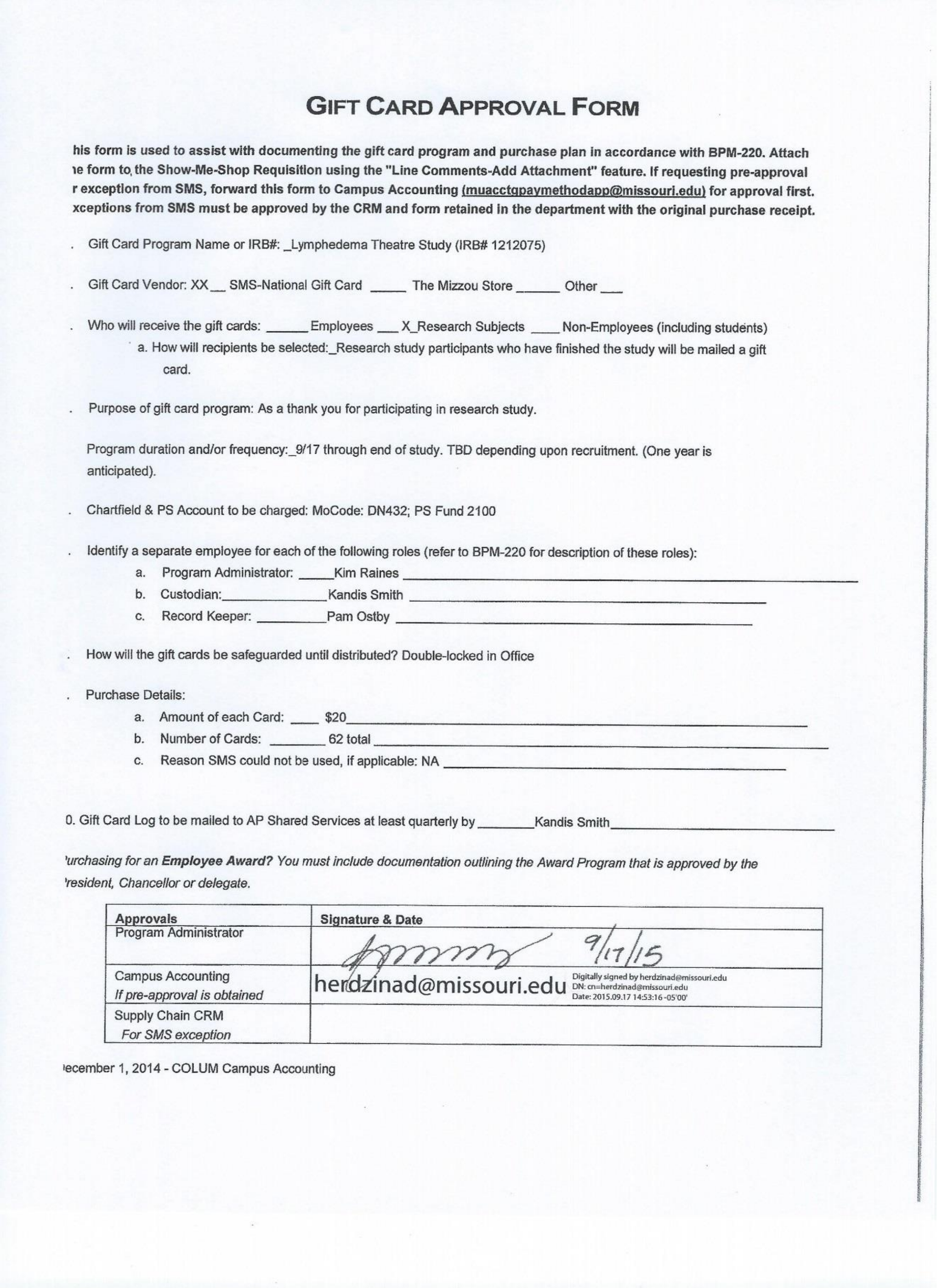
This study cannot be achieved without your help with recruitment. I am focusing on mid-Missouri because participants will need to come to the University of Missouri-Columbia Lymphedema Laboratory directed by Jane M. Armer, PhD, RN, FAAN for a baseline on-site visit; therefore, I want to decrease the burden of transportation as much as I can. I have enclosed an overview of the study as well as a sample recruitment flyer. I can provide flyers to you and/or you can talk with your patients and forward their information to me. Thank you in advance for your help with this innovative approach to improving patient outcomes associated with BCRL.

If you have additional questions or want to discuss further, please contact me at: plo7c9@mail.missouri.edu or 314/255-6677.

Sincerely,

Pamela Ostby, PhD(c), RN, OCN®
Sinclair School of Nursing
University of Missouri-Columbia

Appendix M – Gift Card Approval for Participants



GIFT CARD APPROVAL FORM

his form is used to assist with documenting the gift card program and purchase plan in accordance with BPM-220. Attach ıe form to the Show-Me-Shop Requisition using the "Line Comments-Add Attachment" feature. If requesting pre-approval r exception from SMS, forward this form to Campus Accounting (muacctgpaymethodapp@missouri.edu) for approval first. xceptions from SMS must be approved by the CRM and form retained in the department with the original purchase receipt.

. Gift Card Program Name or IRB#: _Lymphedema Theatre Study (IRB# 1212075)

. Gift Card Vendor: XX__ SMS-National Gift Card _____ The Mizzou Store ______ Other ___

. Who will receive the gift cards: ______Employees ___ X_Research Subjects ____ Non-Employees (including students)
  - a. How will recipients be selected:_Research study participants who have finished the study will be mailed a gift card.

. Purpose of gift card program: As a thank you for participating in research study.

Program duration and/or frequency:_9/17 through end of study. TBD depending upon recruitment. (One year is anticipated).

. Chartfield & PS Account to be charged: MoCode: DN432; PS Fund 2100

. Identify a separate employee for each of the following roles (refer to BPM-220 for description of these roles):
  - a. Program Administrator: _____Kim Raines
  - b. Custodian:_______________Kandis Smith
  - c. Record Keeper: __________Pam Ostby

. How will the gift cards be safeguarded until distributed? Double-locked in Office

. Purchase Details:
  - a. Amount of each Card: ____ $20
  - b. Number of Cards: ________ 62 total
  - c. Reason SMS could not be used, if applicable: NA

0. Gift Card Log to be mailed to AP Shared Services at least quarterly by ________Kandis Smith

*'urchasing for an **Employee Award**? You must include documentation outlining the Award Program that is approved by the 'resident, Chancellor or delegate.*

Approvals	**Signature & Date**
Program Administrator	9/17/15
Campus Accounting *If pre-approval is obtained*	herdzinad@missouri.edu Digitally signed by herdzinad@missouri.edu DN: cn=herdzinad@missouri.edu Date: 2015.09.17 14:53:16 -05'00'
Supply Chain CRM *For SMS exception*	

'ecember 1, 2014 - COLUM Campus Accounting

Lymphedema Breast Cancer Questionnaire (LBCQ)

Symptom and Action items

The following questions pertain to arm, breast, and chest symptoms now* and during the past year:

* Now refers to today or in the past month.

1. Do you have limited movement of your shoulder?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○

2. Have you experienced swelling?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○

3. Have you experienced swelling with pitting? (Pitting is when you press firmly on your skin and the dent stays long enough to feel it when you slide the pad of your finger across it.)

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○

4. Have you experienced redness?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○

5. Have you experienced blistering?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○

6. Have you experienced firmness/tightness?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? ○ None ○ Action

7. Have you experienced increased temperature in your arm?

Now: ○ No ○ Yes

During Past Year: ○ No ○ Yes

What action did you take for this symptom? ○ None ○ Action

8. Have you experienced heaviness?

Now: ○ No ○ Yes

During Past Year: ○ No ○ Yes

What action did you take for this symptom? ○ None ○ Action

9. Have you experienced numbness?

Now: ○ No ○ Yes

During Past Year: ○ No ○ Yes

What action did you take for this symptom? None ○ Action ○

10. Have you experienced stiffness?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○

11. Have you experienced aching?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○

12. Have you experienced chest wall swelling?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○ ☐

13. Have you experienced breast swelling?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○ ☐

14. Have you experienced the development of pockets of fluid?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○ ☐

15. Have you experienced other symptoms?

Now: No ○ Yes ○

During Past Year: No ○ Yes ○

What action did you take for this symptom? None ○ Action ○

Adapted with permission from Dr. Jane M. Armer

Appendix O – Self-Efficacy/Self-Regulation Instrument

Self-Efficacy/Self-Regulation

Directions: The following questions assess your thoughts, feelings, and beliefs in relation to your ability to manage breast cancer-related lymphedema (BCRL) and your ability to control emotion, behavior, or distractions that might interfere with goals set to manage BCRL symptoms and minimize BCRL. Please answer each question by circling your response using the scale provided.

1. To what extent do you believe that you are able to make the necessary lifestyle changes to carry out recommended precautions (e.g., wearing gloves when doing housework, keeping your arm very clean and well moisturized, avoiding sun exposure to the affected arm) to minimize BCRL symptoms?

1	2	3	4	5
not at all	a little bit	somewhat	quite a bit	very much

2. In general, to what extent, do you believe your self-management regimen minimizes symptoms?

1	2	3	4	5
not at all	a little bit	somewhat	quite a bit	very much

3. To what extent, do you believe practicing your prescribed self-management regimen will minimize progression of your BCRL?

1	2	3	4	5
not at all	a little bit	somewhat	quite a bit	very much

4. To what extent do you feel that BCRL interferes with your ability to live life normally?

1	2	3	4	5

1	2	3	4	5
not at all	a little bit	somewhat	quite a bit	very much

5. To what extent do you believe that you are able to limit the amount of stress experienced about your BCRL?

1	2	3	4	5
not at all	a little bit	somewhat	quite a bit	very much

6. To what extent do you believe that you have control in achieving set goals to manage your BCRL symptoms?

1	2	3	4	5
not at all	a little bit	somewhat	quite a bit	very much

7. To what extent do you believe that you are able to calm yourself down when anxious or worried about progression of your BCRL?

1	2	3	4	5
not at all	a little bit	somewhat	quite a bit	very much

8. To what extent do you believe you are able to follow your prescribed self-management regimen?

1	2	3	4	5
not at all	a little bit	somewhat	quite a bit	very much

Adapted with Permission from Dr. K. A. Sherman

Sherman, K. A., & Koelmeyer, L. (2013). Psychosocial predictors of adherence to lymphedema risk minimization guidelines among women with breast cancer. *Psychooncology, 22*(5), 1120-1126. doi: 10.1002/pon.3111

Appendix P – Permission

Re: Permission for Adaptation
Kerry Sherman <kerry.sherman@mq.edu.au>
Wed 07/31/13 20:01
Pre Doc NIH NRSA App
To: Ostby, Pamela L. (MU-Student) <plo7c9@mail.missouri.edu>;
1 attachment
Self-Efficacy and Self-Regulation
Questionnaire_USmodified_KScomments.docx;

Dear Pamela,

Thank you for your email. I have just returned to Sydney and am catching up with emails. I see that Laura has been able to send through to you copies of our measures. I looked over your suggested modifications to accommodate the women who already have a diagnosis of lymphoedema, and they look fine (although I've corrected a few typos, please see attached). Please let me know how you get on with this research, as I'm very interested to see how the measure applies to women with lymphoedema diagnosed already, compared with those at risk.

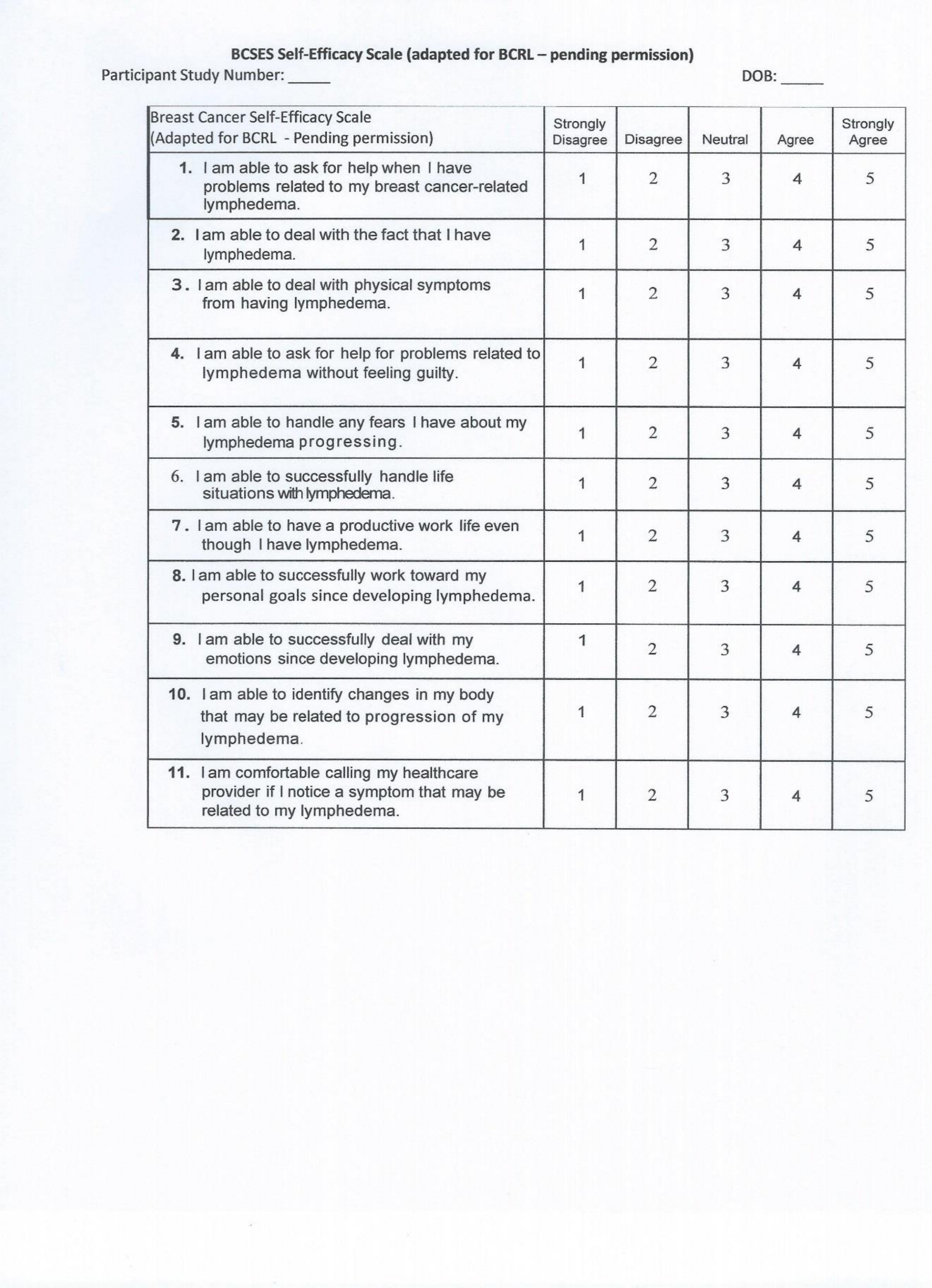
Regards
Kerry

Dr Kerry Sherman
Senior Lecturer
Past President, Australasian Society for Behavioural Health and Medicine (ASBHM)
Centre for Emotional Health
Department of Psychology, C3A 705
Macquarie University NSW 2109

P 02 9850 6874
F 02 9850 8062
E Kerry.Sherman@mq.edu.au

W www.centreforemotionalhealth.com.au

Appendix Q – Breast Cancer Self-Efficacy Scale (BCSES) Instrument



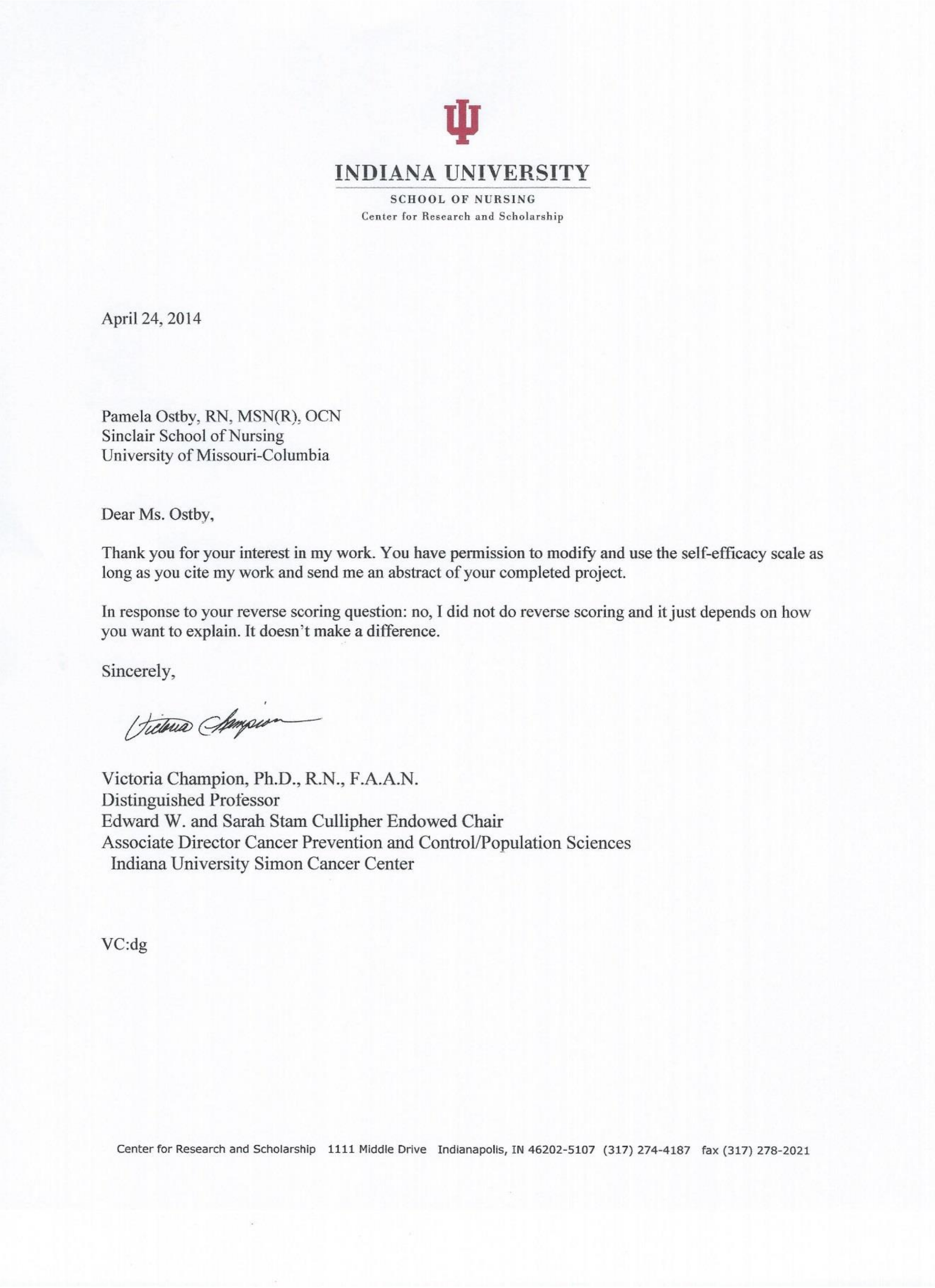
BCSES Self-Efficacy Scale (adapted for BCRL – pending permission)

Participant Study Number: _____

DOB: _____

Breast Cancer Self-Efficacy Scale (Adapted for BCRL - Pending permission)	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I am able to ask for help when I have problems related to my breast cancer-related lymphedema.	1	2	3	4	5
2. I am able to deal with the fact that I have lymphedema.	1	2	3	4	5
3. I am able to deal with physical symptoms from having lymphedema.	1	2	3	4	5
4. I am able to ask for help for problems related to lymphedema without feeling guilty.	1	2	3	4	5
5. I am able to handle any fears I have about my lymphedema progressing.	1	2	3	4	5
6. I am able to successfully handle life situations with lymphedema.	1	2	3	4	5
7. I am able to have a productive work life even though I have lymphedema.	1	2	3	4	5
8. I am able to successfully work toward my personal goals since developing lymphedema.	1	2	3	4	5
9. I am able to successfully deal with my emotions since developing lymphedema.	1	2	3	4	5
10. I am able to identify changes in my body that may be related to progression of my lymphedema.	1	2	3	4	5
11. I am comfortable calling my healthcare provider if I notice a symptom that may be related to my lymphedema.	1	2	3	4	5

Appendix R – Permission for BCSES



INDIANA UNIVERSITY
SCHOOL OF NURSING
Center for Research and Scholarship

April 24, 2014

Pamela Ostby, RN, MSN(R), OCN
Sinclair School of Nursing
University of Missouri-Columbia

Dear Ms. Ostby,

Thank you for your interest in my work. You have permission to modify and use the self-efficacy scale as long as you cite my work and send me an abstract of your completed project.

In response to your reverse scoring question: no, I did not do reverse scoring and it just depends on how you want to explain. It doesn't make a difference.

Sincerely,

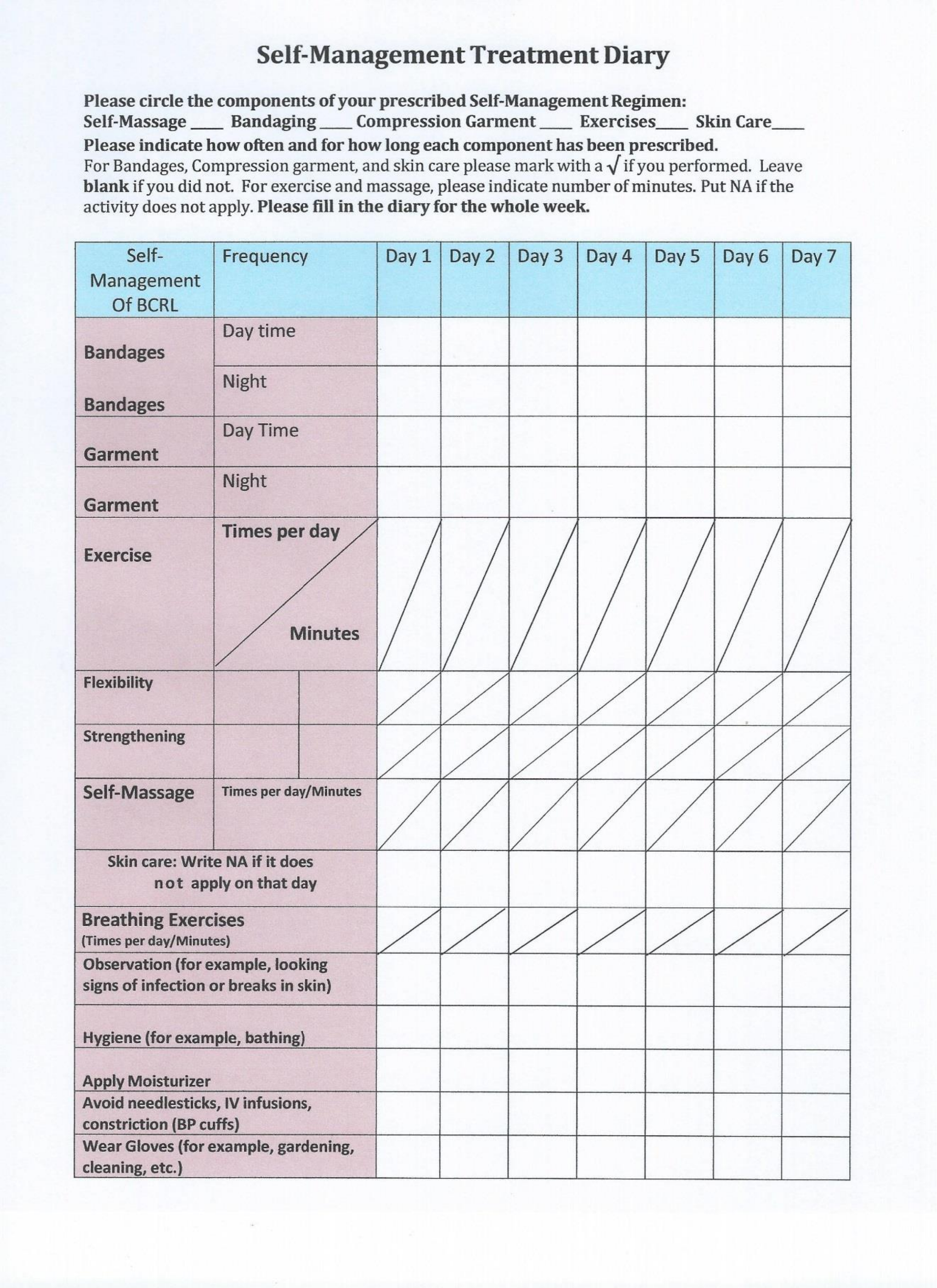
Victoria Champion

Victoria Champion, Ph.D., R.N., F.A.A.N.
Distinguished Professor
Edward W. and Sarah Stam Cullipher Endowed Chair
Associate Director Cancer Prevention and Control/Population Sciences
Indiana University Simon Cancer Center

VC:dg

Center for Research and Scholarship 1111 Middle Drive Indianapolis, IN 46202-5107 (317) 274-4187 fax (317) 278-2021

Appendix S - Instrument



Self-Management Treatment Diary

Please circle the components of your prescribed Self-Management Regimen:
Self-Massage ____ Bandaging ____ Compression Garment ____ Exercises____ Skin Care____

Please indicate how often and for how long each component has been prescribed.
For Bandages, Compression garment, and skin care please mark with a √ if you performed. Leave **blank** if you did not. For exercise and massage, please indicate number of minutes. Put NA if the activity does not apply. **Please fill in the diary for the whole week.**

Self-Management Of BCRL	Frequency	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Bandages	Day time							
Bandages	Night							
Garment	Day Time							
Garment	Night							
Exercise	**Times per day** / **Minutes**							
Flexibility								
Strengthening								
Self-Massage	**Times per day/Minutes**							
Skin care: Write NA if it does not apply on that day								
Breathing Exercises (Times per day/Minutes)								
Observation (for example, looking signs of infection or breaks in skin)								
Hygiene (for example, bathing)								
Apply Moisturizer								
Avoid needlesticks, IV infusions, constriction (BP cuffs)								
Wear Gloves (for example, gardening, cleaning, etc.)								

Appendix T – IT Script

Five O’clock Special

Written by:
M. Heather Carver and Pamela L. Ostby
in collaboration with the MU Interactive Active Theatre Troupe

CAST OF CHARACTERS

VERONICA, "RONNIE,”65, retired art teacher, four-year breast cancer survivor. She had cancer in her left breast treated with radiation and mastectomy, followed by chemotherapy. She is divorced and seeing someone. (Radiation first, then surgery and chemo for inflammatory breast cancer)

LIZA, 52, bank teller, currently in chemotherapy preceded by surgery for stage two breast cancer. She has a female life-partner and no children, but several dogs.

JEN, 45, accountant, 10-year breast cancer survivor. She had stage three cancers in her right breast treated with mastectomy, radiation, and chemo and a recurrence in her left breast treated with lumpectomy and radiation. Separated from her husband of twenty years before she got cancer, she has two tween-age sons and her 70-year-old mother living in her home.

SHELLY, 34, graduate student in journalism, two-year breast cancer survivor who had aggressive cancer in her left breast treated with bilateral mastectomy, chemo, and radiation. She lives in a house with two other graduate students. Her mother died of breast cancer and three of her sisters were diagnosed with it before menopause.

MARK, 20's, waiter, single, struggling to pay rent. It is a lack of knowledge about lymphedema that contributes to people's intolerance, concerning the outward signs of its effects. A large part of the focus group discussion was about how ignorant and mean people can be. We want to capture this feeling when we watch Mark’s performance. His responses to any questions he receives about his behavior should reinforce his discomfort with having to wait on these women because they are clearly not "normal.” We will have to keep a balance to keep Mark’s behavior from overshadowing the aim of encouraging Jen to empower herself to seek help with management of her lymphedema symptoms.

Setting: a table in a half-filled diner around five o'clock on a weeknight

Five O’clock Special

RONNIE and SHELLY are talking at the table.

RONNIE

Did you see the special?

SHELLY

Yes, but I can’t decide. I've been writing all day so I've earned a piece of pie…

JEN rushes in, looking overwhelmed, and disheveled—she flops into a seat and smiles, awkwardly hugging RONNIE and SHELLY across the table.

JEN

How are you two?

RONNIE

Good. How are you?

Before SHELLY can speak, JEN cuts them off—

JEN

You both look really good, I mean really, really good.

RONNIE

Thank you.

SHELLY

Thanks. What’s up with you?

JEN

The usual: driving the thirteen-year-old to swimming and the fifteen-year-old to band. I can't wait till Jeff gets his driver's license!

LIZA enters, looks around, and tries to slip into her chair without much fuss.

RONNIE

There you are!

LIZA

Hi...

The women start to talk with greetings, how are you, more hugs, and pats across the booth as MARK the waiter comes over.

MARK

May I start you ladies off with some drinks?

RONNIE

Ice water, please.

LIZA

Me, too.

SHELLY

Diet Coke for me.

JEN

Makes an "ick face" at Shelly's order.

A cup of herbal tea, please.

RONNIE

You look good, Liza.

LIZA scratches her head underneath a wig, visibly moving it.

LIZA

Except for this.

MARK, the waiter, returns with a question and sees Liza's hair moving.

MARK

Er, did you want lemon in those waters?

RONNIE and LIZA nod yes. MARK moves away quickly, showing discomfort. Liza sees this. Shelly smiles reassuringly at her and continues the conversation.

SHELLY

Been there, done that. Your hair comes back. It might even come back curly like my sister's did!

RONNIE

You're beautiful. All of you!

Liza shakes off her embarrassment.

JEN

Is that real hair? May I…

JEN reaches out to touch the wig, but winces audibly from pain. LIZA looks at JEN's arm.

Ow!

LIZA

Hey, what's the matter with your arm?

JEN

I've been having some tingling in it and now it's a little swollen. This week has been so busy that I haven't had time to pay any attention to it.

RONNIE

It might be lymphedema. You should ask your doctor.

SHELLY

Yeah, it looks painful.

LIZA

Lymphedema? I know I've heard that term. It's not cancer, is it?

JEN

Don't worry. Ronnie said *Lymphedema,* not lymphoma. I've read about it, but I don't think I've got it. I've gone ten years without a problem.

RONNIE

I don't know, Jen. One woman in our support group said she was twenty years out when she got lymphedema. Swelling, heaviness, tightness, tingling–those may be some of the first symptoms. If that's what it is, you want to get right on top of it.

LIZA

When did it start swelling?

JEN

Sunday afternoon. I guess I shouldn't have done all that yard work. Oh, and I lifted a big bag of mulch out of my car. My back's a little achy too.

SHELLY

Good to know I shouldn't be doing yard work, but, remind me, what's the problem with lifting?

RONNIE

You aren't supposed to lift anything *really* heavy, so no big bags of dog food, laundry detergent – or mulch!

JEN

And kids, yeah, don't lift your kids. I heard that too. My boys were three and five when I got diagnosed – how could I not lift my kids?

LIZA

Well, we would have to find someone else's kids to lift. Right now Becca's the one who carries in the dog food bags. She also schleps the dogs' crates back and forth when we go to competitions, so I guess I'm safe.

RONNIE

Actually, it's not that you can't do *any* lifting. Supervised exercise and some weights are okay. I went to a therapist when I had my first symptoms and she got the swelling down with…um…"manual lymphatic drainage." Now I wear a compression sleeve to help prevent more swelling. …

RONNIE holds out her arm and moves her sleeve up, showing her compression garment.

SHELLY

Making a joke.

Oh, no, another breast cancer survivor's fashion accessory! Going bald in grad school isn't embarrassing enough?

RONNIE

…And there are breathing exercises.

LIZA

Exercises?

MARK appears with the drinks. He sees the sleeve and then gives the whole group a "once over," but doesn't say anything out loud. Ronnie sees him and pulls her sweater sleeve back down. He is eager to get them served and out of his section as quickly as possible.

MARK

OK, want to hear about the specials, or are you ready to order?

They all turn and look at him, indicating that he doesn't belong to this tribe of survivors, and they're not ready to deal with him. Liza speaks to her friends.

LIZA

We're hearing about the specials already!

SHELLY

We still need a few minutes.

MARK

Okay! I'll leave you to it…

He exits, glad to get away from the table. The group members look at one another, having all experienced this kind of shunning before. After a beat they get on with their conversation.

JEN

I had some tingling once a few months ago, and got a little scared. So I bought one of those sleeves at the drugstore. But I didn't like the way it felt. And the tingling went away after a few days, so I stopped wearing it. It hasn't bothered me again until now.

SHELLY

Ronnie, how often do you wear your sleeve?

RONNIE

My therapist told me to wear it during the day. It seems to work, but it gets hot. Jen, I don't think you should buy the sleeves at the drug store. They are supposed to be custom fitted.

SHELLY

I didn't know people still got lymphedema. My doctor said now with sentinel lymph node biopsies, people don't get it anymore. I did some research online; but there seems to be a lot of contradictory information out there.

RONNIE

Shelly, you can't believe everything you see on the Internet! I'm living proof that you *can* get it: I had a sentinel lymph node biopsy four years ago, and I've got lymphedema now.

SHELLY

Shaking her head.

Wow. Not one of my doctors acted like it would be a problem. I guess health care providers need more information too.

JEN

When I was being treated ten years ago, I got so much information – I could've filled a grocery bag. I probably got something about lymphedema, but after getting a cancer diagnosis, it's hard to take everything in. I was just trying to keep my sanity, my house, my job, you know? Crap, after a decade, I thought I was home free. I really don't need another thing to do!

LIZA

Well, when I was diagnosed with breast cancer, I never got any information about lymphedema.

SHELLY

Well, apparently, a lot of us didn't get the memo!

Everyone nods in agreement.

LIZA

I don't want to think about lymphedema on top of chemo! I just want things to be as normal as possible again…

RONNIE

You don't have to worry, Liza; you may not ever get it. But you need to know what to look for so you can catch it early. If you let it go, it can get worse and out of control.

LIZA

You know, now that we are talking about it, I remember when Becca's mom had a swollen arm and hand about six months after her breast cancer surgery. She could hardly do anything for herself; we had to help her all the time! Becca finally got her to see a lymphedema therapist, who gave her a regimen that helped her function on her own again. Otherwise she'd still be depressed and hiding out at home!

RONNIE

The swelling makes it hard to find clothes that fit, let alone deal with the looks and stares. So it's worth sticking to whatever works the best to manage your symptoms.

LIZA

I've already lost a breast; I don't want to lose any more of my life to this--!

She catches herself and doesn't say what she's thinking.

RONNIE

Catching it early helps you reduce the risk of it getting worse. There are many resources . . .

SHELLY

Holding out her hand as if she's got a microphone.

Uh, oh, here it comes again! The Daily Special: Ronnie's next "patient education" speech!

Liza pushes Shelly's "microphone" away.

LIZA

No, Ronnie, go ahead, I want to hear your "daily special." What should I do? Besides not picking up random children...

RONNIE

Liza, here's something "special:" you might actually like the treatment. My cousin who took massage therapy training was here for New Year's. And I had some swelling in my hand. She massaged it; the swelling went down! The massage and the deep breathing exercises she taught me were so relaxing!

LIZA

I don't have a cousin who's a massage therapist.

SHELLY

No, you have Becca. She helped her mom, and she'll help you.

RONNIE

That's right. A trained lymphedema therapist can teach *both* you and Becca all kinds of things: exercises for range of motion, good skin care, and precautions like not letting anyone draw blood or check your blood pressure on that arm…

LIZA

Do the rest of you feel as overwhelmed as I do? Right now I'm wondering why I have to become an expert in so many things!

RONNIE

I know what you mean.

Everyone nods in agreement.

SHELLY

Yeah, we have to be our own best care-givers. It's a lot of work.

Liza looks at the others, grateful for the support group they've formed.

LIZA

So we have to keep supporting each other and sharing what we know. Anything else, Ronnie?

RONNIE looks pointedly at JEN.

RONNIE

Wear gloves if you're going to do yard work. Pricks and cuts can lead to infection. And whatever the therapist tells you to do, do it and stick to it.

JEN rubs her arm. She speaks doubtfully.

JEN

I guess I could go to the clinic and ask the lymphedema therapist about the swelling…

SHELLY

So you *have* a lymphedema therapist you don't use?

JEN

Well, there's one on my care team, but I don't want to get in a situation where I feel like I'm letting her down because I get tired of doing the exercises or wearing a sleeve. I don't want her to look at me like my dentist does when I don't floss.

SHELLY

Yeah, how much time do the treatments take? I'm in the middle of writing my dissertation. I don't have time for lymphedema treatments!

RONNIE

Shelly, think about the consequences if you get it and do nothing about it. We're all busy.

JEN

Can you show me that massage thing? Is it complicated?

RONNIE demonstrates on Jen's arm. MARK returns to collect their order and sees JEN and RONNIE. He looks around to see if others are watching, and again seems very uncomfortable.

MARK

Er, maybe you ladies would prefer a booth? There's one over there – in the other section.

All of the ladies look at him in shock as he slaps down a check for their drinks. He turns and walks away with no intention of coming back. He knows his chances of a good tip are blown and wants them to leave as soon as possible. SHELLY finally responds.

SHELLY

Jerk!

JEN

Trying to recover from Mark's rudeness.

I thought I was past feeling like a freak because someone stares or says something mean. Look, most of my current clients don't know I'm a survivor and I like it that way. But if I'm wearing a sleeve, they'll know I'm a member of the cancer club, and I may lose their business.

LIZA

Becca and I are your clients and we're not going to be looking for another accountant any time soon – sleeve or no sleeve.

JEN

Thanks…I guess I’m more stressed out about this swelling business than I knew.

RONNIE

Jen, I spent years dreaming of painting all day instead of teaching kids how to. Then I got lymphedema, and I couldn't even hold a brush. Taking the time to treat it was more than worth it. I can go to my easel now and paint to my heart's content.

JEN

Well…I…

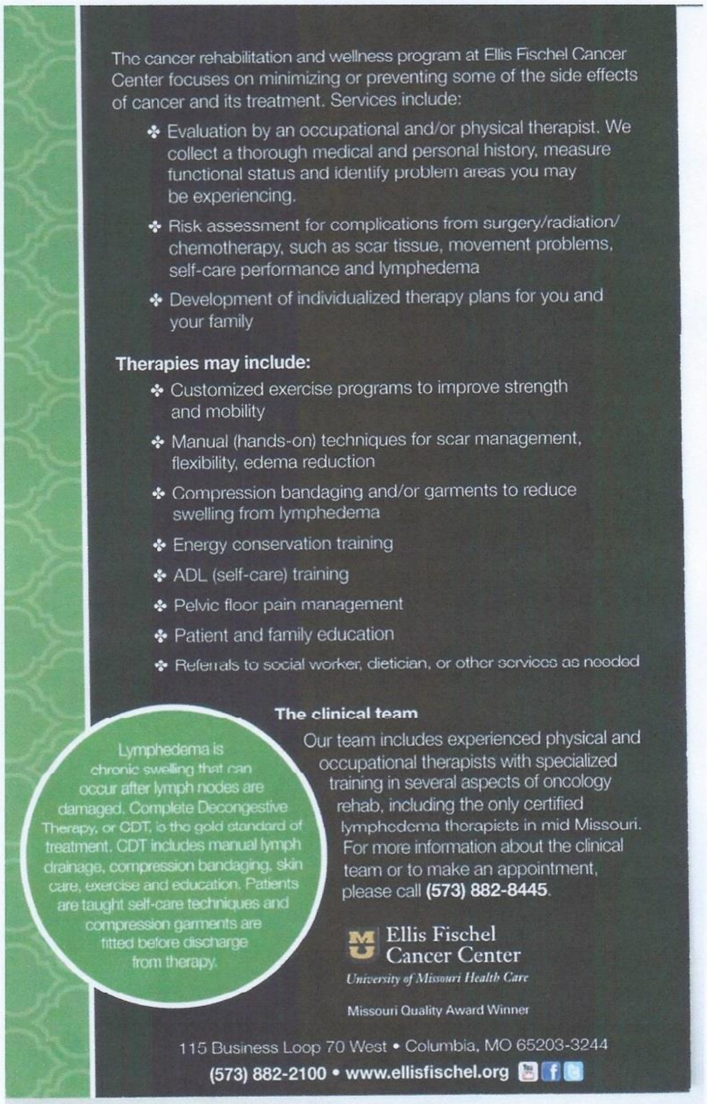
Everyone looks at Jen as she tries to decide whether or not she'll go to the therapist.

Appendix U – Printed Information (original brochure with permissions)

Cancer Rehabilitation

and Wellness Program at Ellis Fischel Cancer Center

Each person who is newly diagnosed with cancer, undergoing treatment or adjusting to changes following treatment has unique needs. Cancer rehabilitation helps individuals become stronger, more mobile and independent and can alleviate the side effects of treatment such as fatigue, pain, scarring, nausea and even cognitive issues (chemo brain). Education and specialized treatment for lymphedema are also available.



The cancer rehabilitation and wellness program at Ellis Fischel Cancer Center focuses on minimizing or preventing some of the side effects of cancer and its treatment. Services include:

- Evaluation by an occupational and/or physical therapist. We collect a thorough medical and personal history, measure functional status and identify problem areas you may be experiencing.
- Risk assessment for complications from surgery/radiation/chemotherapy, such as scar tissue, movement problems, self-care performance and lymphedema
- Development of individualized therapy plans for you and your family

Therapies may include:

- Customized exercise programs to improve strength and mobility
- Manual (hands-on) techniques for scar management, flexibility, edema reduction
- Compression bandaging and/or garments to reduce swelling from lymphedema
- Energy conservation training
- ADL (self-care) training
- Pelvic floor pain management
- Patient and family education
- Referrals to social worker, dietician, or other services as needed

Lymphedema is chronic swelling that can occur after lymph nodes are damaged. Complete Decongestive Therapy, or CDT, is the gold standard of treatment. CDT includes manual lymph drainage, compression bandaging, skin care, exercise and education. Patients are taught self-care techniques and compression garments are fitted before discharge from therapy.

The clinical team

Our team includes experienced physical and occupational therapists with specialized training in several aspects of oncology rehab, including the only certified lymphedema therapists in mid Missouri. For more information about the clinical team or to make an appointment, please call **(573) 882-8445**.

Ellis Fischel
Cancer Center
University of Missouri Health Care

Missouri Quality Award Winner

115 Business Loop 70 West • Columbia, MO 65203-3244
(573) 882-2100 • www.ellisfischel.org

Appendix V: Printed material permission for use:

Van Loo, Maggie J.
Tue 08:11Ostby, Pamela L. (MU-Student)

To whom It May Concern:

Pamela Ostby has permission to use the educational materials for Lymphedema used for Breast Cancer Patients here at Ellis Fischel Cancer Center.

Maggie Van Loo, RN, FNP-BC
Surgical Oncology

Pam,

As long as the pamphlet(s) that you are distributing are the original product that were purchased and not copies from either a scan or copy machine, etc. then distribution of the pamphlet(s) ARE authorized and fall within the copy right guidelines.

If you are handing out copies or any type of reproduction of the pamphlet(s) then distribution is NOT authorized and does NOT fall within the copy right guidelines.

Thank you!

Constance

Constance Hickman
Office Manager

8420 Dorchester Road, Suite 203
North Charleston, SC 29420
Phone: 843.760.6064 | Fax: 843.760.6988
www.educareinc.com

Pam,

Yes. You can use a picture of the brochure in the appendix of your dissertation.

Thank you!

Constance

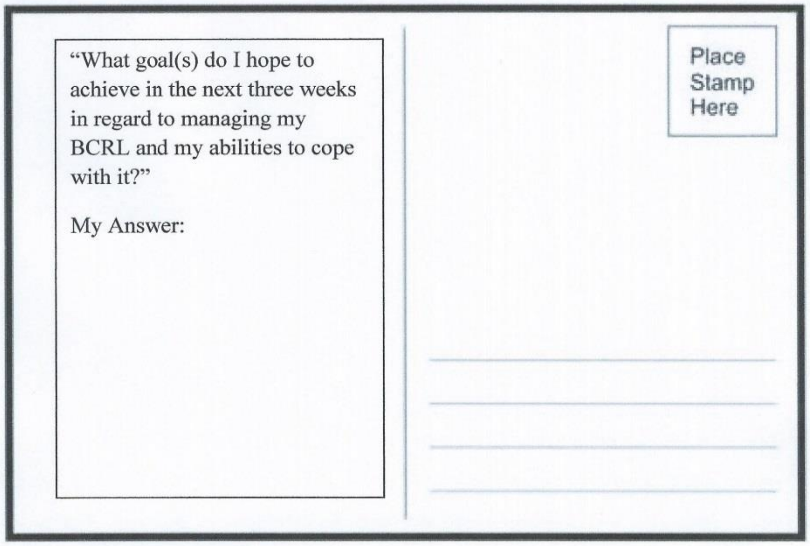
Constance Hickman
Office Manager

8420 Dorchester Road, Suite 203
North Charleston, SC 29420
Phone: 843.760.6064 | Fax: 843.760.6988
www.educareinc.com

Ellis Fischel Cancer Center breast cancer-related lymphedema original handout can be found at the Ellis Fischel Breast Center located at One Hospital Drive, Columbia, MO. 65212.

[redacted]

Appendix W – Post card



"What goal(s) do I hope to achieve in the next three weeks in regard to managing my BCRL and my abilities to cope with it?"

My Answer:

Place
Stamp
Here

Postcard template by www.craftideas4kids.com

Appendix X – Interactive Theatre Evaluations

MU Interactive Theatre Presentation

Program Evaluation

On a scale of 1 to 5, with 1 = Strongly Agree (SA), 2 = Agree (A), 3 = Neutral (N), 4 = Disagree (D), and 5 = Strongly Disagree (SD), please circle the number that best represents your response to the following:

1. The program helped in starting discussion about issues with breast cancer care.

   1------------------2------------------3------------------4-------------------5
   SA A N D SD

2. The use of interactive theatre could be helpful with other topics.

   1------------------2------------------3------------------4-------------------5
   SA A N D SD

3. The use of interactive theatre is an effective teaching strategy.

   1------------------2------------------3------------------4-------------------5
   SA A N D SD

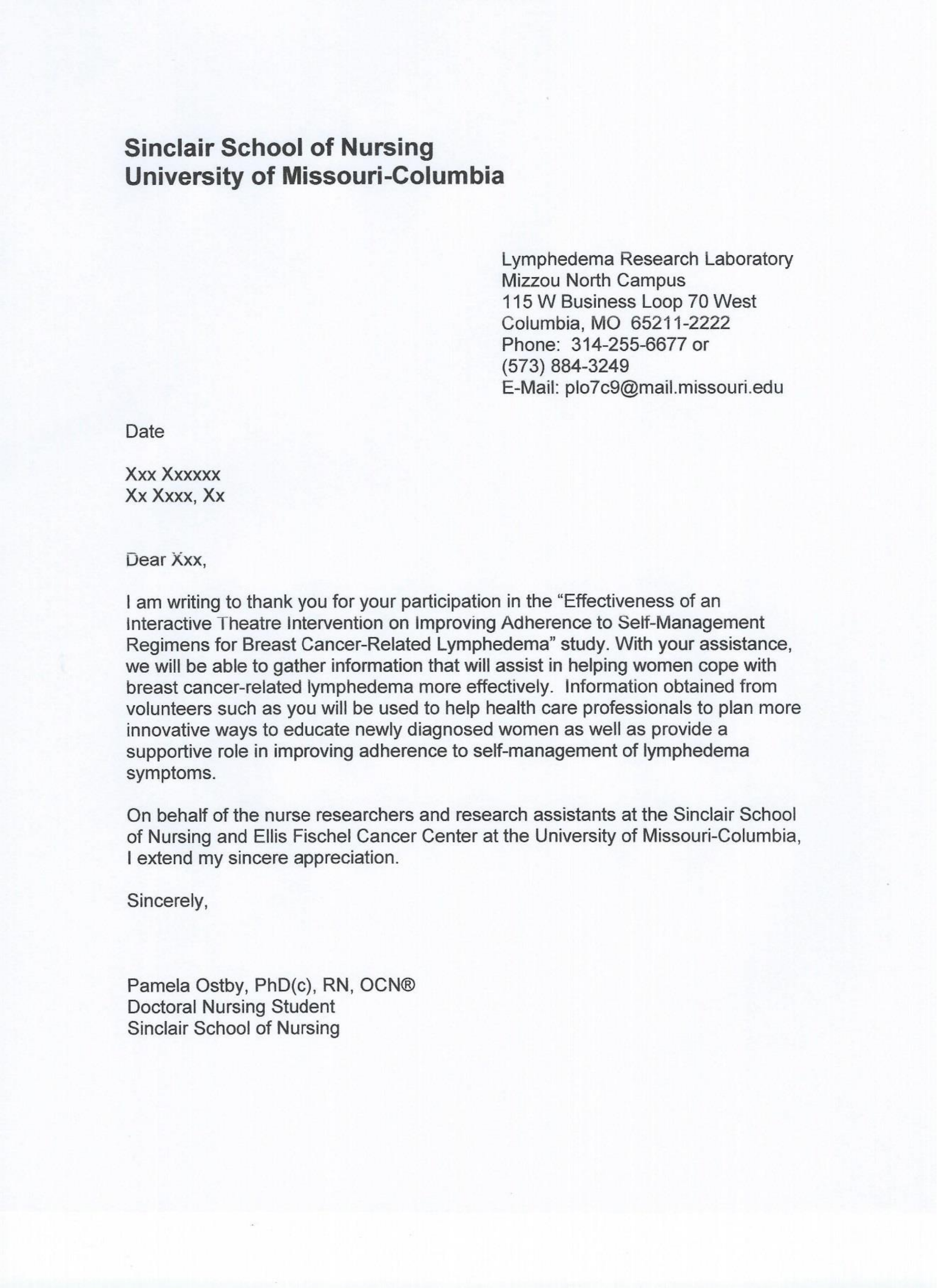
4. The program material was suitable for presentation in this format.

   1------------------2------------------3------------------4-------------------5
   SA A N D SD

5. What suggestions or comments do you have about this program?

Thank you for participating!

Appendix Y – Thank You



Sinclair School of Nursing
University of Missouri-Columbia

Lymphedema Research Laboratory
Mizzou North Campus
115 W Business Loop 70 West
Columbia, MO 65211-2222
Phone: 314-255-6677 or
(573) 884-3249
E-Mail: plo7c9@mail.missouri.edu

Date

Xxx Xxxxxx
Xx Xxxx, Xx

Dear Xxx,

I am writing to thank you for your participation in the "Effectiveness of an Interactive Theatre Intervention on Improving Adherence to Self-Management Regimens for Breast Cancer-Related Lymphedema" study. With your assistance, we will be able to gather information that will assist in helping women cope with breast cancer-related lymphedema more effectively. Information obtained from volunteers such as you will be used to help health care professionals to plan more innovative ways to educate newly diagnosed women as well as provide a supportive role in improving adherence to self-management of lymphedema symptoms.

On behalf of the nurse researchers and research assistants at the Sinclair School of Nursing and Ellis Fischel Cancer Center at the University of Missouri-Columbia, I extend my sincere appreciation.

Sincerely,

Pamela Ostby, PhD(c), RN, OCN®
Doctoral Nursing Student
Sinclair School of Nursing

VITA

Pamela Lynne Ostby was born in Columbus, Ohio, where she lived until 1964, when her family relocated to St. Louis, Missouri. She graduated from de Paul School of Nursing in 1977 and worked as a Medical-Surgical nurse until 1980. Moving to Kansas City, Missouri, she worked in Pediatric ICU at KU Medical Center for one year and at St. Luke’s Health Center where she was charge nurse for an ENT surgical unit. Pam was married in 1982 and moved to Dallas and Houston, Texas, and Troy, Michigan, where she worked in urgent care and OB/GYN/fertility medicine. In 1987, Pam and her husband moved back to Florissant, Missouri, and she became an oncology-certified nurse. Working in both an office and hospital setting, Pam moved to the hospital full-time so she could pursue her education. She graduated in 1992 with a BSN from Maryville University and an MSN(R) in 1996 from Saint Louis University. She managed the Cancer Center, Cancer Registry, Massage Therapy, Fertility Services, and the Outpatient Infusion Center at Mercy Medical Center until 2000, when she accepted an administrative position. Pam had always wanted to teach and made a change to become adjunct faculty for the next seven years at Maryville University and the following two years at Barnes-Jewish Goldfarb College of Nursing as an Associate Professor. In addition, she began training and working as an actress in television/film. In 2012, she returned to school at MU Sinclair School of Nursing to pursue a PhD in Nursing. She currently works part-time developing web-based patient education materials and casework with Sandberg, Phoenix, & von Gontard as an expert nurse witness. She will graduate in 2016, at which time she will pursue post-doctoral opportunities.