Women's Self-management of Arm Morbidity after Breast Cancer: A Secondary Data Analysis

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Thesis Abstract

Background: Arm morbidity continues to impact the lives of many breast cancer survivors long after acute treatments are completed. The most debilitating symptoms of arm morbidity are pain, lymphedema and limitation with range of motion (ROM). As a chronic condition, management of arm morbidity symptoms requires survivors to engage in self-management practices that alleviate symptoms.

Objective: To explore self-management practices performed by breast cancer survivors, and the treatments women receive from healthcare practitioners in managing symptoms of arm morbidity.

Methods: A secondary analysis of quantitative and qualitative data was undertaken. A descriptive correlational design was used to analyze data from breast cancer survivors (N = 740). Logistic regression identified variables related to self-management that were associated with pain, lymphedema and ROM limitations. A descriptive qualitative design was used to analyze data from a subset of participants (n = 40). Inductive content analysis approach was applied to develop codes, categories and themes related to how women self-manage arm morbidity symptoms and the treatments they received from healthcare providers to manage their arm morbidity.

Results: Participants reported ongoing symptoms of pain (24%), lymphedema (21%), and range of motion limitation (34%) 30 to 36 months post-surgery. Pain was associated with experiencing swelling, taking pain medications, and discussing treatments for pain. Lymphedema was associated with swelling and receiving treatment for pain. ROM limitations were associated with swelling, receiving treatment for pain and taking pain medication. Two overarching qualitative

themes emerged: 1) physical symptoms self-management, and 2) psychosocial self-management of uncertainty. Themes for treatments options included: rehabilitation and taking medications. **Conclusion:** Findings highlight that women living with symptoms of arm morbidity require ongoing monitoring and support for self-management, and there is a need for multidisciplinary approaches. Self-management practices reported are in line with the current lymphedema guidelines, however, the complexities associated with self-management practices can be burdensome to women. Chronic pain and ROM limitation necessitates further investigation to understand their cause and develop management strategies. Oncology nurses are well positioned to implement survivorship care plans that address survivorship needs with multidisciplinary teams and primary healthcare practitioners when women with breast cancer transition from acute cancer care to home. Future research is needed to provide an in depth understanding of self-management of arm morbidity in breast cancer survivors.

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Dedication

To our son Samuel who is a source of happiness beyond measure.

Your hugs and kisses are uplifting. We love you buddy!

Table of Contents

List of Tables

List of Figures

List of Abbreviations

ADL	Activities of Daily Living
APN	Advanced Practice Nurse
ALND	Axillary Lymph Node Dissection
BCS	Breast Cancer Survivors
BrCa	Breast Cancer
CCO	Cancer Care Ontario
CDT	Complex Decongestive Therapy
CI	Confidence Interval
GP	General Practitioner
HCP	Healthcare Practitioner
LE	Lymphedema
MD	Medical Doctor
MLD	Manual Lymphatic Drainage
OT	Occupation Therapist
OR	Odds Ratio
PT	Physiotherapist
RCT	Randomized Control Trial
ROM	Range of Motion
SCP	Survivor Care Plan
SLND	Sentinel Lymph Node Dissection

Chapter 1: Introduction

Introduction

1.1 Background

Cancer is the leading cause of death in Canada, impacting the lives of nearly half of all Canadians (Canadian Cancer Statistics, 2015). Cancer is considered a chronic disease, however, medical advancement in cancer treatments has contributed to increasing survival rate (Ridner, Sinclair, Deng, Bonner, Kidd & Dietrich, 2012). Although, many cancer survivors continue to live a productive and rewarding life, a cancer diagnosis presents many challenges, even years after the disease itself has been treated (Canadian Cancer Statistics, 2015). With regard to gender differences, breast cancer (BrCa) is the most common cancer in Canadian women, estimated at 25,000 new cases of BrCa every year (Canadian Cancer Society, 2015). Fortunately, medical advancement has led to better disease management, leading to the current 88% survival rate for BrCa (Canadian Cancer Society, 2015). However, curative treatments (including surgery, chemotherapy, radiation and hormone replacements) are associated with short and long term side effects that may present months or years after completion of acute treatments (Hack et al., 2010; Thomas-MacLean et al., 2010).

1.2 Impact of Acute Breast Cancer Treatments

Breast cancer survivors (BCS) encounter a wide range of potential side effects as a result of the cancer itself and/or cancer treatments (Ridner et al., 2012). Increasing numbers of BCS express the need for ongoing monitoring for early detection of potential side effects during survivorship. One identified concern, is arm morbidity resulting from acute BrCa treatments (Thomas-MacLean et al., 2010). BrCa related arm morbidity is a chronic condition that encompasses symptoms of pain, lymphedema and range of motion (ROM) limitation (Hack et al., 2010; Thomas-MacLean et al., 2010). Arm morbidity has been linked to disability and severe

limitation in functional life. Disability associated with arm morbidity often interferes with activities of daily living, causing devastating limitations for BCS (Ridner et al., 2012; Thomas-MacLean et al., 2010).

Arm morbidity, in the form of lymphedema, is one of the most debilitating complications of treatments affecting BCS (Towers, Carnevale & Baker, 2008). Lymphedema is characterized by accumulation of protein-rich fluids in the interstitial space leading to swelling, skin alterations and functional impairment in the arm or upper body (Hayes et al., 2012). Lymphedema is most often under-recognized and undertreated, (Canadian Lymphedema Framework, 2009; Towers et al., 2008), and contributes to long-term physical, psychological, and social problems in many BCS (Nesvold, Reinertsen, Fossa, & Dahl, 2011). Data on the prevalence of BrCa related lymphedema indicates that 6% to 80% of BCS experience lymphedema (Hayes et al., 2012)

In addition to lymphedema, arm morbidity encompasses pain and ROM limitation (Thomas-MacLean et al., 2010). These symptoms can present at any point during treatments or months to years after acute treatments (Nesvold et al., 2011). Living with symptoms of arm morbidity makes it challenging for BCS to resume normal activities, paid work and participate in physical and leisure activities (Neyt & Albercht, 2006; Miedema et al., 2008; Quinlan et al., 2008 & Thomas-MacLean et al., 2005, 2008). Arm morbidity in BCS has been linked to poor overall quality of life (Nesvold et al., 2011; Thomas-MacLean, Hack, Kwan, Towers, Miedema & Tilley, 2008).

In the last few decades, an increase in publications on BrCa explored topics related to diet, exercise, stress, and access to health care, amongst other issues. For instance, a systematic review on the effects of exercise on BrCa patients and BCS concluded that exercise is an important factor in improving fatigue, cardiorespiratory fitness, physical functioning and overall

quality of life (McNeely et al., 2006). Another systematic review exploring treatment intervention for managing BrCa related lymphedema, reported that compression garments and compression bandaging are effective in reducing arm volume in BCS living with lymphedema (McNeely, Peddle, Yurick, Dayes & Mackey, 2011). Despite the increase in BrCa research, there are gaps that remain on what is known about how women self-manage the symptoms of arm morbidity, and what healthcare practitioners (HCP) communicate to women about how to self-manage their arm morbidity. This thesis strives to provide new insight on self-management of arm morbidity and the treatments women receive from HCP to help them manage their symptoms of arm morbidity.

In this thesis, self-management is perceived as "the day-to-day tasks an individual must undertake to control or reduce the impact of disease on physical health status. At-home self-management tasks and strategies are undertaken with the collaboration and guidance of the individual's physician and other health care providers" including nurses. (Clark, Becker, Janz, Lorig, Rakowski, & Anderson, 1991, p. 5). Supporting people to self-manage is a key component of effective chronic disease management (Clark, 2003). Self-management support is more than patient education and includes the collaboration of the individual and their HCPs to increase individual's skills and confidence in how to manage their symptoms and health problems (Clark 2003). The ongoing collaboration involves "regular assessment of progress and problems, goal setting, and problem-solving support" (Adams, Greiner, and Corrigan, 2004, p. 57). Self-management support is facilitated by effective communication and guidance from HCPs to empower patients to understand and take a more active role in managing their condition and improving their health outcomes (Coleman & Newton, 2005; Lorig & Holman, 2003; McCorkle et., 2011).

1.3 Thesis Design and Objectives

Despite well-documented effects of arm morbidity in BCS (Nesvold et al., 2011; Thomas-MacLean et al., 2005; 2008; 2010, Ridner et al., 2012, Towers et al., 2008), little is known about what women do for themselves, to self-manage symptoms of pain, lymphedema and ROM limitation after acute BrCa treatments. Therefore, to examine women's experiences with self-management of arm morbidity, a secondary data analysis design was undertaken. This study utilized data from a longitudinal study that followed participant (N =740) over a 5-year period (Thomas-MacLean et al., 2008; 2010). Objectives of this secondary data analysis study are:

1. To identify the relationship between self-management practices and arm morbidity symptoms of pain, lymphedema and ROM limitation experienced at three points in time;
2. To understand how women self-manage arm morbidity after breast cancer treatment;
3. To explore the treatments women receive from their healthcare practitioners to assist them manage their symptoms of arm morbidity

1.4 Theoretical Framework

This study is theoretically informed by the symptom management model (SMM), which aims to facilitate symptom management in chronic conditions (Dobbs et al., 2001). The SMM is used to contextualize self-management of arm morbidity in BCS in this study, and it hypothesizes that effective management of a chronic symptom requires ongoing evaluation of the symptom experience, symptom management strategies, and symptom outcomes (Dobbs et al., 2001).). In this study, the "symptom experience" as described by Dobbs et al (2001) guided selection of variables for self-management. The symptom experience is comprised of three parts: 1) perception of symptoms, 2) evaluation of symptoms and 3) response to symptoms. The model

explains that an individual's perception of their symptoms (i.e. noticing changes in the usual or typical way one feels of behaves), how they evaluate those symptoms (i.e. making a judgement about symptoms), and how they respond to their symptoms (i.e. the behaviours they make that are directly associated with the perception and evaluation of their symptoms) ultimately shapes their overall symptom experience which is integral to the symptom management strategies chosen when self managing a chronic condition (Dobbs et al., 2001). This triad of behaviors in the symptom experience (perception, evaluation, response) guided the selection of variables for self-management in this study.

Theoretical selection of independent variables was undertaken because individuals with chronic illnesses such as arm morbidity from breast cancer, may require ongoing self-management that involve self-monitoring and self-evaluation (McCorkle et al., 2011). The variables were ordered from the least clinically invasive to the most clinically invasive, i.e. change in leisure activities, an interaction and dialogue with a HCP about the symptoms, and treatment by HCP to assist with management of the symptoms. It was theorized that when self-managing symptoms of arm morbidity, a breast cancer survivor (BCS) would first perceive a change in their leisure activities, then engages in dialogue with a HCP if their symptoms weren't adequately managed, and finally receive treatment from a HCP to assist with managing their arm morbidity symptoms. In this sense, having dialogue with a HCP and receiving treatments are part of a self-management strategy that breast cancer survivors engage in to manage their symptoms of arm morbidity.

1.5 Thesis Structure

The next chapter is a literature review on symptoms of arm morbidity and management strategies practiced to manage the condition (Chapter 2). The study design and methodology are

detailed in Chapter 3, followed by qualitative and quantitative results (Chapter 4). The last chapter (Chapter 5) discusses study findings and implications for nursing practice including the role of advanced practice nurses, nursing education and nursing research.

1.6 References

Adams, K., Greiner, A. C., Corrigan, J. M. (2004). Institute of Medicine (USA) Committee on the Crossing the Quality Chasm: Next Steps Toward a New Health Care System. Washington (DC): National Academies Press.

Canadian Cancer Statistics (2015). Special topic: Predictions of the future burden of cancer in Canada. Canadian Cancer Society's Advisory Committee on Cancer Statistics. Toronto, ON: Canadian Cancer Society; 2015.

Cancer Care Ontario (2015). Ontario Breast Screening Program Information for Healthcare Providers. Retrieved from: https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=349897

Canadian Lymphedema Framework (2010). Canadian Lymphedema Framework Annual Report, Projects and Activities. Retrieved March 2015 http://www.canadalymph.ca/Annual_Report_2011.pdf

Clark, N.M. (2003). Management of chronic disease by patients. *Annual Review of Public Health*, *24*, 289-313.

Clark, N., Becker, M., Janz, N., Lorig, K., Rakowski, W., Anderson, L. (1991). Self-Management of Chronic Disease by Older Adults. *Journal of Aging and Health 3*(1), 3-27.

Coleman, M.T. & Newton, K. S. (2005). Supporting self-management in patients with chronic illness. *American Family Physician, 72*(8), 1503–1510.

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., . . . Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, *33*(5), 668-676. doi:10.1046/j.1365-2648.2001.01697.x

Hack, T. F., Kwan, W. B., Thomas-MacLean, R., Towers, A., Miedema, B., Tilley, A., & Chateau, D. (2010). Predictors of arm morbidity following breast cancer surgery. *Psycho-Oncology, 19*(11), 1205-1212. doi:10.1002/pon.1685.

Hayes, S. C., Johansson, K., Stout, N. L., Prosnitz, R., Armer, J. M., Gabram, S., & Schmitz, K. H. (2012). Upper-body morbidity after breast cancer: incidence and evidence for evaluation, prevention, and management within a prospective surveillance model of care. *Cancer*, *118*(8), 2237–2249. https://doi.org/10.1002/cncr.27467

Lorig, K. R., Holman, H. (2003). Self-management education: history, definition, outcomes, and mechanisms. Annals of Behavioral Medicine, 26, 1–7.

McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L., Lorig, K., & Wagner, E. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians, 61* (1), 50–62. doi:10.3322/caac.20093.

McNeely, M. L., Peddle, C. J., Yurick, J. L., Dayes, I. S., & Mackey, J. R. (2011). Conservative and dietary interventions for cancer-related lymphedema: A systematic review and meta-analysis. *Cancer, 117,* 1136–1148. doi:10.1002/cncr.25513

McNeely, M. L., Campbell, K. L., Rowe, B. H., Klassen, T. P., Mackey, J. R., & Courneya, K. S. (2006). Effects of exercise on breast cancer patients and survivors: a systematic review and meta-analysis**.** *Canadian Medical Association Journal*, *175*(1), 34-41.

Nesvold, I. L., Reinertsen, K.V., Fossa, S. D., & Dahl, A. A. (2011) The relation between arm/shoulder problems and quality of life in breast cancer survivors: a cross-sectional and longitudinal study. *Journal of Cancer Survivorship*, *5*(1), 62–72. doi: 10.1007/s11764-010-0156-4.

Neyt, M., & Albrecht, J. (2006). The long-term evolution of quality of life for disease-free breast cancer survivors: a comparative study in Belgium. *Journal of Psychosocial Oncology 24*(3), 89-123.

Ridner, S. H., Sinclair, V., Deng, J., Bonner, C. M., Kidd, N., & Dietrich, M. S. (2012). Breast cancer survivors with lymphedema: Glimpses of their daily lives. (CNE article)(clinical report). *Clinical Journal of Oncology Nursing, 16*(6), 609.

Thomas-MacLean, R. (2005). Beyond dichotomies of health and illness: Life after breast cancer. *Nursing Inquiry, 12*(3), 200-209. doi:10.1111/j.1440-1800.2005.00268.x.

Thomas-Maclean, R., Hack, T., Kwan, W., Towers, A., Miedema, B., & Tilley, A. (2008). Arm morbidity and disability after breast cancer: New directions for care. *Oncology Nursing Forum, 35*(1), 65. doi:10.1188/08.ONF.65-71.

Thomas-MacLean R., Miedema B., & Tatemichi S.R. (2005). Breast cancer-related lymphedema: Women's experiences with an underestimated condition. *Canadian Family Physician Médecin de Famille Canadien* (51) 206–208.

Thomas-Maclean, R. Spriggs, P., Quinlan, E., Towers, A., Hack, T., Tatemichi, S., Miedema, B., Kwan, W. & Andrea Tilley, A. (2010). Arm morbidity and disability in Canada: Reporting the current status from Canada. *Journal of Lymphoedema*, 5(2), 33-38.

Thomas-MacLean, R., Towers, A., Quinlan, E., Hack, H., Winkle Kwan, W., Miedema, B. & Graham, P. (2009). “This is a kind of betrayal”: A qualitative study of disability after breast cancer. *Current Oncology*, 16(3), 26-32.

Towers, A., Carnevale, F. A., & Baker, M. E. (2008). The psychosocial effects of cancer-related lymphedema. *Journal of Palliative Care, 24*(3), 134-143.

Chapter 2: Literature Review

Literature Review

2.1 Search Strategy

The aim of the literature review was to identify published research studies on self-management of arm morbidity in breast cancer survivors. A search of three electronic databases was conducted: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline (Ovid) and PubMed. Initially, a broad search in each database started with the key concepts “arm morbidity” “self management” and “breast cancer survivors” yielded limited results. A more comprehensive search was then conducted using different words related to each key term, and each word was separated by the word “OR”. For example, for arm morbidity, terms used in CINAHL were arm morbidity, arm injuries, arm exercises, shoulder pain, lymphedema and shoulder range of motion. For self-management, key search terms were self-management, self-care, and self-assessment. For breast cancer survivors, terms used were breast cancer, breast neoplasms and cancer survivors. Each group of words was then combined with the word “AND” to combine the three main concepts. Subject major headings were set to capture the following terms: breast neoplasms, survivors, exercise, lymphedema, therapeutic exercise, self-care, symptoms, and health behavior. Similar searches were also conducted in Medline and PubMed (See Appendix A for *Search Strategy*).

No time parameters were placed on the search, as this area of research is underdeveloped. However, limitations were put in place to retrieve peer-reviewed articles, research conducted on human subjects only and published in the English language. Inclusion criteria were: studies in breast cancer survivors (BCS) living with breast cancer (BrCa) related arm problems, studies that identified arm morbidity or disability in terms of lymphedema, pain, and range of motion (ROM) limitation, and studies that discussed management of symptoms related to acute BrCa treatments.

Articles were excluded if they discussed other types of cancers, did not address arm morbidity after BrCa treatment, discussed primary lymphedema which is associated with other conditions other than BrCa, or reported pain and ROM limitation in other chronic conditions other than BrCa.

The search yielded 116 articles in CINAHL, 84 articles in PubMed and 71 articles in Medline (Ovid). Duplicates were removed and the remaining 127 articles were assessed for relevance by reading the title and its abstract. Using the inclusion and exclusion criteria to exclude those articles that were not relevant to this review, 22 articles met the inclusion criteria. Additionally, reference lists of systematic reviews were checked and revealed 13 ancestry articles pertinent to the topic as deemed by the writer. Finally, a hand search in Google scholar yielded 3 relevant articles that did not come up during database search. The search also included government agencies and publications by key informants in the area of study. This search yielded recent government reports on breast cancer. Specific websites searched included the International Lymphedema Framework, Canadian Cancer Statistics, and Cancer Care Ontario.

The results of this literature review are discussed with respect to the acute BrCa treatments and incidence of arm morbidity, symptoms of arm morbidity experienced by BCS, and management strategies recommended to manage symptoms of pain, lymphedema and range of motion limitation.

2.2 Breast Cancer Treatments and Incidence of Arm Morbidity

In Canada, approximately 25,000 new cases of BrCa are diagnosed every year, however medical advancement has contributed to the current 88% survival rate for breast cancer (Canadian Cancer Society, 2015). After diagnosis, BrCa treatments include surgery, radiation, chemotherapy and hormonal therapy. Surgery is usually the first line of treatment, and surgical

options include lumpectomy, mastectomy and lymph node removal. Lumpectomy is the removal of the tumour only and a small amount of surrounding tissue, while mastectomy is the removal of all of the breast tissue (Cancer Care Ontario, 2015). Based on the stage of the cancer, there may be a necessity to remove lymph nodes around the breast tissue and under the arm (Hack et al., 2010). Lymph node removal, or axillary lymph node dissection (ALND), can take place during lumpectomy or mastectomy (Mansel et al., 2006). However, in some cases, a less-invasive option called sentinel lymph node dissection (SLND) is performed; this decision is usually based on the severity of the cancer (Mansel et al., 2006; Sclafani & Baron, 2008).

Radiation is the use of high-energy x-ray to kill cancer cells. Radiation therapy usually consists of several treatments given daily for a period of time (Cancer Care Ontario, 2015). Chemotherapy is the use of drugs to destroy cancer cells. Chemotherapy drugs are usually given in the vein for a specific period of time (Cancer Care Ontario, 2015). Hormone replacement therapy is the use of medication that block specific hormones that fuel cancer cell growth (Cancer Care Ontario, 2015). Often times, treatment decisions involve the BrCa patient and a team of healthcare practitioners.

Following acute BrCa treatments, women are referred back to their primary general practitioner (GP), with occasional access to the oncology team for follow up appointments (Shaw & Thomas, 2011). However, as many as two-thirds of the GPs (n = 12) reported that they did not make it a habit practice to ask patients if they had any arm morbidity problems, or if women had any related concerns (Shaw & Thomas, 2011). Evidence reporting the incidents of arm morbidity indicates that 10% to 64% of BCS live with arm or upper body morbidity symptoms, 6 months to 3 years after acute BrCa treatments (Hayes et al., 2012).

2.3 Symptoms of Arm Morbidity Experienced by Breast Cancer Survivors

Arm morbidity after acute BrCa treatments continue to impact the lives of many BCS (Thomas MacLean et al., 2008). Arm morbidity is typically characterized by pain, impaired sensory and motor functioning of the hand, arm, breast, and shoulder, of the affected side (Hayes et al., 2012; Thomas MacLean et al., 2008). Further disability can present in the form of joint weakness, tightness, poor ROM, nerve damage, poor muscle recruitment, numbness, and/or swelling of the shoulder, arm, and breast of the affected side (Hayes et al., 2012). These impairments impact physical functioning and quality of life of BCS (Nesvold et al., 2011; Thomas MacLean et al., 2010). The most prevalent symptoms of arm morbidity are lymphedema, pain and ROM limitation; they are further explored. These three are elaborated on because they are most distressing and problematic symptoms, forcing many BCS to restructure their day-to-day activities (Miedema et al., 2008; Quinlan et al., 2009;Thomas- MacLean et al., 2008, 2009, 2010).

2.3.1 Lymphedema. Lymphedema is the accumulation of protein-rich fluid in the interstitial spaces (Cheifetz & Haley, 2010). Lymphedema develops from an obstruction or damage to small glands called lymph nodes, in the lymphatic system. When lymph nodes are removed during surgical procedures, lymphatic fluid collects in the surrounding tissues, causing swelling (Shah & Vicini, 2011). This swelling is what is known as lymphedema (Thomas-MacLean et al., 2008, 2010). Lymphedema can also occur as a result of radiation to the axilla, but it is mainly recognized as a consequence of surgical procedures such as ALND (Hack et al., 2010; Shah & Vicini, 2011). Lymphedema can occur at any time following acute BrCa treatments, contributing to arm morbidity (Hayes et al., 2012), and its complications can be long lasting (Hack et al., 2010; Thomas-Maclean, 2004).

The negative impacts are disabling, as lymphedema is often associated with feelings of discomfort, heaviness, functional limitation, disfigurement and psychological distress (Hack et al., 2010; Thomas-Maclean, 2004; Thomas & Hamilton, 2014). It is of importance to note that, there are several risk factors that contribute to the development and duration of secondary lymphedema. Some of which include type of surgery, increased number of lymph nodes removed, presence of post-operative infection, and a higher body mass index (Armer, 2010; Hack et al., 2010; Mansel et al., 2006; Thomas- MacLean et al., 2008).

The incidence of BrCa related lymphedema varies depending on the time of assessment and measurement tools used (Engel et al., 2003; Hayes et al., 2012). The risk is estimated at 2% when lumpectomy has been carried out, and the risk increases to 65% when more extensive surgical procedures (e.g. ALND) have been performed (Shah & Vicini, 2011). Some longitudinal studies have reported lymphedema in 12% (n =347) and 40% (n = 96) of participants 6 to 12 months post surgery (Kärki, Simonen, Mälkiä, & Selfe, 2005; Thomas-MacLean et al., 2008), and 22 % (n = 255) of participants 36 months post surgery (Nesvold, Reinertsen, Fosså & Dahl, 2011). These findings suggest that there is a large window of time following surgery, in which the development of lymphedema occurs, which presents a significant challenge to women who have undergone BrCa surgery.

Lymphedema is associated with physical and psychological symptoms, affecting BCS' quality of life (Nesvold, Reinertsen, Fosså & Dahl, 2011). Physical symptoms experienced are heaviness, tightness, numbness, and psychological symptoms are insomnia, decreased self-esteem, body image anxieties and depression (Nesvold et al., 2011; Segen et al., 2009). A qualitative study exploring BCS' embodiment changes after acute treatments, reported that BCS described lymphedema as feelings of numbness, heaviness, tingling, aching, seeping fluid, hard,

tight, and burning (Thomas-MacLean, 2005). These physical symptoms constantly remind BCS that they are eternally different, leading to feelings of loss, vulnerability and disability (Thomas-MacLean et al., 2005; Thomas & Hamilton, 2014). The combination of physical and psychological symptoms during survivorship, further impacts BCS' quality of life negatively (Hayes et al., 2012; Hodgson et al., 2011; Nesvold et al., 2011; Segen et al., 2009 & Thomas-MacLean, 2005).

2.3.2 Pain. Pain can occur and persist at any time during acute treatment and anytime thereafter (Langford et al., 2014; Thomas-Maclean et al., 2008). Even though pain has received significant attention in different acute and chronic illnesses, the literature shows variation in the prevalence of pain in BCS (Hayes et al., 2012; Langford et al., 2014). In BCS, pain contributed to poor arm and shoulder mobility and persisted 6 to 12 months after surgery (Karki, Simonen, Mälkiä, & Selfe, 2005). Pain significantly interfered with upper body mobility and daily functioning, and was significantly associated with poor quality of life (Langford et al., 2014; Nesvold at al., 2011).

A longitudinal study conducted to assess arm and shoulder problems 6 to 36 months after surgery, reported that 37% of BCS (n = 255) reported having arm and shoulder pain at the time of the study (Nesvold et al., 2011). The same study reports that pain was associated with restricted mobility in 16% of the participants 36 months post surgery (Nesvold et al., 2011). Findings are consistent with a prospective longitudinal study, which reported that 35% of women (n = 398) experienced persistent levels of moderate arm/shoulder pain in the first six months following breast cancer surgery (Miaskowski et al., 2014). Persistent arm pain contributed to arm and shoulder movement limitations, leading to long-term impairments of the shoulder joint (Langford et al., 2014).

Another study reported that 39% (*n* = 347) of participants reported pain 6 to12 months post surgery, and associated feelings were tenderness, aching, discomforting or distressing. The presence of pain was highly correlated with problems at work and performing recreational activities that involve arm motion (Thomas-MacLean et al., 2008). Participants also reported limitations in performing heavy household chores, gardening and doing yard work, making a bed, carrying a shopping bag or briefcase, carrying an object heavier than 10 lbs., and putting on a pullover sweater (Thomas-MacLean et al., 2008).

Evidence regarding the occurrence of pain in BCS is prevalent in other studies. Neuropathic pain was significantly associated with acute BrCa treatments (Reyes-Gibby et al., 2010); pain was significantly associated with disability after lymph node dissection (Hack et al., 2010), and pain was reported as a main predictor of recreational difficulties 6 to 12 months after BrCa surgery (Miedema et al., 2011). Evidently, arm morbidity in the form of pain is distressing and contributes to impairments that require evaluation and ongoing management during cancer survivorship.

2.3.3 Range of Motion Limitation. Mobility of the shoulder joint contributes to a large proportion of everyday activities. Any injury to the shoulder and surrounding area contributes to difficulties with daily functioning. Arm morbidity in the form of range of motion (ROM) limitation can occur any time after acute BrCa treatments, affecting productivity of paid work and activities of daily living (ADL) (Thomas-MacLean, Miedema & Tetemichi, 2005; Quinlan et al., 2009). Such impairments can occur during survivorship, contributing to difficulties returning to normal functional (Thomas- MacLean et al., 2008). Some limitations identified occur when BCS are performing personal care, lifting, carrying, reaching, and sleeping (Kärki, Simonen, Mälkiä, & Selfe, 2005). Kärki et al. report that 61.5% and 56.3% (*n* = 96) of women experienced

ROM limitations 6 and 12 months post surgery, respectively (2005). Thomas-MacLean et al. reported that 59% and 46% (n = 347) of women experienced restricted shoulder abduction and restricted external rotation, respectively (Thomas-MacLean et al. 2008).

A study intended to determine difficulties experienced with recreational activities due to arm morbidity reported that that 8.2% of women (n = 574) had difficulty participating in recreational activities that involved "little effort" (e.g. playing cards), 48.5% reported having difficulties performing activities that required "some force or impact" (e.g. playing golf or tennis), and 44% reported difficulty performing activities that involved "moving their arm freely" (e.g. playing Frisbee), 6 to 12 months after surgery (Miedema et al., 2008, p. 265). In terms of leisure activities such as swimming, cycling, sculpting and painting, 29% of women (n =169) reported experiencing a decrease in the level of participation in comparison to their performance before BrCa. When asked about the changes in the level of activities, 60% (n = 101) said, "they slowed down a bit, but have not stopped" (Miedema et al., 2008, p. 265).

Other researchers discuss the implications that ROM limitation has in BCS. Women reported difficulties making a bed, getting dressed, and carrying objects weighing 10lbs or more (Thomas-MacLean, 2004; 2005 & Towers, Carnevale, & Baker, 2008). A qualitative study reports that 12 out of 15 participants interviewed, mentioned that their day-to-day activities were altered (Thomas-MacLean, 2005). Participants identified difficulties with finding clothing that fit their swollen arms, and needing support for the affected arm while driving on long trips (Thomas-MacLean, 2005). This level of disability hampers more than ADLs, because it also restricts BCS' ability to re-integrate back into society at their pre-surgery level. It is reported that ROM limitation was significantly associated with poor quality of life in BCS (Nesvold et al.,

2011). Evidently, arm morbidity in the form of ROM limitation continues to impact the lives of BCS, and demands superior interventions to improve BCS overall quality of life.

2.4 Management of Arm Morbidity

BCS experience multiple symptoms and rarely do symptoms occur in isolation, however many clinical studies have largely focused on the treatment of individual symptoms (Fan, Filipczak & Chow, 2007). The presence of arm morbidity in BCS necessitates exploration of predictors of arm morbidity, interventions and evaluation of symptom outcomes. Arm morbidity encompasses multiple symptoms, and the presence of multiple symptoms in cancer patients is often referred to as a "symptom cluster" (Dodd et al., 2001). Therefore, understanding arm morbidity as a symptom cluster would improve management of symptoms of pain, lymphedema and ROM limitation.

Because no curative interventions exist for arm problems resulting from acute BrCa treatments (Brown et al., 2014; Towers, Carnevale, & Baker, 2008), arm morbidity remains a problem for BCS (Thomas-Maclean et al., 2008, 2010). Due to the complexity of this chronic condition, clinical guidelines for management focus on lifelong practices to manage lymphedema, pain and ROM limitation (Brown et al., 2014 & McCorkle et al., 2011). Practices such as complex decongestive therapy (CDT) which includes compression garments, bandaging, therapeutic exercise, lymphatic drainage, and thorough skin care, are some of the management modalities performed to manage arm morbidity (Brown et al., 2014; Cheifetz & Haley, 2010; Lymphoedema Framework, 2006 & Fu, Deng, & Armer, 2014).

2.4.1 Complex Decongestive Therapy. Complex decongestive therapy (CDT) is an intensive program that combines different interventions to manage arm morbidity. CDT includes bandaging, compression garments, manual lymphatic drainage, exercise, and self care (Cheifetz

& Haley, 2010; Fu, Deng, & Armer, 2014). Compression and bandaging techniques use short-stretch bandages around the swollen arm, to control arm swelling (Kang et al., 2012). The mechanism behind compression and bandaging is to create pressure that improves lymphatic flow, consequently decreasing arm lymphedema (Cheifetz & Haley, 2010; Kang et al., 2012).

A randomized control trial (RCT) involving 109 BCS with lymphedema, grouped them into CDT alone or CDT plus pneumatic compression therapy. After three months, CDT alone group showed a 16.9% arm volume reduction compared to 7.5% reduction with CDT plus pneumatic compression therapy (Haghighat et al., 2010). Another RCT randomized 95 BCS to manual lymph drainage (MLD) plus bandaging and compression garments or compression garments only, the finding reported that increased arm volume loss was reported with MLD plus bandaging and compression garments at a one-year follow-up (Dayes et al., 2013). Other RCTs have evaluated the comparative effectiveness of compression bandaging and compression garments; arm volume reduction with different bandage pressures; and comparison of low-stretch compression dressings and alginate semi-rigid bandages (Damstra & Partsch, 2009; Kasseroller & Brenner, 2010; King, Deveaux, White, & Rayson, 2012).

Conversely, some studies report little benefit from the use of compression garments and bandaging. A small RCT *(n* = 25) demonstrated no significant difference between arm volume reduction after two weeks among BCS who wore compression garments and bandaging in addition to MLD (King, Deveaux, White, & Rayson, 2012). Although, Damstra & Partsch (2009) evaluated bandage pressure among BCS with lymphedema (*n* = 36), and established no significant differences in arm volume reduction with different bandage pressure; their findings suggested that non-elastic multilayer compression bandages with low pressure (20–30 mmHg) were better tolerated and achieved the same amount of arm volume reduction as bandages

applied with higher pressure (44-58 mm Hg) in the first 24 hours. Another RCT randomized 61 BCS with lymphedema into low-stretch compression dressings or alginate semi-rigid bandages, and found no significant difference in arm volume reduction between the two groups, however participants in the semi-rigid bandage group had significantly better comfort (Kasseroller & Brenner, 2010).

A systematic review on interventions for cancer-related lymphedema concluded that moderate evidence supports the effectiveness of compression garments and bandaging in arm volume reduction. Although, the systematic review cautions about the quality of studies reviewed, findings suggest that compression bandaging and compression garments are beneficial, however, further RCTs are necessary with larger sample sizes (McNeely, Peddle, Yurick, Dayes & Mackey, 2011). Regardless of intervention, it is important to note that time, effort, and skill required for effective compression and bandaging, can be challenging for some individuals requiring the use of alternative methods (Fu, Deng, & Armer, 2014).

2.4.2 Exercise. As part of CDT, exercise plays a vital role in improving arm morbidity (Cheifetz & Haley, 2010). Therapeutic exercise programs aim to increase muscle strength, maximize upper extremity function, control swelling and restore arm and shoulder ROM (Lymphoedema Framework, 2006). Although best practice guidelines for lymphedema management established that exercise is considered a common rehabilitative intervention (Lymphoedema Framework, 2006), conflicting understandings continue to exist in practice (Fu, Deng, & Armer, 2014; Thomas-MacLean et al., 2008).

While there is agreement on the importance of exercise as an effective intervention in managing arm morbidity, the type, intensity, frequency, and duration of exercise remains unclear (Galantino & Stout, 2013). A contributing factor to the confusion, surrounding the role of

exercise, is the fact that different types of exercises vary depending on the CDT treatment plan. For example, active resistive exercises were included in CDT to reduce arm volume (Kim, Sim, Jeong, & Kim, 2010), whereas weight lifting exercises were used to increase strength and decrease body fat in BCS (Brown, Troxel & Schmitz, 2012), and yoga was used to improve physical and mental wellness (Thomas et al., 2014).

A study randomized 40 BCS into CDT with or without active resistive exercises to evaluate arm volume differences (Kim et al., 2010). Exercises included shoulder stretching, the use of dumbbells for 15 minutes, while wearing a compression stocking or multilayer bandage, supervised by physical therapists, five days per week for two weeks (Kim et al., 2010). The study reported that significant arm volume reduction was noted in BCS in the active resistive exercise group. Another RCT randomized 23 BCS into a home-based exercise plus self-care or self-care alone. The findings report significant arm volume reduction in the home-based exercise plus self-care than self-care alone after 26-week (Jeffs and Wiseman (2013). Additional benefits are reported by Park et al., who found lower incidences of lymphedema in women who exercised regularly, performed preventive self-care activities, and had received lymphedema education before acute BrCa treatments (Park, Lee, & Chung, 2008).

A systematic review of 24 RCTs in BCS with lymphedema yielded no evidence of negative effect of upper-extremity exercise on upper-limb lymphedema (McNeely et al., 2010). Additionally, another review of 10 studies concluded that resistance, aerobic, and other exercises were effective for lymphedema management (Kwan, Cohn, Armer, Stewart, & Cormier, 2011). The identified individual studies and systematic reviews taken together suggest that, exercise was not associated with an increase in arm volume in BCS, and may have helped improve lymphatic flow and shoulder mobility. It is important to know that exercise with supervision can

be safe for BCS, but recommendations should balance exercise benefits with harms (Fu, Deng, & Armer, 2014).

2.5 Clinical and Communication Limitations

2.5.1 Clinical Limitations. There is poor consensus among healthcare practitioners (HCP) on the appropriate diagnostic tools and treatment methods for arm morbidity (Towers, Carnevale, & Baker, 2008). This problem is largely due to a lack of consensus on symptom definitions and diagnostic tools used to measure am morbidity in clinical settings. Some clinicians measure lymphedema with volumetric calculations using circumferential measurements of both arms, others define lymphedema as: a limb circumference difference of 2 cm (Hack et al., 2010; Thomas-MacLean et al., 2008, 2010), a volume difference of ≥ 10% (Nesvold et al., 2011), a volume difference of > 5cm (Hayes, Janda, Cornish, Battistutta, & Newman, 2008), yet others use other methods such as bioimpedance spectroscopy and "water displacement, perometry, or circumferences with or without conversion of the measure of size to limb volume" (Hayes et al., 2012, p.2239). Although some methods can be used to detect non-pitting and pitting lymphedema, some methods may be insensitive to early changes in extracellular fluid (Hayes et al., 2012, p.2239).

Additionally, there are studies that have used self-reported questionnaires to assess participant's perception of arm morbidity symptoms. Some of the tools used capture different aspects of arm morbidity, such as Disability of the Arm, Shoulder and Hand (DASH) tool, the McGill Pain Questionnaire, the 6-item ID pain tool to detect neuropathic pain that result from chemotherapy treatments and Kwan's arm problem scale (Hack et al., 2010; Nesvold et al., 2011; Reyes-Gibby et al., 2010; Thomas-MacLean et al., 2008, 2010). Various self-report questionnaires are used to capture the perceived sensory changes as well as the presence and

intensity of related symptoms. Given the variations in available diagnostic tools, there are inconsistencies in the incidents and prevalence rates of arm morbidity and management strategies reported in the literature (Engel et al., 2003; Hayes et al., 2012).

2.5.2 Communication Limitations. Poor communication remains a complex challenge in cancer care (Thorne et al., 2009). Clear patient- provider communication is critical in management of many chronic illnesses, and it is as important in cancer management (Cancer Care Ontario [CCO], 2012). A guideline developed by CCO stated that, there is a need to individualize communication styles to meet patient preferences, and promote patient active participation in decision-making in cancer management (CCO, 2012). However, a study by Thorne and colleagues reported that 42% (n = 60) of participants had reported experiencing negative communication. Thorne et al. states that poor communication manifests in different ways including the quantity of information and failure to individualize information provided to cancer patients (Thorne et al., 2009).

Despite the evidence that promote effective patient-provider communication, many BCS living with arm morbidity are not always informed about treatment options available to manage symptoms experienced. A study aimed to chart the course of arm morbidity, found that 61% of women (n = 255) with complaints of pain, had not discussed treatment options with their primary care provider (Thomas-MacLean et al., 2008). When asked the reasoning behind not discussing treatment options, women expressed the idea that symptoms were “not that bad” (p. 69). Other reasons included: lack of awareness of available treatment options, perception that healthcare practitioner are over-worked, perceptions that symptoms would diminish over time, perception that symptoms were normal, and “an expectation that symptoms would abate if certain activities were ceased” (Thomas-MacLean et al., 2008, p. 69).

Another concern identified by BCS, is difficulty obtaining appropriate medical information (Towers, Carnevale, & Baker, 2008). BCS living with arm morbidity report difficulties obtaining appropriate information regarding management of symptoms. BCS report being frustrated by their healthcare provider's lack of "interest, awareness and knowledge" (Towers, Carnevale, & Baker, 2008, p. 136).

> *You have to go all over the place to get information… You get an answer from a specialist, "Ah no, I don't know how to treat that," or, "We don't do that anymore." And the other [specialist], "No, I don't think the decongestive therapy will help you." And [the lymphedema therapist] told me, "Yes, I think it can help you." So you say, you know, where's the error*? (Towers, Carnevale, & Baker, 2008, p.138).

This lack of information can be significantly challenging for those seeking medical advice during survivorship. One study revealed that while 50% (n = 60) of participants said that they would seek information from their healthcare providers, only 11% actually consulted their healthcare practitioners, and 49% consulted the Internet, family and friends for information (Clayton, Dudley & Musters, 2008). A longitudinal study following BCS for five years reported that communication was the second greatest predictor of quality of life in BrCa patients (Engel et al., 2003). Engel et al concluded that, if clinicians were aware of the prevalence and consequences of arm morbidity, they could give more information concerning early treatment and management of arm problems (2003).

Effective patient-provider communication provides BCS with realistic expectations during survivorship and empowers them in managing symptoms experienced. The evidence suggests that, there is still a need to enhance ways in which arm morbidity is understood (Towers, Carnevale, & Baker, 2008). Furthermore, it is important to develop effective strategies that promote consistency in managing arm morbidity.

2.6 Summary of the Literature Review

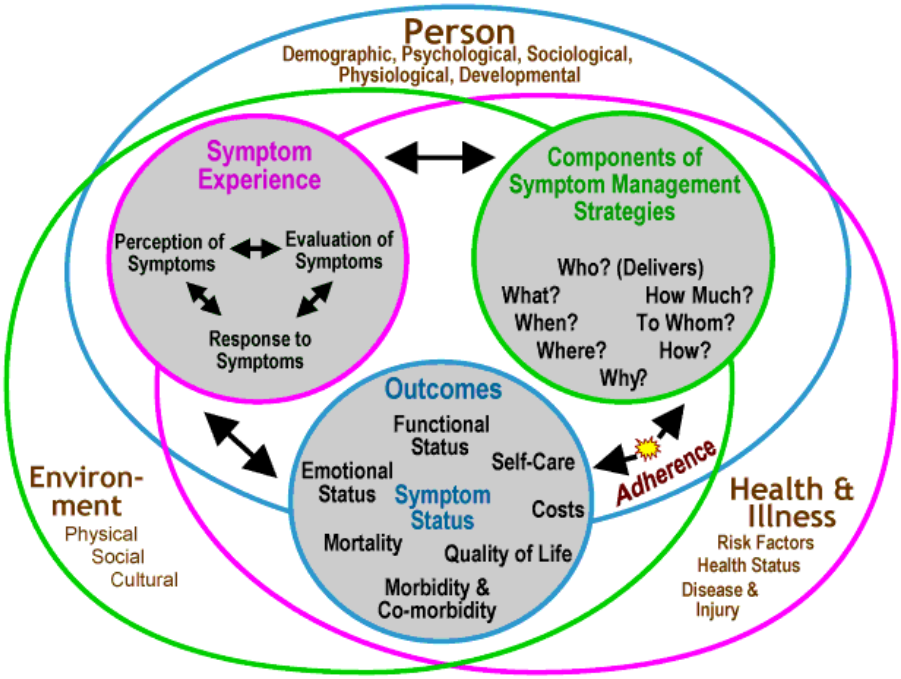
In summary, this literature review has shown that arm morbidity significantly impacts BCS, affecting their quality of life months to years after acute BrCa treatments (Sagen et al., 2009). Symptoms of lymphedema, pain and ROM limitation are debilitating and have negative outcomes affecting everyday functioning for BCS (Nesvold et al., 2011). Lymphedema is the most recognized form of arm morbidity; however it remains under diagnosed and undertreated (Thomas-MacLean et al., 2010).

Arm morbidity management strategies include complex decongestive therapy such as compression garments, bandaging, and lymphatic drainage and therapeutic exercises (Lymphoedema Framework, 2006). Although these interventions are effective, the benefit of exercise is inconsistent (Fu, Deng, & Armer, 2014). The current limitations in arm morbidity management include varying clinical diagnostic measures and poor communication between BCS and their healthcare practitioners. Therefore, with the current conflicting ideas, there is a need to further expand the current state of knowledge, by exploring self-management practices performed by breast cancer survivors, and the treatments women receive from healthcare practitioners in managing symptoms of arm morbidity.

2.7 Theoretical Support

To guide this study, the Symptom Management Model (SMM) was used (Figure 1). The SMM facilitates symptom management in chronic conditions (Dobbs et al., 2001). The model was used as a framework in contextualizing self-management of arm morbidity in BCS. The SMM defines a symptom as “a subjective experience reflecting changes in the biophysical functioning, sensations, or cognition of an individual” (Dobbs et al., 2001, p.669).

Figure 1. Symptom Management Model



The model focuses on symptoms as experienced by individuals subjectively, and suggests that it is the subjective experiences that generate the most distress (Dobbs et al., 2001). The SMM is comprised of three main concepts: symptom experience, symptom management strategies and symptom outcomes. Dobbs and colleagues revised the original model, developed by Larson et al (1994), to include the dimensions of nursing science: person, health and illness, and environment as contextual variables influencing and surrounding the main three concepts (Dobbs et al., 2001).

The symptom experience component is described as the beginning of the SMM, and guided this study by conceptualizing BCS's experiences with self-management of arm morbidity. Symptom experience consists of the individual's symptom perception, evaluation, and response, and there are bidirectional arrows used to depict the relationships between these three components (Dobbs et al., 2001). These relationships are recognized as occurring in a repetitious or even simultaneous manner (Humphreys et al., 2008). Perception of symptoms refers to

whether an individual notices a change from the way he or she usually feels or behaves (Dobbs et al., 2001). Evaluation of symptoms refers to the judgments the affected person makes about their symptoms, e.g. severity, intensity, location, temporal nature, frequency, and treatability of symptoms (Dobbs et al., 2001). Responses to symptoms include feelings, thoughts, or behaviors that are secondary to actual or potential health problems (Dobbs et al., 2001). The response to symptoms can be demonstrated through psychological, physiological and behavioural components (Dobbs et al., 2010).

The SMM illustrates that an individual's perceptions and evaluations of their symptoms shape their response to the symptom experience. The triad of behaviours in the symptom experience (perception, evaluation, response) guided selection of independent variables related to self-management in this thesis. It was hypothesized that when self-managing symptoms of arm morbidity, an individual would first notice a change in their leisure activities, then dialogue with a HCP about their symptoms, and finally receive treatment from a HCP to assist them manage their arm morbidity symptoms.

The selection of the SMM for this study is consistent with the researcher's social constructivism worldview that suggests, briefly, that people develop subjective meanings of their experiences (Peters, 2000).

2.8 References

Armer, J. M. (2010). Research on risk assessment for secondary Lymphedema following breast cancer treatment. *Cancer Epidemiology Biomarkers & Prevention, 19*(11), 2715–2717. doi:10.1158/1055-9965.epi-10-0962

Brown, J. C., Cheville, A. L., Tchou, J. C., Harris, S. R., & Schmitz, K. H. (2014). Prescription and adherence to lymphedema self-care modalities among women with breast cancer-related lymphedema. *Supportive Care in Cancer*, *22*(1), 135–143. https://doi.org/10.1007/s00520-013-1962-9

Brown, J. C., Troxel, A. B., & Schmitz, K. H. (2012). Safety of Weightlifting Among Women with or at Risk for Breast Cancer-Related Lymphedema: Musculoskeletal Injuries and Health Care Use in a Weightlifting Rehabilitation Trial. *Oncologist*, *17*(8), 1120–1128.

Canadian Cancer Statistics (2015). Special topic: Predictions of the future burden of cancer in Canada. Canadian Cancer Society's Advisory Committee on Cancer Statistics. Toronto, ON: Canadian Cancer Society; 2015.

Cancer Care Ontario (2015). Ontario Breast Screening Program Information for Healthcare Providers. Retrieved from: https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=349897

Cheifetz, O., & Haley, L. (2010). Management of secondary lymphedema related to breast cancer. *Canadian Family Physician*, *56*, 1277–1284.

Clayton, M. F., Dudley, W. N., & Musters, A. (2008). Communication with breast cancer survivors. *Health Communications, 23* (3), 207-21. doi: 10.1080/10410230701808376.

Damstra, R. J. & Partsch, H. (2009). Compression therapy in breast cancer-related lymphedema: A randomized, controlled comparative study of relation between volume and interface pressure changes. *Journal of Vascular Surgery, 49*(5), 1256-1263.

Dayes, I. S., Whelan, T. J., Julian, J. A., Parpia, S., Pritchard, K. I., D'Souza, D. P., … Levine, M. N. (2013). Randomized trial of decongestive lymphatic therapy for the treatment of lymphedema in women with breast cancer. *Journal of Clinical Oncology, 31*(30), 3758–3763. https://doi.org/10.1200/JCO.2012.45.7192

Dobb, M. J., Cho, M. H., Cooper, B. A. & Miaskowski, C. (2010). The effect of symptom clusters on functional status and quality of life in women with breast cancer. *European Journal of Oncology Nursing, 14(2),* 101–110. doi: 10.1016/j.ejon.2009.09.005

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., . . . Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing, 33*(5), 668-676. doi:10.1046/j.1365-2648.2001.01697.x

Engel, J., Kerr, J., Schlesinger-Raab, A., Sauer, H., & Hölzel, D. (2003). Axilla surgery severely affects quality of life: Results of a 5-year prospective study in breast cancer patients. *Breast Cancer Research and Treatment, 79* (1), 47–57. Doi: 10.1023/a:1023330206021

Fan, G., Filipczak, L., & Chow, E. (2007). Symptom clusters in cancer patients: A review of the literature. *Current Oncology, 14(5),* 173–179. doi:10.3747/co.2007.145

Fu, M. R., Deng, J., & Armer, J. M. (2014). Putting Evidence Into Practice: Cancer-Related Lymphedema. *Clinical Journal of Oncology Nursing, 18*(Journal Article), 68–79 12p. https://doi.org/10.1188/14.CJON.S3.68-79

Galantino, M. L., & Stout, N. L. (2013). Exercise interventions for upper limb dysfunction due to breast cancer treatment. *Physical Therapy*, *93*(10), 1291–1297. https://doi.org/10.2522/ptj.20120049

Hack, T. F., Kwan, W. B., Thomas-Maclean, R. L., Towers, A., Miedema, B., Tilley, A., & Chateau, D. (2010). Predictors of arm morbidity following breast cancer surgery. *Psycho-Oncology*, *19*(11), 1205–1212 8p. https://doi.org/10.1002/pon.1685

Haghighat, S., Lotfi-Tokaldany, M., Yunesian, M., Akbari, M., Nazemi, F., & Weiss, J. (2010). Comparing two treatment methods for post mastectomy lymphedema: Complex decongestive therapy alone and in combination with intermittent pneumatic compression. *Lymphology*, *43* (1), 25–33.

Hayes, S. C., Janda, M., Cornish, B., Battistutta, D., & Newman, B. (2008). Lymphedema after breast cancer: incidence, risk factors, and effect on upper body function. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, *26*(21), 3536–3542. https://doi.org/10.1200/JCO.2007.14.4899

Hayes, S. C., Johansson, K., Stout, N. L., Prosnitz, R., Armer, J. M., Gabram, S., & Schmitz, K. H. (2012). Upper-body morbidity after breast cancer: incidence and evidence for evaluation, prevention, and management within a prospective surveillance model of care. *Cancer*, *118*(8 Suppl), 2237–2249. https://doi.org/10.1002/cncr.27467

Hayes, S. C., Rye, S., Battistutta, D., DiSipio, T., & Newman, B. (2010). Upper-body morbidity following breast cancer treatment is common, may persist longer-term and adversely influences quality of life. *Health & Quality of Life Outcomes*. https://doi.org/10.1186/1477-7525-8-92

Hodgson, P., Towers, A., Keast, D. H., Kennedy, A., R. Pritzker, R., & Allen, J. (2011).

Lymphedema in Canada: A qualitative study to help develop a clinical, research, and education strategy. *Rehabilitation and Survivorship, 18* (6), 260-264.

Humphreys, J., Lee, K. A., Carrieri-Kohlman, V., Puntillo, K., Faucett, J., Janson, S., & Donesky-Cuenco, D. (2008). Theory of Symptom Management. In: Smith MJ, Liehr PR, editors. Middle range theory for nursing, 2nd Ed, New York, NY: Springer; 145–158.

Jeffs, E. & Wiseman, T. (2013). Randomised controlled trial to determine the benefit of daily home-based exercise in addition to self-care in the management of breast cancer-related lymphoedema: A feasibility study. *Supportive Care in Cancer, 21* (4), 1013-1023. DOI: 10.1007/s00520-012-1621-6

Kang, Y., Dae-Hyun Jang, Jae, Y. J., Sook, J. L., Soon, Y. J., Shin, D. I., & Hwa, J. K. (2012). Pressure Monitoring of Multilayer Inelastic Bandaging and the Effect of Padding in Breast Cancer-Related Lymphedema Patients. *American Journal of Physical Medicine & Rehabilitation*, *91*(9), 768–773. https://doi.org/10.1097/PHM.0b013e3182643c36

Kärki, A., Simonen, R., Mälkiä, E., & Selfe, J. (2005). Impairments, Activity limitations and participation restrictions 6 and 12 months after breast cancer operation. *Journal of Rehabilitation Medicine 37* (3), 180-188.

Kasseroller, R. G., & Brenner, E. (2010). A prospective randomized study of alginate-drenched low stretch bandages as an alternative to conventional lymphologic compression bandaging. *Support Care Cancer, 18* (3), 343-50.

King, M., Deveaux, A., White, H., & Rayson, D. (2010). Compression garments versus compression bandaging in decongestive lymphatic therapy for breast cancer-related lymphedema: a randomized controlled trial. *Support Care Cancer, 20* (5), 1031-1036. doi: 10.1007/s00520-011-1178-9

Kim, D. S., Sim, Y., Jeong, H. J., & Kim, G. C. (2010). Effect of Active Resistive Exercise on Breast Cancer–Related Lymphedema: A Randomized Controlled Trial. *Archives of Physical Medicine & Rehabilitation, 91*(12), 1844–1848 5p. https://doi.org/10.1016/j.apmr.2010.09.008

Kwan, M. L., Cohn, J. C., Armer, J. M., Stewart, B. R., & Cormier, J. N. (2011). Exercise in patients with lymphedema: a systematic review of the contemporary literature. *Journal of Cancer Survivorship, 5* (4), 320-336. doi: 10.1007/s11764-011-0203-9.

Langford, D. J., Paul, S. M., West, C., Abrams, G., Elboim, C., Levine, J. D., … Miaskowski, C. (2014). Persistent arm pain is distinct from persistent breast pain following breast cancer surgery. *The Journal of Pain : Official Journal of the American Pain Society, 15*(12), 1238–1247. https://doi.org/10.1016/j.jpain.2014.08.013

Larson, P. J., Carrieri-Kohlman, V., Dobb, M. J., Douglas, M., Faucett, J., Froelicher, E., ... Underwood, P. (1994). A model for symptom management. *Journal of nursing scholarship, 26* (4), 272-276.

Mansel, R. E., Fallowfield, L., Kissin, M., Goyal, A., Newcombe, R. G., Dixon, J. M., … Ell, P. J. (2006). Randomized multicenter trial of sentinel node biopsy versus standard axillary treatment in operable breast cancer: the ALMANAC Trial.[Erratum appears in J Natl Cancer Inst. 2006 Jun 21;98(12):876]. *Journal of the National Cancer Institute*, *98*(9), 599–609.

McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L., Lorig, K., & Wagner, E. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians, 61* (1), 50–62. doi:10.3322/caac.20093.

McNeely, M. L., Campbell, K., Ospina, M., Rowe, B. H., Dabbs, K., Klassen, T. P., … Courneya, K. (2010). Exercise interventions for upper-limb dysfunction due to breast cancer treatment. *The Cochrane Database of Systematic Reviews, (6):CD005211. doi*(6), CD005211. https://doi.org/10.1002/14651858.CD005211.pub2

McNeely, M. L., Peddle, C. J., Yurick, J. L., Dayes, I. S., Mackey, J. R. (2011). Conservative and dietary interventions for cancer-related lymphedema: a systematic review and meta-analysis. *Cancer, 117*(6), 1136-1148. doi: 10.1002/cncr.25513.

Miaskowski, C., Paul, S. M., Cooper, B., West, C., Levine, J. D., Elboim, C., … Aouizerat, B. E. (2014). Identification of patient subgroups and risk factors for persistent arm/shoulder pain following breast cancer surgery. *European Journal of Oncology Nursing, 18* (3), 242–253. doi:10.1016/j.ejon.2013.12.002.

Miedema, B., Hamilton, R., Tatemichi, S., Thomas-Maclean, R., Hack, T. F., Quinlan, E., … Kwan, W. (2011). Do breast cancer survivors' post-surgery difficulties with recreational activities persist over time? *Journal of Cancer Survivorship*, *5*(4), 405–412. https://doi.org/10.1007/s11764-011-0190-x

Miedema, B., Hamilton, R., Tatemichi, S., Thomas-MacLean, R., Towers, A., Hack, T. F., … Kwan, W. (2008). Predicting recreational difficulties and decreased leisure activities in women 6-12 months post breast cancer surgery. *Journal of Cancer Survivorship : Research and Practice*, *2*(4), 262–268. https://doi.org/10.1007/s11764-008-0068-8

Nesvold, I. L., Reinertsen, K. V., Fossa, S. D., & Dahl, A. A. (2011). The relation between arm/shoulder problems and quality of life in breast cancer survivors: a cross-sectional and longitudinal study. *Journal of Cancer Survivorship, 5* (1), 62–72. doi: 10.1007/s11764-010-0156-4.

Park, J., Lee, W., & Chung, H. (2008). Incidence and risk factors of breast cancer lymphoedema. *Journal of Clinical Nursing, 17* (11), 1450–1459. doi: 10.1111/j.1365-2702.2007.02187.x.

Peters, M. (2000). Does constructivist epistemology have a place in nurse education? *Journal of Nursing Education, 39*(4), 166-172.

Reyes-Gibby, C., Morrow, P. K., Bennett, M. I., Jensen, M. P. & Shete, S. (2010). Neuropathic pain in breast cancer survivors: Using the ID pain as a screening tool. *Journal of Pain Symptom Management, 39 (*5), 882–889. doi:10.1016/j.jpainsymman.2009.09.020.

Quinlan, E., Thomas-MacLean, R., Hack, T., Kwan, W., Miedema, B., Tatemichi, S., … Tilley, A. (2009). The impact of breast cancer among Canadian women: disability and productivity. *Work (Reading, Mass.), 34*(3), 285–296. https://doi.org/10.3233/WOR-2009-0926

Sagen, A., Kåresen, R., Sandvik, L., & Risberg, M. (2009). Changes in arm morbidities and health-related quality of life after breast cancer surgery-A five-year follow-up study. *Acta Oncologica, 48* (8), 1111–1118. DOI: 10.3109/02841860903061691.

Sclafani, L. M., & Baron, R. H. (2008). Sentinel lymph node biopsy and axillary dissection: added morbidity of the arm, shoulder and chest wall after mastectomy and reconstruction. *Cancer Journal, 14*(4), 216–222.

Shah, C., & Vicini, F. A. (2011). Breast cancer-related arm Lymphedema: Incidence rates, diagnostic techniques, optimal management and risk reduction strategies. *International Journal of Radiation Oncology*Biology*Physics, 81* (4), 907–914. doi:10.1016/j.ijrobp.2011.05.043

Shaw, R., & Thomas, R. (2011). Role of GPs in breast cancer- related arm morbidity care. *Journal of Lymphoedema, 6*(2), 10–19.

Thomas-MacLean, R. (2005). Beyond dichotomies of health and illness: Life after breast cancer. *Nursing Inquiry*, *12*(3), 200–209. https://doi.org/10.1111/j.1440-1800.2005.00268.x

Thomas-Maclean, R. L., Hack, T., Kwan, W., Towers, A., Miedema, B., & Tilley, A. (2008). Arm morbidity and disability after breast cancer: new directions for care. *Oncology Nursing Forum*, *35*(1), 65–71. https://doi.org/10.1188/08.ONF.65-71

Thomas, R., & Hamilton, R. (2014). Illustrating the (in)visible: Understanding the impact of loss in adults living with secondary lymphedema after cancer. *International Journal of Qualitative Studies on Health and Well-being, 9*, 24354 - http://dx.doi.org/10.3402/qhw.v9.24354

Thomas-MacLean, R., Miedema, B., & Tatemichi, S. (2005). Breast cancer-related lymphedema: Women's experiences with an underestimated condition. *Canadian Family Physician, 51*, 246–254.

Thomas-MacLean, R., Towers, A., Quinlan, E., Hack, T., Kwan, W., Miedema, B., Tilley, A., & Graham, P. (2009). "This is a kind of betrayal": A qualitative study of disability after breast cancer. *Current Oncology, 16* (3), 26–32.

Thomas-Maclean, R. Spriggs, P., Quinlan, E., Towers, A., Hack, T., Tatemichi, S., Miedema, B., Kwan, W., & Andrea Tilley, A. (2010). Arm morbidity and disability in Canada: Reporting the current status from Canada. *Journal of Lymphoedema, 5* (2), 33-38.

Towers, A., Carnevale, F. A., & Baker, M. E. (2008). The psychosocial effects of cancer-related lymphedema. *Journal of Palliative Care*, *24*(3), 134–143.

Thorne, S., Armstrong, E. A., Harris, S. R., Hislop, T. G., Kim-Sing, C., Oglov, V., Oliffe, J. L., & Stajduhar, K. I. (2009). Patient real-time and 12-month retrospective perceptions of difficult communications in the cancer diagnostic period. *Qualitative Health Research, 19* (10), 1383-1394. doi: 10.1177/1049732309348382.

Chapter 3: Methods

Methods

3.1 Study Design

A secondary data analysis was undertaken to analyze both quantitative and qualitative data from a longitudinal study called, Long-term *Disability After Breast Cancer (DABC): Expanding an empirical foundation for education, prevention and rehabilitation* (Thomas-MacLean et al., 2008, 2009, 2010). A descriptive correlational design was used to analyze data from breast cancer survivors (N = 740), and a descriptive qualitative analysis design was used to analyze data from a subset of participants (n = 40). (See Appendix B for *Permission to Use Data*). The DABC study will hereafter be referred to as "the primary study".

3.2 Overview of the Primary Study

The DABC study was a longitudinal, multi-site, mixed methods study conducted from 2005 to 2013. Professor Roanne Thomas, as the principal investigator, together with a multidisciplinary team representing oncology, sociology, psychology, family medicine and physiotherapy, conducted the study with funding from the Canadian Institutes of Health Research (CIHR). The overarching aim of the DABC study was to create multidisciplinary knowledge about the impact of arm morbidity in women after acute breast cancer (BrCa) treatments (Thomas-MacLean et al., 2010). The experiences of breast cancer survivors (BCS) (N = 740) from four Canadian sites: Fredericton/Saint John, New Brunswick (NB), Montreal, Quebec (QC), Winnipeg, Manitoba (MN) and Surrey, British Columbia (BC), were examined over a five-year period (Thomas-MacLean et al., 2008, 2009, 2010). The five specific objectives of the primary study were to:

1. Chart the course of lymphedema, pain, and restricted range of motion
2. Identify possible triggers of arm morbidity

3. Further document, measure, and analyze the psychological and social impact of arm morbidity
4. Compare provision of care and access to appropriate treatment across demographic groupings
5. Qualitatively explore the longitudinal impact of arm morbidity

3.2.1 Setting and Sample

Study participants (N = 740) were recruited from oncology clinics where they were receiving post-surgical BrCa management and examination of arm morbidity post treatment: Fredericton/Saint John, NB, Montreal, QC, Winnipeg, MN and Surrey, BC. Oncology nurses identified participants who met inclusion criteria and provided relevant information pertaining to the study. The nurses also obtained informed consent for participants to be further contacted by the study research assistant. Research assistants then followed up with potential participants who met inclusion criteria to participate in the longitudinal study. Inclusion criteria required participants to be 18 years of age at the time of enrolment, be fluent in either French or English, previously diagnosed with unilateral breast cancer stage 1 to 3, and competent to provide informed consent. Exclusion criteria included individuals with bilateral disease, metastatic diseases, stage 4 BrCa, and a cognitive impairment that would disable participants from providing informed consent. Research ethics committees approved the study at each participating institution (Hack et al., 2010; Thomas-MacLean et al., 2008, 2009, 2010).

3.2.2 Data Collection

Charting the course of arm morbidity involved collecting longitudinal descriptive data to meet study objectives. Data collection involved documenting incidents of symptoms of arm morbidity, i.e. pain, lymphedema and range of motion (ROM) limitation, and the impact these

symptoms had on BCS. Data were collected from chart reviews, annual clinical assessments of arm function, questionnaires administered to assess experienced symptoms and their psychosocial impact, as well as in-depth qualitative interviews with selected participants.

3.2.2.1 Chart Reviews. Data collected from one-time chart reviews explored different aspects of treatment during the acute stages of cancer, such as antibiotics taken for post-operative infections. Other invasive treatments collected included radiation, chemotherapy, and surgical procedures such as lumpectomy, mastectomy and lymph nodes removed (Hack et al., 2010; Miedema et al., 2008).

3.2.2.2 Clinical Assessments. Annual clinical assessments measured arm functioning to identify lymphedema and range of motion (ROM) limitation. Different arm measurements were collected to define lymphedema that included circumferential measurements, volumetric difference in millimeters (mL), and self-reported data on swelling. Seven sequential circumferential arm measurements were taken for both arms: metacarpophalangeal (MCO) joint, thumb base, wrist crease, and wrist crease up the arm (wrist + 10, 20, 30, and 40 cm). Lymphedema was operationally defined in two ways: a greater than 2 cm difference between the affected and the unaffected arm on any measurement, and the percentage volume increase of the affected arm after comparing the two arms, based on geometric arm volume measurements calculated using a truncated cone formula (Armer & Fu, 2005; Brown, 2004). The truncated cone formula is calculated as:

$$\textbf{Volume (V)} = H\,[Ct^2 + (Ct \times Cb) + Cb^2]/12\pi$$

Where H is the height or length of the segment, Ct is the circumference at top of the segment, and Cb is the circumference at bottom of the segment. Each segment is calculated in the same manner, and the total volume is the sum of each segment's volume. Same calculations are made

on the unaffected limb to compare the volume difference of the two arms. The percentage (%) of change in edema was then calculated as follows:

Percent change in edema = (Vf – Vi)/(Vi – Vn) x 100

Where Vf is the final volume of the affected limb, Vi is the initial volume of the affected limb, and Vn is the volume of the normal limb (Brown, 2004).

Range of motion (ROM) was assessed through measurements of angles of shoulder abduction and external rotation. Using a goniometer, shoulder abduction and external rotation angles were measured to the point of pain sensation expressed by participant. Full shoulder abduction ends with a straight arm raised above the head with fingers pointed upwards, whereas an example of a full external rotation is signaling a left turn on a bicycle. Shoulder abduction and external rotation were regarded as restricted if less than 170 degrees (°) or 80°, respectively (Thomas-MacLean et al., 2008). Keeping in mind that certain physical conditions, such as arthritis, not related to BrCa treatments can also restrict movement, an additional criterion of restricted ROM was applied if the affected arm was limited 10° or more, in comparison to the unaffected arm (Hack et al., 2010; Thomas-MacLean et al., 2010).

3.2.2.3 Questionnaires. Four different questionnaires were used to document changes observed over time: the Short-Form McGill Pain Questionnaire (SF-MPQ), the Profile of Mood States Brief (POMS Brief), the Disability of Arm, Shoulder and Hand (DASH), and the Social Impact of Arm Morbidity (SIAM) questionnaire. These four questionnaires were completed every six months.

The SF-MPQ is comprised of 15 items rated on a four-point scale: 11 sensory descriptors and 4 affective descriptors, which are rated on an intensity scale where 0 = none, 1 = mild, 2 = moderate or 3 = severe (Melzack, 1975). Three pain scores were derived from the sum of the

intensity rank values of the words chosen for sensory, affective and total descriptors. The tool includes the Present Pain Intensity (PPI) index and the Visual Analogue Scale (VAS). The PPI index ranks pain from 0 to 5, where 0 = no pain, 1 = mild, 2 = discomforting, 3 = distressing, 4 = horrible, 5 = excruciating. The PPI provides a measurement of different dimensions of pain. For the VAS, the participant's degree of pain was indicated along a 10 cm line. It requires measuring the point at which the participant marked the line. At least 2 cm from the no pain mark indicates mild pain, at least 5cm indicates moderate pain, and at least 8 cm indicates severe pain. The SF-MPQ is highly correlated to a previous longer version, the Long Form MPQ (r = .90, p <. 001) (Dudgeon, Raubertas, Rosenthal, 1993). Several studies have validated the SF-MPQ as an appropriate tool measuring pain in the cancer population, and report a Cronbach's alpha ranging from 0.89 to 0.93 (Dudgeon, Raubertas, Rosenthal, 1993; Gauthier et al., 2014). Additionally, Participants were also asked to verbally rate discomfort 'during the past week, including today' of the affected arm, shoulder, axilla, breast, and chest wall on a scale of 0–100 (0 = no pain, 100 = worst possible pain) (Hack et al., 2010).

The Profile Of Mood States (POMS) BRIEF is a tool used to capture the psychological impact of arm morbidity. POMS BRIEF is a shortened version of the original 65-item POMS. The tool has been shown to be useful for measuring changes in mood states over periods of time. It has subscales that include confusion, anxiety, depression, anger, fatigue and vigor. POMS BRIEF has been validated with Cronbach's alphas ranging from 0.78 to 0.91 (Baker, Denniston, Zabora, Polland & Dudley, 2002).

DASH is a 30 items tool that pertains to disability, regarding everyday activities that involve the arm, shoulder and hand such as work, sports and hobbies. Responses range from 1= no difficulty or symptom, 2 = slight difficult or mild symptom, 3 = moderate difficult or

symptom, 4 = severe difficulty or symptom, to 5 = unable to perform or very severe symptom. The total score is calculated by summing the points of all answers. A minimum score of 30 indicates 'no disability', while a maximum score of 150 indicates 'extreme disability'. This score is usually adjusted to create a range from 0 to 100, which is calculated by taking the sum of all responses and divide by the number of responses. From this number, 1 is subtracted and then multiplied by 25 to achieve an adjusted score. The adjusted score (out of 100) allows for easy comparison to other measures. This formula for calculating adjusted score is only applicable when at least 27 of 30 questions have been answered. The higher the score, the greater the disability experienced by a participant. The DASH has been validated using test-retest reliability and showed a highly significant (r = .96) intra-class correlation coefficient (Beaton et al., 2001). The DASH has been validated to measure disability in upper extremity disorders (Beaton, Davis, Hudak & McConnell, 2001).

The Social Impact of Arm Morbidity (SIAM) was specifically developed and used in the primary study. The questionnaire was developed to gather medical, demographic, and social information from each participant (Miedema et al., 2011; Thomas-MacLean et al., 2010). The SIAM also allows for identification of triggers of arm morbidity and the social impacts of the condition on everyday life (Thomas-MacLean et al., 2010). To ensure content validity, ease of completion, and clarity of questions, the SIAM was pilot tested by several patients with BrCa and by individuals with knowledge of BrCa survivorship (Thomas-MacLean et al., 2010).

3.2.2.4 Interviews. To meet the final objective of the DABC study, two sets of semi-structure qualitative interviews were conducted to gain an in-depth understanding of longitudinal impact of arm morbidity. A purposeful sampling technique was used to identify a diverse group of women *(n* = 40, 10 per site) using age, severity of symptoms, socioeconomic status, ethnicity,

marital status and urban/rural location as selection criteria. Interviews conducted lasted approximately 60 minutes, and were tape recorded and transcribed verbatim (Thomas-MacLean et al., 2009).

3.3 The Current Study

The current study was a secondary analysis of data from the primary study. A secondary analysis of both quantitative and qualitative data was undertaken using data already collected to save process steps that might otherwise be costly and burdensome on participants (Fielding, 2004; Polit & Beck, 2008; Szabo & Strang, 1997). However, conducting a secondary analysis can place researchers at a disadvantage due to the lack of control over how the original research was conducted, generated, or recorded (Jacobson, Hamilton, & Galloway, 1993). Thus, discussions were conducted for this thesis with the thesis supervisor (WG) and the primary study principal investigator, Professor Roanne Thomas (RT), to verify that the data collected would be appropriate for secondary analysis for the purpose of this study (Long-Sutehall, Sque & Addington-Hall, 2011). RT is also on the thesis committee of the current study.

3.3.1 Study Objectives

The overall purpose of this secondary analysis was to explore self-management practices and treatments experienced by breast cancer survivors in managing symptoms of arm morbidity. As recommended with secondary analysis, the questions and methods of the primary study guided the development of objectives in the current study (Long-Sutehall, Sque & Addington-Hall, 2011). The specific objectives for the current study are:

1. To identify the relationship between self-management practices (as defined in this study) and arm morbidity symptoms of pain, lymphedema and ROM limitation experienced, at three points in time (Quantitative);

2) To understand how women self-manage symptoms of arm morbidity (Qualitative);

3) To explore the treatments women receive when they go to their healthcare practitioners to manage their symptoms of arm morbidity (Qualitative).

3.3.2 Quantitative Data

In the primary study, data collection occurred every six months for a total of ten time-points in a 5-year period. Data collected at odd time-points (i.e. 1, 3, 5, 7, 9) were collected in person through clinical assessments whereas data collected at even time-points (i.e. 2, 4, 6, 8, 10) were collected over the telephone. At each odd time-point, lymphedema and range of motion (ROM) measurements were obtained. The same four questionnaires (MPQ, POMS BRIEF, DASH & SIAM) were completed at both odd and even time-points.

3.3.2.1 Data Sources

Quantitative data used in this study were collected through post surgery clinical assessments and questionnaires at 6 to 12 months (T1, $N = 740$), 18 to 24 months (T3, $n = 653$), and 30 to 36 months (T5, $n = 537$). Data collected at the three time-points were used to meet study objective number one: to identify the relationship between self-management practices and arm morbidity symptoms of pain, lymphedema and ROM limitation experienced, at three points in time.

3.3.2.2 Variable Selection and Development

Quantitative data were accessed in the form of data tables containing the results of all instruments used. Descriptive variables were obtained from the SIAM questionnaire and were used to describe the sample demographics and clinical characteristics. Dependent variables were obtained from clinical assessments data and independent variables were obtained from the SIAM questionnaire. All variables are detailed below.

3.3.2.3 Dependent Variables

3.3.2.3.1 Pain. The variable used to measure pain was obtained form the SF-MPQ Present Pain Intensity (PPI) index. Pain in the PPI is ranked from 0 to 5 where 0=no pain, 1=mild pain, 2=discomforting, 3=distressing, 4=horrible, 5=excruciating pain. In this study, pain was dichotomized into two categories, to indicate the presence or absence of pain. Responses were transformed and PPI ranks of 1 to 5 were coded as 1=pain present, and a PPI rank of 0 was coded as 0=pain absent. The pain variable was dichotomized for binary logistic regression analysis because descriptive analyses showed highly skewed data and there was not sufficient number of cases in each cell for multinomial regression analysis.

3.3.2.3.2 Lymphedema. The variable used to measure lymphedema was obtained from clinical assessment data containing circumferential measurements of both arms. The percentage volume increase of the affected arm, after comparing the two arms, was based on the geometric arm volume measurements calculated using a truncated cone formula (Brown, 2004). In this study, lymphedema was dichotomized into two categories: presence (>5%) or absence (<= 5%) of lymphedema. These percentages indicate the differences in arm swelling (lymphedema). Presence of lymphedema was coded as 1, and the absence of lymphedema was coded as 0. The 5% cut off was commonly used in previous studies, including the primary study and a RCT that reported that by using a 4 to 5% difference, one could predict up to 50% of women to develop lymphedema three months after BrCa surgery (Mansel et al., 2006; Miedema et al., 2011; Quinlan et al., 2015; Thomas-MacLean et al., 2010)

3.3.2.3.3 ROM limitation. The variable used to measure ROM limitation was obtained from clinical assessments data, i.e. measurements of angles of shoulder abduction and external rotation using a goniometer. Standard shoulder abduction angle is 180°, whereas a standard

external rotation angle is 90°. Shoulder abduction and external rotation were regarded as restricted if less than 170° or 80°, respectively, in the primary study. In this study, ROM was dichotomized into two categories: presence or absence of ROM limitation by an angle difference of 10°, using the standard agreed upon degree of impairment in previous studies (Hack et al., 2010; Miedema et al., 2011; Thomas-MacLean et al., 2010. Presence of ROM limitation was coded as 1 (ROM angle difference of 10° between arms), and the absence of ROM limitation was coded as 0 (no angle difference between arms).

3.3.2.4 Independent Variables

The 12-items that made up three theoretically divided independent variables were obtained from specific questions in the SIAM questionnaire. The 12-items were theoretically allocated to variables related to: 1) change in leisure activities, 2) dialogue with healthcare practitioner (HCP), and 3) treatment by healthcare practitioner (HCP). Further descriptions of items in each predictor variable are provided in Appendix *C* (*Variable Selection and Coding).*

3.3.2.5 Quantitative Data Analysis

3.3.2.5.1 Descriptive Analysis. Quantitative data was analyzed using Statistical Package for the Social Sciences (SPSS) analysis program, version 22.0. Normality of the distribution of all variables was examined by visual inspection of histograms and frequencies. Outcome variables were dichotomized and their frequencies obtained. Independent variables were also categorical and their frequencies were obtained.

3.3.2.5.2 Bivariate Analysis. Bivariate analyses were used to examine the relationship between each outcome variable (pain, lymphedema and ROM limitation) and each independent variable. Additionally, bivariate analyses examined the relationship between each outcome variable and demographics and clinical characteristics variables. Bivariate analyses were

performed to identify those independent variables that were significantly associated with each outcome. Analysis used chi square phi coefficient for nominal variables, crammer's *V* for ordinal variables and point bi-serial correlation for continues variables. These tests provided information on the magnitude of association between variables analyzed. Those significant variables were included in the multivariate logistic regression model.

Multicollinearity was assessed using the same bivariate tests and one variable was removed from analysis because it was highly associated with others. The variable was “having a provider for swelling treatment”. Power analysis was not conducted because of the large sample size, *N* = 740. Additionally, when using a10 to 20 events per variable rule, the sample size necessary would have been 220 participants and *N* = 740 were beyond that (Peduzzi et al., 1996; Polit, 2010).

3.3.2.5.3 Multivariate Analysis. Since the dependent variables were categorical, binary logistic regression models were used. Multivariate analysis determined the effect of independent variables combined on dependent variables of pain, lymphedema and ROM limitation. i.e. to identify self-management practices associated with symptoms of each type of arm morbidity. Analyses were performed on each outcome variable separately, three at each time point, for a total of nine models. Wald chi-square, odds ratios and 95% confidence intervals were obtained for each variable included in the models.

Demographics variables analyzed were: age, race, education, marital status and income. Clinical characteristics analyzed were: tumour stage, type of surgery, treatments of radiation, treatment of chemotherapy and treatment of hormone replacement therapy. Demographics and clinical characteristics at T3 and T5 were not in the dataset received for secondary analysis; it was assumed that demographics (i.e. race) and clinical characteristics (i.e. surgery, radiation

treatments) had not changed from baseline. These variables were therefore carried forward from baseline for all time-points, except for age, which was calculated at each time-point. Age was calculated by subtracting birth year from the year that data was collected for each participant.

3.3.3 Qualitative Data

Qualitative data from the primary study were accessed in the form of transcriptions of interviews. A qualitative descriptive approach was used for this secondary data analysis. Qualitative descriptive allows for a rich description of individuals' experiences related to a phenomenon (Sandelowski, 2000). A naturalistic approach was useful in helping the researcher attempt to make sense of BCS' experiences with self-management of arm morbidity. The nature and complexity of arm morbidity symptoms necessitates the understanding of individuals' experiences in managing their symptoms.

With limited information on self-management of arm morbidity in BCS, a descriptive qualitative approach was useful in describing survivors' experiences (Sandelowski, 2000). In doing so, the meanings of the participants' words were captured as they describe their experiences with self-management. The process allowed a comprehensive summary of facts associated with the BCS' experiences from their perspective (Sandelowski, 2000).

3.3.3.1 Data Sources

Qualitative data included semi-structured interviews with a subset of women (n = 40) from the total number of participants (N = 740) of the primary study (Thomas-MacLean et al., 2009). Participants were purposefully sampled in the primary study because of symptoms experienced, and were willing to discuss the effects of symptoms on their everyday life. Interviews were conducted to document the impact of arm morbidity and identify the need for

additional support required in managing arm morbidity. Further descriptions of study sampling are described elsewhere (Thomas-MacLean et al., 2009).

Two sets of interviews were conducted in the primary study, however this study utilizes qualitative data collected 12 to 24 month post BrCa surgery (Thomas-MacLean et al., 2009). Qualitative data used in the current study were extracted from interview questions that elicited participants to describe: a) actions taken to self-manage arm morbidity after acute BrCa treatments, b) treatment options experienced for managing arm morbidity. Thus, three out of the ten semi-structured interview questions were used as data sources in the current study (Appendix D for *Qualitative Interview Questions*).

3.3.3.2 Data Collection

An interview guide with ten questions was developed specific to the primary study (Thomas-MacLean et al., 2009). The guide had two main focuses: first, to document symptoms and the scope of arm problems experienced by participants, and second, to understand the types of resources and experiences needed by BCS. The interview guide contained open-ended questions to facilitate participants' disclosure of their personal experiences with management of arm morbidity (Sandelowski, 2000). Open ended-questions allowed for replies that were unanticipated by the researcher, and further disclose important elements of participants' experiences (Milne & Oberle, 2005).

Research assistants (RA) trained in qualitative interview techniques, conducted individual semi-structured interviews. Ten interviews were conducted at each study site. The RAs had previously worked at the site from which the interview participants were recruited, thus were familiar with, and had access to important background information pertinent to each participant.

Each interview was conducted in person, at a time and place convenient for the participant. All interviews were tape-recorded and transcribed verbatim (Thomas-MacLean et al., 2009).

3.3.3.3 Qualitative Data Analysis

To understand how women self-manage symptoms of arm morbidity and treatment options experienced (Objective #2 and #3), a content analysis was used following Sandelowski's qualitative descriptive method (2000). An inductive content analysis was used systematically to condense data into categories that represent a broader description of the phenomenon. Similar words and phrases were used to provide new insights that represent participants' perspectives (Elo & Kyngas, 2008). With limited knowledge about women's experiences with self-management of arm morbidity, an inductive approach was undertaken whereby the categories were constructed from the data (Braun & Clarke, 2006). The inductive approach moved from the specific to the general, so that particular instances observed were combined into a larger whole or general statement (Elo & Kyngas, 2008).

Content analysis facilitated making sense of the raw data by developing coding units utilizing representative quotations from the transcribed text (Graneheim & Lundman, 2004). By developing a coding system that corresponds to the data, interpretations stay close to the data and enhance accuracy (Sandelowski, 2000). Content analysis was performed by reading transcribed interviews line by line, to look for a meaning unit consisting of a pattern of words or statements that share the same central meaning (Braun & Clarke, 2006). This unit was labeled as a code. Codes were generated inductively according to what the data said while keeping focus on the research questions guiding the study (Braun & Clarke, 2006). The coding of data continued until all essential features of the data were captured. Codes were then compared, contrasted and grouped according to similarities and then put into categories. Categories were compared and

contrasted and formed the over arching themes that captured all essential features self-management of arm morbidity symptoms in BCS (Braun & Clarke, 2006; Elo & Kyngas, 2008). NVivo 11.0 computer software was used for data storage and management.

The research committee carried out ongoing discussions and revisions of codes, categories and themes until the analysis completed. The ongoing discussions ensured that data were grouped appropriately and analyzed correctly (Graneheim & Lundman, 2004).

3.4 Study Strength

Several techniques were used to enhance scientific rigour of this study. To ensure trustworthiness of results, credibility, dependability, confirmability and transferability of the study findings were displayed through the research process (Lincoln & Guba, 1985).

Credibility refers to the truth-value obtained from human experiences as perceived by informants (Lincoln & Guba, 1985). To ensure credibility, the researcher examined findings with persons familiar with the phenomenon of arm morbidity in BCS, Roanne Thomas (R.T). Sandelowski (1986) suggested that a qualitative study is credible when it presents such accurate descriptions or interpretation of human experience that people who also share that experience would immediately recognize the descriptions. Verification of the research process was conducted using peer review and feedback from Wendy Gifford (G.W), R.T., and Craig Phillips (C.P). Peer review involved reviewing the coding and analysis process at frequent intervals through the research process (Lincoln & Guba, 1985).

Dependability, which goes hand in hand with credibility, refers to the potential to replicate the study findings with similar participants in a similar context (Lincoln & Guba, 1985). The analysis process was thoroughly reported, thereby enabling a future researcher to repeat the work, if not necessarily to gain the same results (Lincoln & Guba, 1985).

Confirmability refers to the objectivity of the researcher from the data, and is achieved by acknowledging the researcher's own bias (Lincoln & Guba, 1985). A detailed methodological description was presented to enable the reader to determine how far the data and emerging themes may be accepted. The researcher ensured confirmability by maintaining an audit trail to allow for transparency of the research process. Thus, by showing how the data eventually led to the formation of themes generated, other observers can trace the course of the research step-by-step via the decisions made and procedures described (Shenton, 2004). The thesis supervisor, W.G., audited the coding and analysis process.

Transferability is the extent to which the study findings can be applied to other contexts (Lincoln & Guba, 1985). Therefore a detailed description of the context, setting, participants, data collection and process of analysis was elaborated to provide researchers with adequate information to evaluate transferability of the findings (Lincoln & Guba, 1985). Together, the four elements of credibility, dependability, confirmability, and transferability enhanced the trustworthiness of the research findings.

3.5 Ethical Considerations

The data from the primary study had been cleaned and all potential identifying information removed prior to access being granted for secondary analysis. Approval to access the data was granted by R.T., the principal investigator of the primary study. The University of Ottawa Research Ethics Board granted approval for this secondary data analysis study (See Appendix E for *Ethics Approval*).

In regards to privacy and confidentiality, as outlined by the Tri-Council Policy Statement, data received for secondary analysis had been de-identified previously. Participants were assigned identification numbers to protect their identities throughout the research process. No

personal information can be linked to participants is associated with this research study. Data used is kept in a locked cabinet in the Nursing Best Practice Research Unit at the University of Ottawa where it will remain for up to 5 years, at which time it will be destroyed.

3.6 Summary

To meet the current study's objective to explore self-management practices and treatments experienced by breast cancer survivors in managing symptoms of arm morbidity, a secondary analysis of both quantitative and qualitative data from the primary study was undertaken. Quantitative data were analyzed to identify the relationship between self-management practices and symptoms of arm morbidity (pain, lymphedema ROM limitation). Using a computer program, SPSS, descriptive, bivariate and multivariate logistic regression analyses were conducted and reported. Qualitative data from transcribed semi-structured interviews were utilized to understand how women self-manage symptoms of arm morbidity and the treatments women received from healthcare practitioners in managing their arm morbidity. Inductive content analysis, informed by Sandelowski's qualitative descriptive methods guided the coding, analysis and interpretation of qualitative data. Several validation strategies were used to ensure trustworthiness was achieved in the current study.

3.7 References

Armer, J. & Fu, M.R. (2005). Age differences in post-breast cancer lymphedema signs and symptoms. *Cancer Nursing, 28,* 200–207.

Baker, F., Denniston, M., Zabora, J., Polland, A., & Dudley, W.N. (2002). A POMS short form for cancer patients: Psychometric and structural evaluation. *Psycho-Oncology, 11,* 273-81.

Beaton, D. E., Davis, A.M., Hudak, P., & McConnell, S. (2001). The DASH (Disabilities of the Arm, Shoulder and Hand) outcome measure: What do we know about it now? *British Journal of Hand Therapy*, *6*(4), 109-118.

Beaton, D., Katz, J., Fossel, A., Wright, J., Tarasuk, V., & Bombardier, C. (2001). Measuring the whole or the parts? Validity, reliability, and responsiveness of the disabilities of the arm, shoulder and hand outcome measure in different regions of the upper extremity. *Journal of Hand Therapists, 14* (2), 128–46.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3, 77-101.

Brown, J. (2004). A clinically useful method for evaluating lymphedema. *Clinical Journal of Oncology Nursing, 8(1),* 35-38. doi: 10.1188/04.CJON.35-38

Dudgeon, D., Raubertas, R.F., & Rosenthal, S.N. (1993). The short-form McGill Pain Questionnaire in chronic cancer pain. *Journal of Pain Symptom Management, 8*(4) 191-195.

Elo, S. & Kyngas, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing, 62* (1), 107-115. doi: 10.1111/j.1365-2648.2007.04569.x

Graneheim, U.H. & Lundman, B. (2004). Qualitative content analysis in nursing research:

concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* (24), 105–112. doi:10.1016/j.nedt.2003.10.001

Fielding, N. (2004). Getting the most from archived qualitative data. *International Journal of Social Research Methodology, 7*(1), 97-104.

Gauthier, L., Young, A., Dworkin, R., Rodin, G., Zimmermann, C., Warr, D., … Gagliese, L. (2014). Validation of the short-form McGill pain questionnaire-2 in younger and older people with cancer pain. *The Journal of Pain*, *15*(7), 756 – 770.

Hack, T. F., Kwan, W. B., Thomas-MacLean, R., Towers, A., Miedema, B., Tilley, A., & Chateau, D. (2010). Predictors of arm morbidity following breast cancer surgery. *Psycho-Oncology, 19*(11), 1205-1212. doi:10.1002/pon.1685.

Jacobson, A.F., Hamilton, P., & Galloway, J. (1993). Obtaining and evaluating data sets for secondary analysis in nursing research. *Western Journal Nursing Research, 15(4),* 483-494.

Kaiser, K. A., Affuso, O., Beasley, T.M. & Allison, D. B. (2012). Getting carried away: a note showing baseline observation carried forward (BOCF) results can be calculated from published complete-cases results. *International Journal of Obesity*, *36* (6), 886-889. doi: 10.1038/ijo.2011.25.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, California: Sage Publications.

Liu-Seifert, H., Zhang, S., D'Souza, D. & Skljarevski, V. (2010). A closer look at the baseline-observation-carried-forward (BOCF). *Patient Preference and Adherence, 4,* 11–16.

Long-Sutehall, T., Sque, M., & Addington-Hall, J. (2011). Secondary analysis of qualitative data: A valuable method for exploring sensitive issues with an elusive population?

Journal of Research in Nursing, 16(4), 335-344. Doi: 10.1177/1744987110381553.

Mansel, R. E., Fallowfield, L., Kissin, M., Goyal, A., Newcombe, R. G., Dixon, J. M., … Ell, P. J. (2006). Randomized multicenter trial of sentinel node biopsy versus standard axillary treatment in operable breast cancer: the ALMANAC Trial.[Erratum appears in J Natl Cancer Inst. 2006 Jun 21;98(12):876]. *Journal of the National Cancer Institute*, *98*(9), 599–609.

Melzack, R. (1975). The McGill Pain Questionnaire: major properties and scoring methods. *Pain, 1*(3), 277-299.

Miedema, B., Hamilton, R., Tatemichi, S., Thomas-MacLean, R., Towers, A., Hack, T., … Kwan, W. (2008). Predicting recreational difficulties and decreased leisure activities in women 6-12 months post breast cancer surgery. *Journal of Cancer Survivorship: Research and Practice*, *2*(4), 262–268.

Miedema, B., Hamilton, R., Tatemichi, S., Thomas-MacLean, R., Towers, A., Hack, T.F., et al. (2011). Do breast cancer survivors' post-surgery difficulties with recreational activities persist over time? *Journal of Cancer Survivorship, 5*, 405–412. DOI 10.1007/s11764-011-0190-x.

Milne, J., & Oberle, K. (2005). Enhancing rigor in qualitative description. *Journal of Wound, Ostomy and Continence Nursing, 32* (6), 413-420.

Peduzzi, P., Concato, J., Kemper, E., Holford, T. R., Feinstein, A. R. (1996). A simulation study of the number of events per variable in logistic regression analysis. *Journal of Clinical Epidemiology, 49* (12), 1373-1379.

Polit, D. G. & Beck, C. T. (2008). Nursing research: Generating and assessing evidence for nursing practice, 8th Ed. New York: Lippincott Williams & Wilkins.

Polit, D. F. (2010) “Statistics and Data Analysis for Nursing Research” 2e. Upper Saddle River, NJ, Pearson Education Inc.

Quinlan, E., Thomas, R., Towers, A., Hack, T., Kwan, W., Miedema, B., Tatemichi, S., Tilley, A. (2015). Improving best practices for diagnosing lymphedema: A proposal to assess limbs according to segment. *Research Perspectives*. Retrieved from http://canadalymph.ca/wp-content/uploads/2015/05/Improving-best-practices.pdf

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science,* 8, 27-37.

Sandelowski, M. (2000). Whatever Happened to Qualitative Description? *Research in Nursing and Health*, (23) 334- 40.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, 63–75

Szabo, V. & Strang, V.R. (1997). Secondary analysis of qualitative data. *Advances in Nursing Science, 20*(2), 66-74.

Thomas-Maclean, R., Hack, T., Kwan, W., Towers, A., Miedema, B., & Tilley, A. (2008). Arm morbidity and disability after breast cancer: New directions for care. *Oncology Nursing Forum, 35*(1), 65. Doi: 10.1188/08.ONF.65-71.

Thomas-Maclean, R. Spriggs, P., Quinlan, E., Towers, A., Hack, T., Tatemichi, S., Miedema, B., Kwan, W. & Andrea Tilley, A. (2010). Arm morbidity and disability in Canada: Reporting the current status from Canada. *Journal of Lymphoedema*, *5*(2), 33-38.

Thomas-MacLean, R., Towers, A., Quinlan, E., Hack, H., Winkle Kwan, W., Miedema, B. & Graham, P. (2009). “This is a kind of betrayal”: A qualitative study of disability after breast cancer. *Current Oncology*, *16*(3), 26-32.

Chapter 4: Results

4.1 Quantitative Results

The following section describes results from quantitative data. The aim of the quantitative analysis was to identify the relationship between self-management practices and arm morbidity symptoms of pain, lymphedema and ROM limitation experienced, at three points in time (objective 1).

4.1.1 Demographic Characteristics

All participants in the study were female (N = 740), with an average age of 55 ($\pm$11) years old, ranging from 28 to 85 years old. Most of the participants (n = 463, 63.1 %), 52.6% (n = 386) had some college education or had obtained an undergraduate university degree. The majority were Caucasian/white (n = 659, 89.8%) and 32.2% (n = 236) had an annual family income ranging from $40,000 to $80,000. Demographic characteristics are summarized in Table 1.

Table 1. Demographic Characteristics (N = 740)

Demographics	**Variables**	**Number *(n)***	**Percentage (%)**
Race	Caucasian/White	659	89.9
	Blacks	12	1.6
	Asian heritage	42	4.6
	Other	21	3.8
Marital Status	Single	88	12
	Married/ Common law	523	71.3
	Divorced/ Separated	78	10.6
	Widow	45	6.1
Education	High school and below	258	35.1
	Some college – university undergraduate degree	386	52.6
	Graduate degrees	90	12.3
Income	Under 40,000	185	25.2
	40,001 – 80,000	236	32.2
	Over 80,001	180	24.5
	Did not answer	133	18.1

4.1.2 Clinical Characteristics

Clinical characteristics of the sample indicated that most participants had Stage I or II BrCa, 43.3% (303) and 45.1% (316), respectively. Acute BrCa treatment reported by participants included partial mastectomy or lumpectomy (*n* = 538, 73.3%), radiation (*n* = 682, 94.2%), chemotherapy (*n* = 486, 67.1%), and hormonal therapy replacement (*n* = 539, 74.4%). Clinical characteristics for the women in the sample are summarized in Table 2.

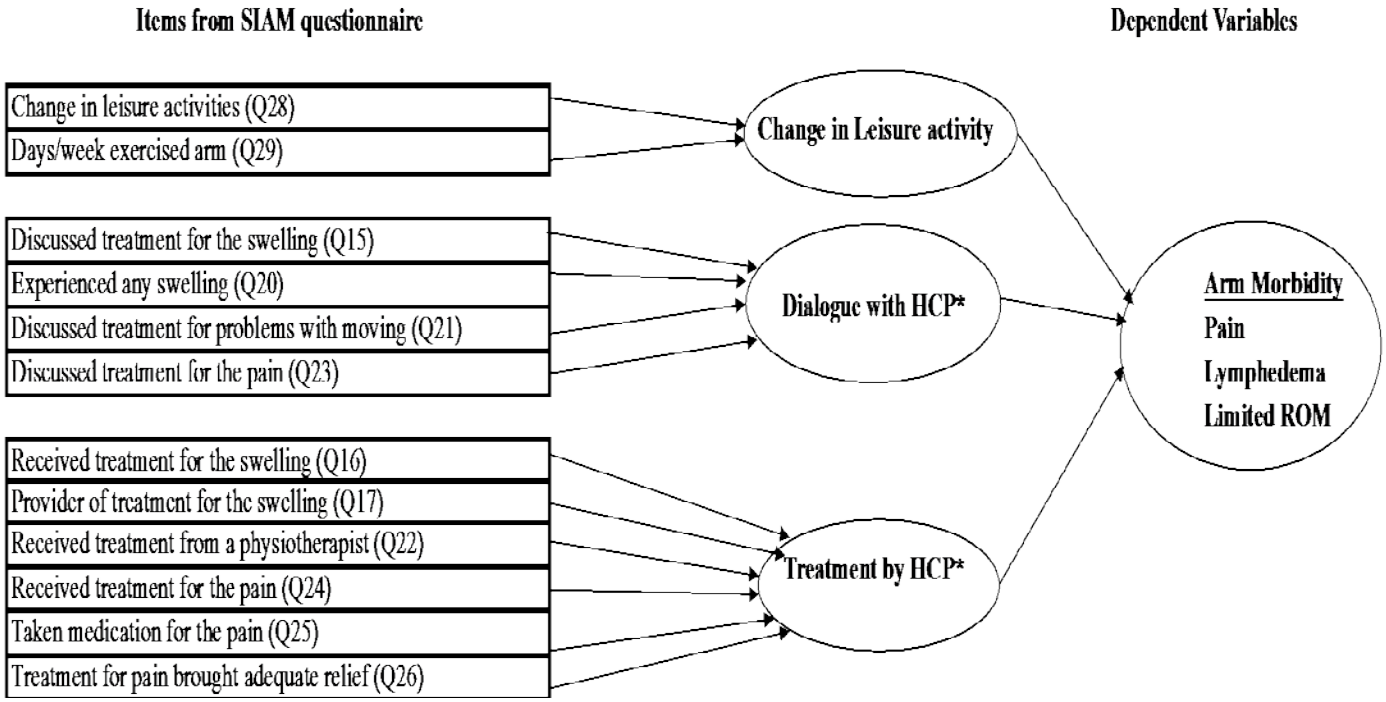
Table 2. Clinical Characteristics Table (*N* = 740)

Variable	Variable details	Number (*n*)	Percentage (%)
Tumor Stage:	Stage I	303	43.3
	Stage II	316	45.1
	Stage III	81	11.6
Type of Surgery:	Radical mastectomy	14	1.9
	Modified radical mastectomy	172	23.8
	Partial mastectomy or lumpectomy	538	73.3
Radiation	Yes	682	94.2
	No	42	5.8
Chemotherapy	Yes	486	67.1
	No	238	32.9
Hormonal therapy	Yes	539	74.4
	No	185	25.6

4.1.3 Descriptive Analysis Results

Descriptive statistics and frequencies were performed on all data. Outcome variables (pain, lymphedema and ROM limitation) were dichotomized as occurring or not occurring and frequencies for each variable obtained (Table 3). The 12 independent variables were items from the SIAM questionnaire, which were grouped into three: 1) change in leisure activities, 2) dialogue with healthcare practitioner (HCP), and 3) treatment by HCP, and their frequencies were computed. Independent variables were grouped and presented in Figure 2. (See Appendix F *Independent Variables Frequencies*).

Figure 2. Grouped Independent Variables



* HCP = Health Care Practitioners

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* HCP including family physicians, oncologists, surgeons, nurses, physiotherapists, occupational therapist, lymphedema specialists/lymph drainage therapists

All statistical tests were two-tailed, and the level of significance was set at $p < 0.05$. Results indicated that the percentage of women experiencing pain was 35.3% 6 to 12 months post surgery (T1), and 23.5% of participants still had pain 30 to 36 months post-surgery (T5). The percentage of women with lymphedema was 17.2 % at T1 and 21.2 % at T5. The percentage of women with ROM limitations was 63.6% at T1 and 34.3% at T5. Frequencies of outcome variables are detailed in Table 3.

Table 3: Frequencies of Outcome Variables

	Total *N* = 740	**T1** (6 to 12 months) **(*N* = 740)**	**T3** (18 to 24 months) **(*n* = 650)**	**T5** (30 to 36 months) **(*n* = 531)**
		n (%)	*n* (%)	*n* (%)
Pain				
	No pain	479 (64.1)	472 (72.6)	406 (76.5)
	Some pain	261 (35.3)	178 (27.4)	125 (23.5)
Lymphedema (5% arm volume difference)				
	< = 5%, no LE	612 (82.8)	528 (81)	422 (78.9)
	> 5%, LE	127 (17.2)	124 (19)	113 (21.2)
ROM (10^0 angle difference)				
	No ROM limitation	269 (36.4)	366 (56.2)	351 (65.7)
	Some ROM limitation	471 (63.6)	285 (43.8)	183 (34.3)

4.1.4 Bivariate Analysis Results

Bivariate analyses were conducted to determine the relationships between arm morbidity symptoms of pain, lymphedema and ROM with independent variables related to self-management practices, at each point in time. To identify those independent variables that were significantly associated with each dependent variable, bivariate analysis used chi square phi coefficient (φ) for nominal variables, crammer's V (ϕ) for ordinal variables and point bi-serial correlation (r_{pb}) for continues variables. Several independent variables related to self-management were significantly associated with outcome variables, at the 3 times analyzed.

Pain was associated with many of the independent variables, then ROM limitation, and then lymphedema. Only those significant independent variables were added to multivariate logistic regression models. Table 4, 5 and 6 shows bivariate results and provides details of significant independent variables at each time, T1, T3 and T5, respectively.

Table 4. Bivariate Analyses of Arm Morbidity Symptoms with Independent Variables Related to Self-management Practices, 6 – 12 months post surgery (T1)

	Pain	**Lymphedema**	**ROM limitation**
Demographics and Clinical characteristics	Age (r_{pb} = -.12, p = .001) Income (ϕ = .103, p = .05)	Age (r_{pb} = .116, p = .002) Tumor stage (ϕ = .14, p = .001) Type of surgery (ϕ = .13, p = .002)	Education (ϕ = .16, p = .003) Marital status (ϕ = .13, p = .039) Type of surgery (ϕ = .1, p = .028)
Self-management practices	Noticing change in leisure activities (φ = .21, p <. 001) Days in a week exercised arm (r_{pb} = .115, p = .001) Experienced any swelling (notice change) (φ = .18, p <. 001) Discussing treatment for problems with moving (φ = .14, p = .006) Discussing treatment for pain (φ = .19, p <. 001) Having a provider of treatment for the swelling (φ = .086, p = .029) Receiving treatment from a physiotherapist (φ = .12, p = .025) Receiving treatment for the pain (φ = .19, p <. 001) Medication taken for the pain (φ = .26, p <. 001)	Experienced any swelling (notice change) (φ = .086, p = .02) Receiving treatment for the swelling (φ = –. 214, p = .038) Having a provider of treatment for swelling (φ = .271, p <. 001)	Noticing change in leisure activities (φ = .138, p <. 001) Experienced any swelling (notice change) (φ = .13, p <. 001) Receiving treatment for the swelling (φ = .206, p = .044) Having a provider of treatment for swelling (φ = .13, p =. 001) Receiving treatment for the pain (φ = .112, p = .009) Medication taken for the pain (φ = .15, p <. 001)

φ = chi square phi coefficient, ϕ = Cramer's V, r_{pb} = point biserial correlation statistics, p = 0.05 level (2-tailed)

Table 5. Bivariate Analyses of Arm Morbidity Symptoms with Independent Variables Related to Self-management Practices, 18 – 24 months post surgery (T3)

	Pain	**Lymphedema**	**ROM limitation**
Demographics and Clinical characteristics	Type of surgery (ϕ = .11, p = .028)	Tumour stage (ϕ = .17, p < .001) Type of surgery (ϕ = .17, p < .001)	Age (rpb = .153, p < .001) Education (ϕ =. 14, p = .024) Type of surgery (ϕ = .13, p = .004)
Self-management practices	Noticing change in leisure activities (φ = .19, p < .001) Experienced any swelling (notice change) (φ = .19, p < .001) Discussing treatment for problems with moving (φ = .23, p < .001) Discussing treatment for pain (φ = .22, p < .001) Having a provider of treatment for swelling (φ = .18, p < .001) Receiving treatment for the pain (φ = .21, p < .001) Medication taken for the pain (φ = .33, p < .001)	Experienced any swelling (notice change) (φ = .1, p = .015) Having a provider of treatment for swelling (φ =. 32, p < .001) Receiving treatment for the pain (φ = .15, p = .004)	Experienced any swelling (notice change) (φ = .16, p < .001) Having a provider of treatment for swelling (φ =. 11, p = .024) Receiving treatment for the pain (φ =. 18, p < .001) Medication taken for the pain (φ = .20, p < .001)

φ = chi square phi coefficient, ϕ = Cramer's V, r_{pb} = point biserial correlation statistics, p = 0.05 level (2-tailed)

Table 6. Bivariate Analyses of Arm Morbidity symptoms with Independent Variables Related to Self-management Practices, 30 – 36 months post surgery (T5)

	Pain	**Lymphedema**	**ROM limitation**
Demographics and clinical characteristic	Tumour stage (ϕ =. 11, p = .036) Chemotherapy (ϕ = .09, p = .038)	Tumor stage (ϕ =. 15, p = .003) Type of surgery (ϕ = .11, p = .042)	Age (r_{pb} = .26, p < .001) Education (ϕ = .16, p = .027) Hormone therapy (ϕ = .11, p = .012)
Self-management practices	Days in a week exercised arm (rpb = .1, p = .023) Experienced any swelling (notice change) (φ = .24, p < .001) Discussing treatment for problems with moving (φ = .27, p < .001) Received treatment from a physiotherapist (φ = .17, p = .028) Receiving treatment for the pain (φ = .19, p = .002)	Discussing treatment for the swelling (φ = .24, p = .015) Experienced any swelling (notice change) (φ = .15, p = .002) Having a provider of treatment for the swelling (φ =. 27, p = .001)	Discussing treatment for the swelling (φ =. 13, p = .003) Having a provider of treatment for swelling (φ =. 19, p = .024) Receiving treatment for the pain (φ =. 22, p < .001)

φ = chi square phi coefficient, ϕ = Cramer's V, r_{pb} = point biserial correlation statistics, p = 0.05 level (2-tailed)

4.1.4.1 Pain. Results indicated that pain was statistically significantly associated with nine of the twelve independent variables related to self-management practices at T1. The significant variables were: noticing change in leisure activities (p <. 001), days in a week a participant exercised affected arm (p = .001), experiencing swelling (noticing change) (p <. 001), discussing treatment for problems with moving (p = .006), discussing treatment for pain (p <. 001), having a provider of treatment for the swelling (p = .029), receiving treatment from a physiotherapist (p = .025), receiving treatment for the pain (p <. 001), and taking medication for the pain (p <. 001).

Similarly, at T3, pain was statistically significantly associated with seven of the twelve independent variables. These were: noticing change in leisure activities (p < .001), experiencing

swelling (noticing change) ($p < .001$), discussing treatment for problems with moving ($p < .001$), discussing treatment for pain ($p < .001$), having a provider of treatment for swelling ($p < .001$), receiving treatment for the pain ($p < .001$), taking medication for the pain ($p < .001$).

Likewise, at T5, pain was statistically significantly associated with five of the twelve independent variables. These were: days in a week a participant exercised affected arm ($p = .023$), experiencing swelling (noticing change) ($p < .001$), discussing treatment for problems with moving ($p < .001$), receiving treatment from a physiotherapist ($p = .028$), and receiving treatment for the pain ($p = .002$).

4.1.4.2 Lymphedema. The results indicated that lymphedema was statistically significantly associated with three of the twelve independent variables related to self-management practices at T1. There were: experiencing swelling (noticing change) ($p = .02$), receiving treatment for the swelling ($p = .038$), and having a provider of treatment for swelling ($p <. 001$).

Similarly, at T3, lymphedema was statistically significantly associated with three of the twelve self-management variables. These were: experiencing swelling (noticing change) ($p = .015$), having a provider of treatment for swelling ($p < .001$), and receiving treatment for the pain ($p = .004$).

Likewise, at T5, lymphedema was statistically significantly associated with three of the twelve self-management practices. These were: experiencing swelling (noticing change) ($p = .002$), discussing treatment for the swelling ($p = .015$), and having a provider of treatment for the swelling ($p = .001$).

4.1.4.3 ROM limitation. Results indicated that ROM limitation was statistically significantly associated with six of the twelve independent variables related to self-management practices at T1. The significant variables were: noticing change in leisure activities ($p <. 001$), experiencing swelling (notice change) ($p <. 001$), receiving treatment for the swelling ($p = .044$), having a provider of treatment for swelling ($p =. 001$), receiving treatment for the pain ($p = .009$), and taking medication for the pain ($p <. 001$)

Similarly, at T3, ROM limitation was statistically significantly associated with four of the twelve self-management variables. These were: experiencing swelling (noticing change) ($p < .001$), having a provider of treatment for swelling ($p = .024$), receiving treatment for the pain ($p < .001$), and taking medication for the pain ($p < .001$).

Likewise, at T5, ROM limitation was statistically significantly associated with three of the twelve self-management variables. These were: discussing treatment for the swelling ($p = .003$), having a provider of treatment for swelling ($p = .024$), and receiving treatment for the pain ($p < .001$).

4.1.5 Multivariate Logistic Regression Results

Logistic regression tests were conducted to assess the effect of independent variables combined on outcomes of pain, lymphedema and ROM limitation. Demographic and clinical characteristic variables that were significant in bivariate analyses were also included in multivariate analyses. Three models were run at each time point for a total of nine models. Significance was set at $p < 0.05$, Wald statistics, odds ratios (O.R) and 95% confidence intervals (C.I) were obtained (See Appendix G for *Bivariate and Multivariate Results Tables*).

4.1.5.1 Pain. Analysis revealed that self-management practices of experiencing swelling (noticing change) (O.R = .580, C.I = .348 – .968, p = .037) and taking medications (O.R = .514, C.I = .312 – .848, p = .009) made significant contribution in pain at T1. The model chi-square, χ^2 = 39.116, df = 12, $p < .001$, Nagelkerke R^2 = .157 indicated that significant self-management practices accounted for approximately 16% of variance in pain. The prediction success of the null model was 64.4 % initially and increased to 66% for the final model with significant variables included.

Similarly, at T3, pain was associated with discussing treatment for pain (O.R = .389, C.I = .183 – .827, p = .014) and taking medication for pain (O.R = .477, C.I = .240 – .946, p = .034). The model χ^2 = 23.640, df = 8, p = .003, R^2 = .176 indicated that significant self-management practices accounted for approximately 18% of variance in pain. The prediction success of the null model was 53.3% initially and increased to 64.7% for the final model with significant variables included. The multivariate model for pain was not significant at T5.

4.1.5.2 Lymphedema. At T1, lymphedema was not significantly associated with any self-management practices, but age was a significant contributor. The older a woman is, the likelihood that they will develop lymphedema after breast cancer surgery (O.R =1.058, C.I =

1.011 – 1.107, p = .015). The prediction success of the null model was 65.2% initially and increased to 74.2% for the final model with significant variables included.

At T3, receiving treatment for pain was a significant self-management practice (O.R = .535, C.I = .286 – 1.000, p =. 05), and having advanced tumour stage was also significant (O.R = .454, C.I = .212–. 971, p = .042). The model χ^2 = 23.727, df = 6, p = .001, R^2 = .10, indicated that these variables accounted for 10% of variance in lymphedema. The prediction success of the null model was 79% initially and remained unchanged for the final model with significant variables included.

Similarly, at T5, experiencing swelling (noticing change) was a significant self-management practice for lymphedema (O.R = .277, C.I = .102–. 751, p = .012). The model χ^2 = 17.203, df = 6, p = .009, R^2 = .214, indicated that significant self-management practices accounted for approximately 21% of variance in lymphedema. The prediction success of the null model was 65.2% initially and increased to 74.2% for the final model with significant variables included.

4.1.5.3 ROM limitation. At T1, Analysis revealed that experiencing swelling (noticing change) was a self-management practice for ROM limitation (OR = .091, C.I = .013 –. 646, p = .017). Additionally, having a more invasive BrCa surgery made significant contribution to ROM limitation (O.R = 20.107, C.I. = 2.408 – 167.908, p = .006). The model Chi-square, χ^2 = 31.275, df = 16, p = .012, R^2 = .489 indicated that significant self-management practices accounted for approximately 48% of variance in ROM limitation. The prediction success of the null model was 75.9% initially and increased to 83.5% for the final model with significant variables included.

Similarly, at T3, receiving treatment for pain (O.R = .458, C.I =. 250–. 840, p = .012) and taking medications for pain (O.R = 1.704, C.I = 1.056 – 2.747, p = .029) were significant

self-management practices. Advanced age (O.R = 1.028, C.I = 1.005–1.050, p = .014) and having a modified radical mastectomy (O.R = 1.729, C.I. =1.018–2.937, p = .043) also made significant contribution to ROM limitation. The χ^2 = 37.740, df = 7, p <. 001, R^2 = .134, indicated that that significant self-management practices accounted for approximately 13% of variance in ROM limitation. The prediction success of the null model was 53.1% initially and increased to 63.5% for the final model with significant variables included.

Likewise, at T5, ROM limitation was associated with taking medication for pain as a self-management practice (O.R = 2.273, C.I = 1.338–3.862, p = .002). Additionally, advanced age made significant contribution (O.R = 1.045, C.I= 1.018–1.074, p = .001). The model χ^2 = 31.743, df = 5, p <. 001, R^2 = .155, indicated that significant self-management practices accounted for approximately 15% of variance in ROM limitation. The prediction success of the null model was 54.9% initially and increased to 62.3% for the final model with significant variables included.

It is evident that there is a relationship between self-management practices of '*change in leisure activities, dialogue with HCP* and *receiving treatment from HCP'* and symptoms of arm morbidity experienced months to years after breast cancer surgery.

4.1.6 Summary of Quantitative Results

In summary, findings indicated that 24% of participants reported pain 30 to 36 months post-surgery (T5). Lymphedema was experienced by 21% of participants at T5, and ROM limitation equally experienced by 34% of participants at T5. Bivariate analyses indicated that pain was associated with many of the self-management practices, followed by ROM limitation, and then lymphedema. Multivariate analyses indicated that self-management practices had small to moderate association with symptoms of pain, lymphedema and ROM limitation. These

quantitative findings validate and confirm the challenges BCS face in self-managing arm morbidity. When symptoms of pain, lymphedema and ROM limitations persist at 30-36 months, a significant proportion of BCS noticed change in leisure activities, then discussed their symptoms with a HCP and received treatment for their symptoms from HCP. Results suggest that self-management of arm morbidity requires ongoing collaboration between BCS and practitioners to improved self-management required for women to achieve optimal wellbeing after breast cancer.

4.2 Qualitative Results

The following section describes results from qualitative data. The aim of the analysis was to understand how women self-manage symptoms of arm morbidity after acute breast cancer (BrCa) treatments (objective 2), and the treatments options women experienced for managing their arm morbidity (objective 3). This section will first describe characteristics of the participants followed by thematic details of the findings.

4.2.1 Characteristics of the sample

All participants were female (n = 40) with an average age of 52 years old, ranging from 30 to 79 years old. Nearly half of the participants (47.5%, n = 19), had an income above $80,000 and 40% ($n$ =16) had obtained a university degree. In relation to clinical characteristics, many participants had received a combination of surgery, radiation and chemotherapy as part of their acute BrCa treatments. Following acute treatments, participants reported experiencing arm morbidity in the form of pain 62.5% (n = 25), swelling 72.5% (n = 29) and ROM limitation 82.5% (n = 33). Further descriptions of study participants are detailed in Table 7.

4.2.2 Themes Relating to Self-Management of Arm Morbidity

Two broad themes emerged related to breast cancer survivors' (BCS) self-management of arm morbidity after acute BrCa treatments (objective 2): 1) physical symptoms self-management and 2) psychosocial symptoms self-management. Three sub-themes related to physical symptoms: complex decongestive therapy, physical activity and increased self-awareness, whereas one sub-theme related to psychosocial symptom: self-management of uncertainty. Figure 3 provides a summary of self-management practices reported. Themes related to treatment options (objective 3) for arm morbidity were: rehabilitation and medications. Theme and subsequent sub-themes are detailed further.

Table 7. Demographics and Clinical Characteristics of Study Participants (*n* = 40)

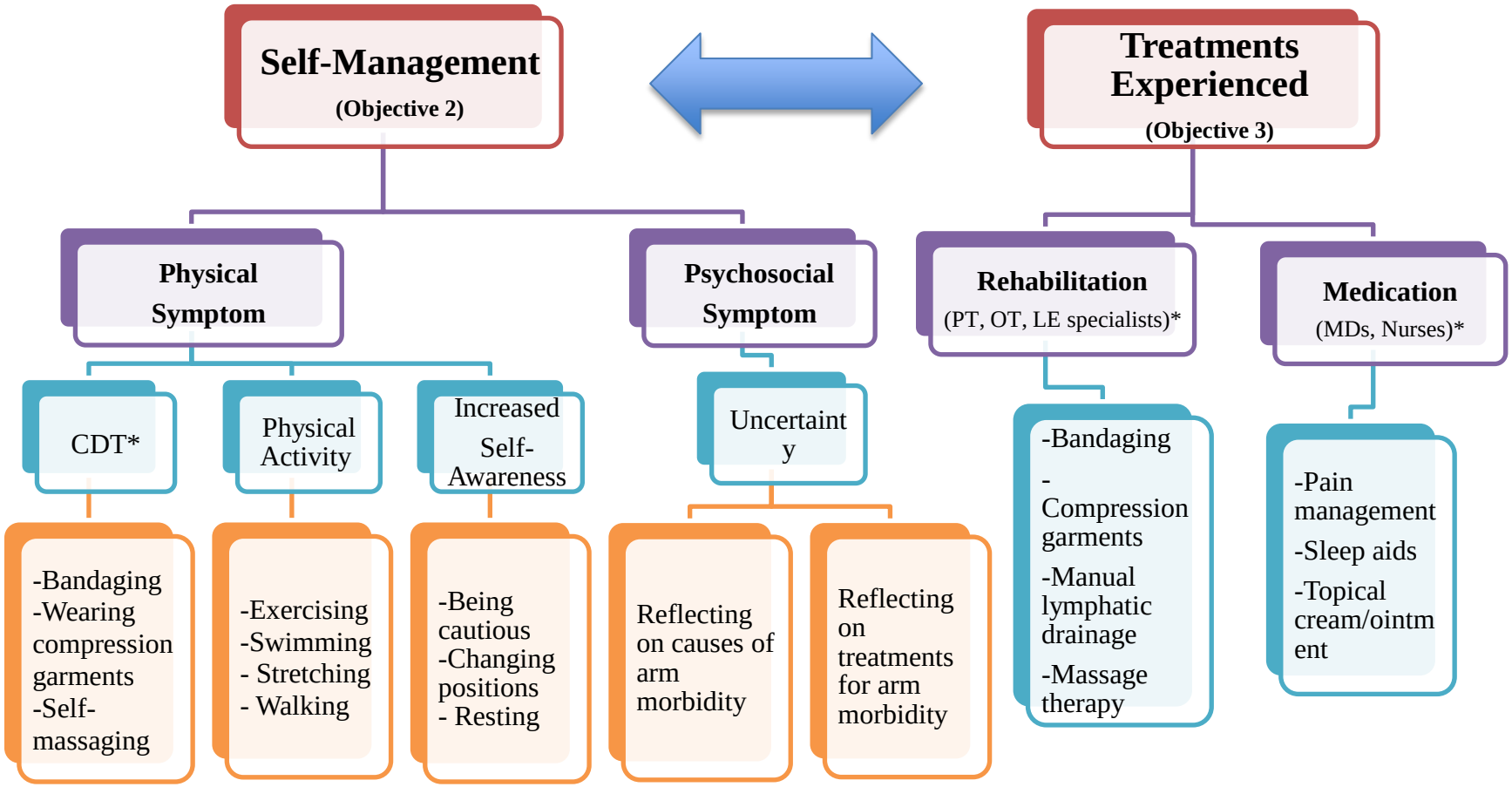
Characteristic	Responses	Number (*n*)	Percentage (*%*)
Age in years	Mean = 52, range 30 to 79		
Family Income	≤ $40,000	7	17.5
	$40,000 to 80,000	6	15
	≥ $80,000	19	47.5
	Not reported	8	20
Education	High school or less	11	27.5
	College	13	32.5
	University	16	40
Cancer Treatments	Radical mastectomy	1	2.5
	Modified radical mastectomy	12	30
	Partial mastectomy	27	67.5
	Radiation	38	95
	Chemotherapy	30	75
Arm Morbidity	Self-reported swelling	29	72.5
	Pain	25	62.5
	Range of motion limitation	33	82.5
	Discussed treatment for arm morbidity with healthcare practitioner	32	80
	Received treatment for arm morbidity by healthcare practitioner	21	52.5

4.2.2.1 Physical Symptom Self-Management

4.2.2.1.1 Complex Decongestive Therapy. The first sub-theme of physical symptom self-management is engagements with complex decongestive therapy (CDT). CDT is a treatment plan that combines different approaches (including bandaging, compression garments, manual lymphatic drainage, exercise, and self-care) depending on the needs of an individual. Participants expressed engaging in several practices that are consistent with CDT, as defined by the literature (Chapter 2). Examples of specific activities included bandaging, wearing compression garments and self-massaging.

Figure 3. Summary of Qualitative Themes

Women's perspectives of self-management practices performed and treatments experienced for managing arm morbidity



*CDT = Complex decongestive Therapy, PT = physiotherapy, OT = occupational therapy, LE = lymphedema, MD = medical doctor

4.2.2.1.1.1 ***Bandaging (n = 4)***. Of the 40 participants, 10% reported performing bandaging regularly to manage symptoms of lymphedema. Bandaging involves creating a soft cast on the arm by wrapping the arm with multiple layers. Bandaging is a main component of CDT, and is fundamental in managing moderate to severe lymphedema. One participant talked about her experiences with bandaging to manage swelling "*I wore the elastic bandage every day...then I started wearing just half days and then I started wearing just a couple days a week and slowly...the bandage seemed to compress it so that the swelling went down"* (f010)[†]. Another participant reported the need to bandage her arm before engaging in any activity that she anticipated the swelling to get worse, *"now when we go off hiking or anything, we've flown a few times since and I always wear my elastic bandage when I know I'll need it so that I shouldn't have to wear it all the time*" (f031).

4.2.2.1.1.2 ***Wearing compression garments (n = 16)***. Compression garments were used to manage mild lymphedema in different treatment plans. Compression garments were made of flexible material designed to apply pressure to the limb to keep lymphatic fluid moving in the right direction. Many participants (40%) expressed the need to wear compression garments regularly to manage symptoms of lymphedema and pain. When asked about self-management practices, one participant stated*"I do wear it [compression sleeve] if I feel the hand…the arm being a little thicker or heavier or achy, and then I'll put it on and I'll wear it a few hours a day"* (w041). Another participant stated "*I find sometimes, if it gets a little more swollen, it does help*

[†] Participants were assigned an alpha numeric: identified by site (m, Montreal; f, Fredericton/Saint John; s, Surrey; w, Winnipeg) and a participant identification number.

to have the sleeve on, like there does come a point where I say, "o.k. If I wear the sleeve for a day, it's going to feel better"" (f017).

4.2.2.1.1.3 *Self-massaging (n = 9)*. Of the 40 participants, almost quarter (22.5%) reported self-massing the arm to relieve stiffness and improve lymphatic fluid circulation. When asked to elaborate on self-management practiced, one participant explained, "*Symptoms are relieved if I massage my arm upward, in an upward motion… I do the manual exercises myself every day"* (w033). Another participant reported self-massing as an intervention she practiced to help her get through a work day, "*I started doing like a massage and going up the arm and stuff like that. When it gets really bad I'll do that even at work sometimes"* (m240).

4.2.2.1.2 Physical Activity. Physical activity was the second sub-theme that emerged as a type of physical symptom self-management. This encompassed different forms of physical activity that included exercising, stretching, swimming, and walking.

4.2.2.1.2.1 *Exercising (n = 16)*. Exercising encompasses the specific exercises that were suggested by a health care practitioner (HCP) to manage symptoms of arm morbidity, as opposed to physical activities participants engaged in independent of a HCP's recommendation. Most participants reported receiving recommendations for specific exercise, either from a physiotherapist or a lymphedema specialist, to improve arm or shoulder range of motion (ROM) limitations. When asked about exercises performed, one participant stated, *"I am doing a lot of exercises that were recommended. Those exercises were given by the therapist that I am receiving lymphatic drainage from"* (m313). Participants expressed that exercises performed were initially suggested by a HCP and were carried on and performed on a regular basis. Another participant stated, "*I try to make it a regular routine where I do my exercises every morning after I've had my shower. If I don't do them by 3 or 4 in the afternoon I really notice that it is less mobile* (s154).

4.2.2.1.2.2 *Stretching (n = 5)*. To alleviate symptom of shoulder stiffness and arm discomfort, some participants reported stretching the affected arm. When asked to describe self-management practiced, one participant stated "*A little body stretch and that's how I start my day…*"(w075). Another one stated, "*I've tried to stretch it. I've tried to stretch the tendons to see if that will ease it up, and it does for a short time*" (s094).

4.2.2.1.2.3 *Swimming (n =4)*. Few participants reported that swimming was a way to manage symptoms of arm morbidity. Engaging in swimming contributed to better range of motion (ROM) of the arm and/or shoulder. One participant described the activity well, saying, *"I kept swimming. I swam all the time…I was swimming and that I had such complete mobility in my arm. I could move it backwards; I could move it up, down, forwards, etc. ... You know, because that water pressure on your arm all the time helps"* (f027).

4.2.2.1.2.4 *Walking (n = 2)*. A few participants reported walking as the physical activity to manage their symptoms and walking was reported to be part of attaining a healthier lifestyle. One participant stated, "*I've done a lot of walking and I've really tried to be consciously healthy about everything"* (f031). Another participant emphasized the need to be vigilant in monitoring symptoms of swelling, even when one engaged in physical activities such as walking, "*Well, you'd think it was pretty funny, sometimes I walk along for a little while with my arm above my head (laughter)...*"(s154).

4.2.2.1.3 Increased Self-Awareness. Self-awareness was a third sub-theme that emerged as a type of physical symptom self-management. This encompassed different forms of self-awareness that included being cautious, changing positions and resting.

4.2.2.1.3.1 ***Being cautious (n = 26)***. More than half of the participants (65%) expressed becoming more aware of their affected arm and being cautious of how they performed certain tasks. Participants expressed the need to be vigilant in noticing changes to the affected arms.

One participant described the need to make conscious adjustments on a regular basis, "*Now it's an adjustment you know in what I can do, like even picking up a bag of groceries I have to consciously use my right hand"* (f031). Another participant expressed encountering ROM limitations; she did not have prior to acute BrCa treatments,

> *I'm cautious about not carrying as much weight in my left arm, which is my affected arm. As I do in my right arm, or supporting my left arm when I'm doing something where as I normally wouldn't have supported it, I would of let it just, I, I'm more conscious about, protecting it.* (w009).

Another participant stated,

> *If l walk the dog and I put the leash on my left side and the dog pulls, ... I have a problem by the time I get back, so, I've done some minor adjustments there, but, it's really a trial and error*. (w037).

Another participant detailed how she became more aware of how her arm felt like. She richly detailed her symptoms saying,

> *I compare it like if you were wearing a leather glove that is too small for you…pressure from inside. Even the hand will burn, swell, prickle, mostly at night, you are not able to sleep because all the inside swell, it is painful, and then prickles, like numb.* (m243).

4.2.2.1.3.2 *Changing positions (n = 9).* Some participants expressed lifting up the affected arm to alleviate swelling. Usually, elevation of the arm involved propping the arm on an incline, so that the hand is above the wrist and the elbow is higher than the shoulder. This slanting of the affected limb encourages lymphatic flow up the affected arm; alleviating subtle swelling that comes and goes. One participant reported, "*She* [physiotherapist] *does say to raise the my arm over my head and open and close my hand, about as often as I can during the day, which keeps the liquid, fluid I guess, pushing down*" (w041). To alleviate pain and numbness, participants expressed supporting affected arm using pillows or cushions. One participant explained, "*It helps when I um... I put my arm up on the chesterfield with a pillow on top of it and that does relieve the pain an awful lot*" (w073). Another participant mentioned "*I try to*

watch the positioning at night to make sure that I'm not doing something awkward that might be producing the numbness" (s063).

4.2.2.1.3.3 *Resting (n = 11).* Even though several participants (27.5%) had returned to their pre-cancer routines, in regards to the use of the affected arm, participants reported the need to rest to alleviate symptoms of arm morbidity experienced. Participant described their experiences with pain and how resting resolves symptoms. One participant said, "*Then it tends to, you know* [ache]*, then I have to rest it a day or two and then I'm back to normal*" (m042). Another participant expressed taking time off paid work when necessary, "*every once in a while I kind of overdo it and I didn't think I would still feel the effects of it, but I just talk to my boss and take a day off and kind of rest"* (f010). Another participant reported taking time to rest while exercising, then resuming exercising after symptoms abate "*The first thing I know that I have to do is, is rest it, and not work it anymore…then I rest it, and then I start doing a little bit more exercise..."*(w037).

In summary, self-management of physical symptoms required participants to engage in different practices such complex decongestive therapy, physical activity and increased self-awareness, to manage symptoms of pain, lymphedema and ROM limitations.

4.2.2.2 Psychosocial Self-Management of Uncertainty

Psychosocial symptom self-management involved managing uncertainty about the future of arm morbidity. Uncertainty was a common experience that occurred, and many participants continued to question the ambiguity of whether or not the physical symptoms of arm morbidity were long-term and would continue after acute cancer treatments had completed. Participants discussed reflecting on the causes and treatments of arm morbidity, which was the root cause of their uncertainty. Thus, two sub-themes emerged that included reflecting on causes of arm morbidity, and reflecting on treatments for arm morbidity.

4.2.2.2.1 Reflecting on Causes of Arm Morbidity (*n* = 19). Reflecting on causes of arm morbidity was the first sub-theme of uncertainty. Almost half of the study sample (47.5%) expressed concerns of worry about the causes of arm morbidity. Uncertainty arose because of participants' inability understand and predict their future living with the unpredictable symptoms and ambiguous triggers of arm morbidity. One participant describes her uncertainty saying,

> *I really don't know what triggered it* [pain], *but I was fine one day and I got up the next morning and I had pain in my arm and I couldn't put my bra on. My breast swelled up overnight … it was definitely worrisome because I was fine one day and the next day... and it has never really been resolved.* (f016).

Another participant recounted,

> *I don't think there was anything that triggered it that I noticed. I hadn't done anything, you know, out of the ordinary… I feel a little more strain in the shoulder and under the arm from that, but I don't know whether it causes any more swelling or not.* (w041).

Participants continued to emphasize the need for ongoing symptom management during survivorship. Nonetheless, participants raised concerns about the lack of knowledgeable HCP to support their needs in understanding causes of arm morbidity during cancer survivorship. One participant recalled her struggle in finding solutions to her arm problems, reporting "*I said, what do I do next because I can't seem to get any cooperation from Dr.* [name]*'s office. The other thing was their lack of interest and knowledge of breast cancer and my, my special case of that*" (f027). Another participant detailed her experience saying,

> *I did talk about it with my medical oncologist and ... She said that there's, they don't know why but they have noticed it amongst other patients who've had chemotherapy that they have this dysfunction* [arm numbness]. *Sometimes it resolves over time, sometimes it doesn't.* (s063).

Another participant reported questioning why she was experiencing swelling, especially when her primary HCP was unfamiliar with arm morbidity. She explained,

> *I kept thinking you know, what did I do, you know? Was I doing this or was I doing, you know, how you just…well it persisted and it got worse and ... I went in to see my GP and she said I've never seen anything like that.* (f029).

While some participants described encountering HCP with limited knowledge on management of arm morbidity, one participant reported having a HCP that recognized the need for a specialized practitioner in managing lymphedema. The participant reported,

> *I saw oncology, I saw my surgeon. My surgeon suggested I see a massage therapist. The massage therapist after a few sessions said, no, I'm not doing anything for you, you should see a physiotherapist that specializes in lymphedema. It was quite a process.* (f016).

For many participants, reflecting on causes of arm morbidity persisted long after acute cancer treatments completed. However, reflecting on causes of arm morbidity was hypothesized as a first step towards finding solutions for symptoms experienced; therefore, a first step in self-management of psychosocial needs of uncertainty.

4.2.2.2.2 Reflecting on Treatments for Arm Morbidity (*n* = 12): Reflecting on treatments for arm morbidity was the second sub-theme in management of psychosocial needs of uncertainty. More than quarter (30%) of participants expressed ongoing uncertainty about treatments of arm morbidity during cancer survivorship. Despite the current guidelines for clinical management of arm morbidity available to HCPs, several participants encountered difficulties in finding HCP who would manage their symptoms. One participant recalled initiating dialogue with a HCP about symptoms of arm morbidity, who acknowledged the symptoms, but did not intervene. The participants reported, "*I could feel the heaviness. It's just heavy, like* [a] *leg… why does this one feel like that? ... all he said, its urn, it's from the treatment*" (m210). Another participant explained her experience, "*I went in there for my first appointment and the young man said, oh you are the first person and for the next appointment I'll have to look it up and all and refresh myself. So I didn't go back*" (f031).

Another participant expressed having no HCP who could refer her to a lymphedema specialist, and she had to be proactive in seeking help to manage symptoms. "*I decided, nobody*

referred me anywhere, I found by myself the information. I decided to go for lymphatic drainage" (m313). Another participant reported getting conflicting views on lymphedema management, "*when I told that I was going for lymphatic drainage every week during radiation, the radio oncologist said it was good. But, the surgeon said ... she found that funny. To her, she wasn't seeing that it will do anything*" (m313). Another participant stated,

> *My shoulder's been sore ever since the radiation and um, and I actually remember the oncologist saying that it was normal to have the pain there, um I tried going to, having acupuncture for it* [shoulder pain] *and I didn't see that that was helping at all, and that has gotten less over the years too, but every once in a while it just aches.* (s164)

One participant reported that she recognized a need to find lymphedema specialists. The participant stated,

> *The family physician is the first person you go to of course, but then you can't expect your family physician to do everything. You have to take it upon yourself...when you get ill; it's your responsibility to look for care and the right person to look after you. Because if you don't, you can fall through the cracks*. (f027)

While reflecting on treatment options experienced, many participants raised concerns about fear of cancer reoccurrence, guilt for surviving cancer, anxiety about body image and ongoing worry. Fear of cancer reoccurrence represented ongoing concern intensified by ongoing physical symptoms experienced. One participant recounted her fear of cancer reoccurrence, stating "*I was feeling* [numbness], *... didn't necessarily mean that there was a tumor back pressing on more nerves or something like that, which was my biggest concern"* (s063).

Another participant said,

> *I survived so I have to move on because there's obviously something for me to do. A reason for me to be here. There's a lot of guilt. I'm thankful that I've survived too, so I have to try to, get myself back together and, figure out why God's let me stay.…*(w009)

Another participant expressed anxiety about her appearance when wearing compression garment. She stated, "*I am wondering if it* [swelling] *will stop or continue, I certainly don't want*

to have a swollen hand or a compression garment ... It seems that everybody will look at me with that. So yes, there is quite a lot of anxiety" (m313).

Conversely, one participant reported that she had learned to live with the symptoms despite ongoing worry, she stated,

> *I think... it* [swelling] *was always the same, you know like... it will always be there and it's not going to go away...I have to keep my health up, if I keep worrying about my health and my cancer, I am going to get worse...but I am a strong woman and I like to keep my attitude to stay alive yet for a while...* (w002)

Therefore, with regard to psychosocial self-management of uncertainty, participants reported ongoing reflections about causes and treatments of arm morbidity during breast cancer survivorship. Participants described poor understanding of causes of arm morbidity and reported difficulties in managing pain, lymphedema and ROM limitations. Due to limited knowledge on self-management or management by HCPs of arm morbidity symptoms, participants reported fear of cancer reoccurrence, worry and anxieties related to impaired body image. Additionally, participants reported heightened uncertainties when they encountered HCP with limited expertise in managing arm morbidity.

4.2.3 Themes Relating to Treatment Options for Arm Morbidity

To ensure that BCS can resume their physical functioning, management of arm morbidity aimed to reduce the sequellae of acute BrCa treatments. Themes related to treatment options experienced were categorized as: rehabilitation and medications. It is important to note that these themes overlap and can occur concurrently.

4.2.3.1 Rehabilitation

Rehabilitation is the first theme reported by participants living with arm morbidity. Rehabilitation involved managing pain, decreasing swelling, regaining arm and shoulder strength and improving physical functioning of the affected arm. For management of pain, lymphedema

and ROM limitation, participants reported receiving rehabilitative treatment interventions from different HCPs, including physiotherapists, occupational therapists, lymphedema specialists and massage therapists. Figure 2 provides a summary of rehabilitative interventions reported by participants. Interventions provided by HCP are classified as complex decongestive therapy (CDT) or non-CDT/unknown. The classification is based on the international best practice guidelines for the management of lymphedema (Lymphedema Framework, 2006).

4.2.3.1.1 Complex Decongestive Therapy. The first sub-theme of rehabilitation of physical symptoms is complex decongestive therapy (CDT). CDT is a treatment plan that combines different interventions including bandaging, compression garments, manual lymphatic drainage, exercise, and self-care. To improve symptoms of pain, lymphedema and ROM limitation, participants reported receiving treatment interventions that are in line with CDT. Several participants reported improved symptoms with the use of one intervention or a combination of interventions. One participant stated, "*I went to see* [name] *who is a physiotherapist and she knew a lot about breast cancer...she said, we'll measure your arm radiation* [radius] *and get you one of those sleeves that are custom fitted for you*" (f027). Another participant stated, "*So I made an appointment through the* [name] *physiotherapy clinic and I asked specifically for someone who was familiar with lymphedema because at the time I did have swelling*" (f031). Another participant reported,

> *The physiotherapist in the breast center clinic... she noticed it* [swelling] *right away that it was, getting a little bit out of control, she showed me exercises and gave a lot of information... I saw her a week ago, and she says everything is down...*(w073)

Many participants reported improved arm and shoulder mobility by utilizing CDT interventions provided by physiotherapists. One participant said, "*it* [physiotherapy] *certainly has made a difference in my* [arm] *movement*" (f013). Another participant said, "*I had*

experienced movement problems with my arm and I went to [name of physiotherapist] *for some time, and we did get the arm moving, it is moving properly*" (f011). Another participant said,

> *I'm feeling better, because since then I've had some physio [physiotherapy] and resolved some of the issues with my shoulder*" (f016). Another stated, "*The swelling has always been there, but then I was doing therapy at* [name of clinic] *and then I could move my arm, further up*. (m210)

Another participant stated, "*I've gone to see some um, lymphedema massage, and just to kind of make sure that I've learned how to massage so that I'm improving drainage and circulation in my arm*" (w009).

Depending on symptom severity, some participants required combined treatment interventions to manage symptoms experienced. One participant said "*Lymphedema drainage, compression and the sleeve*" (m243). Another participant reported the benefits of combined treatments, "*Along with the manual massage, the compression did help and it* [painful lymphedema] *never came back*" (f016). While combined treatment is the gold standard in managing arm morbidity, associated complexities can be challenging for BCS. One participants highlights the complexity of combined treatment modalities,

> *I have to leave work early so I can have a massage done, so I can get the sleeve fitted... I was going to physio... It* [lymphedema] *did come back and this time the lymphopress was totally ineffective. So I have now changed and I am doing manual lymphatic drainage, which is extremely hard to find out about and hard to pay for. Its very expensive*. (s135)

4.2.3.1.2 Non-CDT/Unknown. Other participants reported receiving treatment for experienced physical symptoms, however it is unclear from the data whether the treatment received is CDT. Therefore, such interventions are classified as non-CDT or unknown. Participants reported receiving massage therapy, but it is undistinguishable whether the massage provider or massage therapist was specialized in managing symptoms of arm morbidity or not. One participant reported, "... *she* [massage therapist] *did the massage and everything, but other than that, that's been the extent of my treatment*" (f017).

Another participant stated, "*I used to notice that my breast about once a month would be swollen... and I haven't noticed that in a while and I think it is because of the massaging that is helping that*" (f011). Another one stated, "*So, I did start massage therapy and that really did help. And, it lasted, the roping actually was the worst for probably about say a month to six weeks, and then it started to diminish and lessen a bit* (f012).

It is unclear whether one participant received CDT or not, but she stated "*Each time I would go in she* [therapist] *would mark my arm and would measure and compare it to my other arm to see if there was a difference. But there were no extra, any exercises or anything*" (f010). One participant acknowledges that the massage received was from a non-HCP, she stated "*... not by anyone that's, has a medical background... she massages my arm and that seems to help a lot*" (s118).

4.2.3.2 Medications

Medications, is a second theme related to treatment options experienced by BCS in managing symptoms of arm morbidity. Of the 40 participants, 5 (12.5%) reported taking medications to manage symptoms associated with arm morbidity. Few participants described taking medications that are classified as: analgesics for pain management (n = 3), sleep aids to promote better sleep (n = 1), and topical creams to manage painful swelling (n = 1). To manage symptoms of pain, one participant stated, "*Sometimes just an extra strength Tylenol or a 2-22 and then the pain, you know I rest my arm then and then the pain goes away...*"(w073). Another participant mentioned the need to take pain medication regularly to manage pain, "*I was popping ibuprofen quite regularly to try to, um, 'cause it has an anti-inflammatory effect*" (s114).

Some acute cancer treatments were associated with sleep difficulties. One participant reported taking sleep aids to promote better sleep, she says, "*I actually take sleeping pills so I*

can sleep... I'm still experiencing a lot of night sweats and I have right since the whole process of radiation" (s164).

Another type of medication reported is classified as a topical cream. One participant reported using a topical cream to manage pain and swelling to the affected breast, she stated, "*I do put the cream on in the morning and at night. This keeps it* [painful lymphedema] *under control, as long as one does not, push, uh, on the side of the breast, too hard, I'm fine, I can function*" (w037).

Therefore, with regard to treatment options experienced for managing symptoms of arm morbidity, participants reported receiving treatments from HCP including physiotherapists, lymphedema specialists and massage therapists. Rehabilitative treatments received were classified as CDT (such as bandaging, compression garments, manual lymphatic drainage and exercise) or non-CDT/unknown (such as massage therapy). A small number of participant reported taking medications to manage symptoms associated with arm morbidity, such as pain and sleep difficulties.

4.2.4 Summary of Qualitative Results

In summary, this qualitative descriptive analysis was set out to understand how women self-manage symptoms of arm morbidity, and treatment options experienced for managing pain, lymphedema and ROM limitation during BrCa survivorship. Inductive content analysis of participants' descriptions of their experiences, revealed that self-management has many components, encompassing physical symptoms self-management and psychosocial self-management of uncertainty; these can overlap and can occur concurrently. Treatments options experienced were rehabilitative interventions to manage pain, decrease swelling and improve arm and shoulder functioning, and medications to manage pain, painful swelling and sleep difficulties.

4.3 References

Brown, J., Cheville, A., Tchou, J., Harris, S., & Schmitz, K. (2014). Prescription and adherence to lymphedema self-care modalities among women with breast cancer-related lymphedema. *Supportive Care in Cancer, 22*(1), 135–43.

Kaiser, K. A., Affuso, O., Beasley, T.M. & Allison, D. B. (2012). Getting carried away: a note showing baseline observation carried forward (BOCF) results can be calculated from published complete-cases results. *International Journal of Obesity, 36* (6), 886-889. doi: 10.1038/ijo.2011.25.

Liu-Seifert, H., Zhang, S., D'Souza, D. & Skljarevski, V. (2010). A closer look at the baseline-observation-carried-forward (BOCF). *Patient Preference and Adherence, 4*, 11–16.

Polit, D. F. (2010). Statistics and data analysis for nursing research (2nd ed.). Upper Saddle River, New Jersey: Pearson.

Thomas-Maclean, R. Spriggs, P., Quinlan, E., Towers, A., Hack, T., Tatemichi, S., Miedema, B., Kwan, W. & Andrea Tilley, A. (2010). Arm morbidity and disability in Canada: Reporting the current status from Canada. *Journal of Lymphoedema,* 5(2), 33-38.

Thomas-MacLean, R., Towers, A., Quinlan, E., Hack, H., Winkle Kwan, W., Miedema, B. & Graham, P. (2009). “This is a kind of betrayal”: A qualitative study of disability after breast cancer. *Current Oncology, 16*(3), 26-32.

Chapter 5: Integrated Discussion

Integrated Discussion

5.1 Introduction

The objective of this thesis was to explore self-management practices performed by breast cancer survivors and the treatments women receive from healthcare practitioners in managing symptoms of arm morbidity. A literature review indicated that various clinical diagnostic standards and limited knowledge about arm morbidity contributed to poor management of the condition (Chapter 2). A secondary data analysis design was detailed (Chapter 3), followed by study findings (Chapter 4). This chapter will highlight key findings in relation to the current literature, followed by study strengths and limitations. The chapter will conclude with discussion of results implications for nursing practice, including the role of advanced practice nurses, nursing education and nursing research.

5.2 Summary of Thesis Findings

To meet the study objective, a secondary analysis of both quantitative and qualitative data were undertaken. Quantitative analysis of data (N = 740) identified the relationship between self-management practices and associated symptoms of arm morbidity. Qualitative analysis of data from a subset of BCS (n = 40) was used to understand how women self-manage and treatments women receive from healthcare practitioners (HCP) in managing arm morbidity.

Descriptive results showed that participants reported ongoing symptoms of pain (24%), lymphedema (21%), and range of motion limitation (34%) 30 to 36 months post-surgery . Bivariate results indicated that pain was associated with many self-management practices, followed by ROM limitation, and then lymphedema. Multivariate results showed that that self-management practices had small to moderate association with symptoms of pain, lymphedema and ROM limitation.

Through inductive content analysis of qualitative data, two themes emerged relating to self-management of arm morbidity: 1) self-management of physical symptoms and 2) self-management of psychosocial symptom of uncertainty. Two themes emerged relating to treatment options for arm morbidity management: 1) rehabilitation and 2) medications. Findings indicated that BCS continue to express unmet needs during survivorship and highlighted the complexities associated with self-management of arm morbidity. Moreover, uncertainty about causes and treatments of physical symptoms were heightened by encountering HCP with limited knowledge on clinical management of arm morbidity. Treatment options reported the most often by participants included physiotherapy, massage therapy, manual lymphatic drainage, as well as medications. It was noted that self-management practices overlap and can occur concurrently for managing multiple symptoms. A summary of findings is detailed in Table 8.

Table 8. Summary of Thesis Findings

Study Objectives	Study Findings
1. To identify the relationship between self-management practices and symptoms of pain, lymphedema and ROM limitations experienced at three points in time **Quantitative** analysis	**Descriptive analyses** indicated that the percentage of women with pain lowered: 24% of participants reported pain 30 to 36 months post surgery (T5); a change from 35% 6 to 12months post surgery (T1) and 27% at 18 to 24 months post surgery (T3). The percentage of women with lymphedema was higher at T5 21%, a change from 17% at T1, 19% at T3. The percentage of women with ROM limitation lowered: 34% of participants reported ROM limitation at T5, a change from 64% at T1 and 44% at T3. **Bivariate analyses** indicated that pain was associated with the most self-management strategies, then ROM, the lymphedema. See Table 4, 5 and 6 for details. - Pain was statistically significantly associated with nine of the twelve independent variables related to self-management practices at T1, seven of the twelve self-management practices at T3, and five of the twelve self-management practices at T5. - Lymphedema was statistically significantly associated with three of the twelve independent variables related to self-management practices at T1, T3 and T5 - ROM limitations were statistically significantly associated with six of the twelve independent variables related to self-management practices at T1, four of the twelve self-management practices at T3, and three of the twelve self-management practices at T5. **Multivariate logistic regression analyses** revealed that: - At T1, when significant independent variables were considered, self-management practices had small association with pain (R^2 = .157), and lymphedema (R^2 = .222), and moderate association with ROM limitation (R^2 = .489). - Similarly, at T3, when significant independent variables were considered, self-management practices had small association with pain (R^2 = .176), lymphedema (, R^2 = .10) and ROM limitation (R^2 = .134). - The model for pain was non-significant at T5, however, when significant independent variables were considered, self-management practices had small association with lymphedema (R^2 = .214) and ROM limitation (R^2 = .155).

Study Objectives	Study Findings
2. To understand how women self-manage symptoms of arm morbidity after acute breast cancer treatment (**Qualitative** analysis)	Self-management has many components involving physical symptoms and psychosocial management of uncertainty. - Physical self-management included practices of complex decongestive therapy (CDT), physical activity and increased self-awareness. CDT encompassed bandaging, wearing compression garments and self-massaging. Physical activities involved arm and shoulder exercises, swimming, stretching and walking. Increased self-awareness involved being cautious, changing positions and resting. - Psychosocial management of uncertainty was achieved through reflections about causes and treatments of arm morbidity. Participants expressed ongoing concerns of worry, fear of cancer reoccurrence and body image anxiety. Encounters with healthcare practitioner (HCP) with limited knowledge on management of arm morbidity contributed to heightened uncertainty. Self-management strategies may overlap and can occur concurrently for managing multiple symptoms.
3. To explore the treatments women receive from healthcare practitioners to manage their symptoms of arm morbidity (**Qualitative** analysis)	Participants reported receiving treatments from multidisciplinary HCPs, most of which were physiotherapists, massage therapists, lymphedema specialists for manual lymphatic drainage therapists, and physicians for medications. - HCPs offered rehabilitative treatment interventions to manage pain, lymphedema and ROM limitations. Rehabilitative treatment options reported were classified as CDT (e.g. bandaging, compression garments and manual lymphatic drainage) or non-CDT/unknown interventions (e.g. massage therapy). - A few participants reported receiving treatment in the form of medications prescribed by physicians. Different medications were taken to alleviate symptoms of painful lymphedema and sleep difficulties. Medications received were classified as: analgesics, sleep aids and topical creams.

This research has demonstrated that BCS continue to experience symptoms of arm morbidity, and HCPs do not always clearly communicate self-management strategies to them. These finding underscore opportunities to improve arm morbidity self-management education and support. The literature indicated that evidence-based clinical guidelines have been developed for lymphedema; however, this study found that management of arm morbidity is associated with limited knowledge of evidence-based management strategies. BCS living with lymphedema, pain and ROM limitations experience symptoms beyond that of simple swelling of the affected limb, and management of symptoms is burdensome (Ridner, Dietrich & Kidd, 2011; Thomas & Hamilton, 2014).

Oncology nurses are well positioned as part of the broad health care system, to utilize their clinical knowledge and skills to identify and implement survivorship care plans, as communication tools, to facilitate improved transition from acute cancer settings to primary HCPs during survivorship (Ferrell, Virani, Smith, & Juarez, 2003; Miller, 2008; Schulmeister & Gobel, 2008). A multidisciplinary approach to arm morbidity management, which includes physicians, nurses, therapists and specialists, is likely needed to maximize not only self-management practices, but also to improve all symptom outcomes during survivorship (Ridner, Dietrich & Kidd, 2011).

5.3 Relating Findings

5.3.1 Symptoms of Arm Morbidity.

Pain. This study revealed that a significant number of BCS live with unresolved symptoms of pain, lymphedema and ROM limitation. The number of participants who reported pain at 30 to 36 months post surgery (24%) showed a slight improvement in the number of participants who reported post-operatively up to 6 months post surgery (58%) (Miaskowski et

al., 2014). Similar findings have been reported in studies evaluating pain 6, 12 and 36 months post surgery (Karki, Simonen, Mälkiä, & Selfe 2005; Nesvold, Reinertsen, Fosså & Dahl 2011). However, neither of these studies was conducted in Canada, and this study shows that Canadian patients are reporting similar pain without adequate relief from management strategies in place. Chronic pain is frequently reported after breast cancer surgery, and it is not well managed by HCPs (Schou Bredal et al., 2014). High intensity pain has been reported shortly after surgery and lower incidences reported years later, but pain still affects recreational and leisure activities up to 43 months post surgery (Miaskowski et al., 2014; Miedema et al., 2011).

The cause of chronic pain in BCS remains unknown to date, but factors associated with pain have previously been explored and include: aggressive surgical procedures with extended nodal dissection, age, pre-existing chronic pain, pre-existing comorbidities, obesity, anxiety and depression (Boquiren et al., 2016; De Groef et al., 2017; Hack et al., 2010; Mansel et al., 2006; Nesvold et al., 2011; Stubblefield & Keole, 2014). Other factors include scar tissue formation after surgery, nerve dysfunction, protective posturing and kinesiophobia, which may lead to shortening of surrounding tissue, including the pectoralis major and minor muscles (Stubblefield & Keole, 2014). Furthermore, many participants expressed anxiety from their arm morbidity and reciprocal relationship have been found between chronic pain and anxiety (Schou Bredal et al., 2014). As evidenced by the percentage of BCS living with pain up to 36 months post-surgery in this study, finding highlights the need for improved management strategies to identify the cause and treatment of pain for BCS.

Lymphedema. The percentage of participants with lymphedema increased from 17% (6 to 12 months post-surgery) to 21% (30 to 36 months post surgery). Comparable findings are reported 36 months and 47 months post BrCa surgery (Nesvold et al., 2008; Nesvold et al.,

2011). Higher incidences of lymphedema are reported in a study examining lymphedema education, practices, and perceived barriers at 12 and 24 months post surgery (Ridner, Dietrich & Kidd, 2011). Incidences and risk factors associated with various degrees of lymphedema have been reported by Cormier and colleagues, who found that 20% of the participants already had arm volume difference greater than 5% post-surgery (Cormier, Xing, Zaniletti, Askew, Stewart & Armer, 2009). Of those with lymphedema, 30.1% had mild (5.0-9.9%), 26% had moderate (10.0-14.9%), and 5.2% (15.0%) had severe, arm volume difference, respectively; lymphedema was present in 61.3% of participants by 24 months postoperatively (Cormier et al. 2009). The evidence on lymphedema at 30 to 36 months post surgery in this study provides support for the integration of regular surveillance of lymphedema during BrCa survivorship.

Other researchers have reported that even though lymphedema may not significantly increase for BCS (i.e. 8 and 43 months post BrCa surgery), the presence of pain while using the arm was a significant predictor of recreational difficulties (Miedema et al., 2011). A review of the literature on the prevalence of lymphedema reports a range of 6% to 80% 2 months to 5 years after BrCa treatments (Hayes et al., 2012). Although lymphedema has received a lot of attention in the recent past differences in reported findings may be, in part, due to study designs, (i.e. cross-sectional vs. longitudinal), though, another recent systematic review similarly identified a wide range in lymphedema incidence reported in the literature (Fu, Deng & Armer, 2014). Although factors associated with lymphedema have been explored and include surgical (e.g. axillary node dissection), physiological (e.g. body mass index) and genetic explanations, the etiology of BrCa related lymphedema remains unclear (Cormier et al., 2010, Mansel et al., 2006; Miaskowski et al., 2013). Women living with lymphedema experience other symptoms including

pain, tenderness, heaviness, numbness, tingling and limited ROM (Radina et al., 2012; Thomas-MacLean, Miedema, & Tatemichi, 2005).

With the effects of lymphedema extending beyond physical limitations, the presence of multiple symptoms necessitates multi-symptom management. Oncology nurses can provide further resources and advocate for effective interventions to reduce the risks of lymphedema and assist in management of associated symptoms (Fu, Deng & Armer, 2014). Additionally, nurses have a role in supporting BCS through ongoing collaboration about risk-reduction and prevention methods to manage arm morbidity (Fu, Deng & Armer, 2014).

ROM limitation. ROM limitation is common after acute breast cancer treatments; this study found that a significant number of participants (34%) still reported ROM limitation 30 to 36 months post surgery. Findings are consistent with a previous study that analyzed arm morbidity at 43 months post-surgery (Miedema et al., 2011). Lower incidence of ROM limitations have been reported by other researchers: 17% and 22% reported 6 to 12 months post surgery, respectively (Karki et al., 2005), and 10% and 16% reported at 12 and 36 months post surgery, respectively (Levy et al., 2012; Nesvold et al., 2011). A study examining long-term changes to upper limb morbidity, found significant decrease in shoulder, elbow and wrist movement limitation six months post surgery, but no significant changes at five-year follow up (Sagen et al., 2009).

Researchers have explored factors associated with ROM limitations, and these include: tissue scaring after BrCa surgery, fear of movement, perceived disability, pain vigilance and awareness, and the loss of passive and active glonehumeral motion, also known as frozen shoulder (Boquiren et al., 2016; De Groef et al., 2017; Hack et al., 2010; Mansel et al., 2006; Stubblefield & Keole, 2014). Suggested management for ROM limitation include early physical

exercises to stretch and strengthen affected muscles (De Groef et al., 2017;Stubblefield & Keole, 2014). Additionally, when ROM limitations are addressed shortly after surgery, lower incidences are reported years later. There is a need for ongoing monitoring of arm morbidity symptoms as a cluster of symptoms, to prevent deterioration at long term (De Groef et al., 2017).

Incidences of arm morbidity vary from study to study and differences are dependent on measurement techniques, definition of morbidity, study sample size and length of follow-up (Engel et al., 2003). The use of objective measures in this study could be considered an effective method for decreasing errors in measuring arm and shoulder ROM in BCS. A systematic review concluded that at least 10% and as many as 60% of BCS experience one arm/shoulder problem 6 to 36 months post BrCa surgery, highlighting the need for effective self-management strategies (Hayes et al., 2012).

5.3.2 Self-Management of Arm Morbidity. The current study revealed that self-management of arm morbidity is complex and involves managing physical and psychosocial symptoms. This study found that self-management of physical symptoms included the use of complex decongestive therapy (CDT), engaging in physical activities and increased self-awareness. CDT practices were: bandaging, wearing compression garments and self-massaging. Physical activities that participants engaged in were: exercising, swimming, stretching and walking. Increased self-awareness involved being more cautious of tasks performed with the affected arm, changing positions and resting the affected arm when necessary. The use of CDT practices is in line with the current evidence based practices (Fu, Deng & Armer, 2014), however, the complexity of self-management can be burdensome to BCS (Ridner, Dietrich & Kidd, 2011). A study examining lymphedema self-care education, practices and perceived barriers and burdens, report that lack of knowledge about equipment use (such as bandaging),

self-management of symptom and control of psychological distress were barriers to effective lymphedema self-care (Ridner, Dietrich & Kidd, 2011). Findings speak to the need for thorough patient education and support during follow up care, to ensure compliance with arm morbidity self-management (International Lymphoedema Framework, 2006; Miller, 2008).

In addition, this study found that psychosocial self-management of uncertainty was achieved through reflections about causes and treatments of arm morbidity. Uncertainty is recognized as a significant part of living with cancer, however the nature of uncertainty differs from cancer diagnosis to cancer survivorship (Miller, 2012; Ness et al., 2013; Wonghongkul et al., 2006). Participants in this study expressed ongoing worry about physical symptoms, guilt for survival, fear of cancer reoccurrence and anxiety about body image. The results are similar to other studies that reported poor quality of life was associated with fear of recurrence, uncertainty, stress, sleep disturbance and fatigue in cancer survivors (Ness et al., 2013; Wonghongkul et al., 2006).

Heightened uncertainty was also attributed to interactions with HCP who had limited knowledge on arm morbidity management. Uncertainty related to arm morbidity, in addition to uncertainty related to cancer, has been associated with feelings of (in)visibility by individuals living with secondary lymphedema after cancer (Thomas & Hamilton, 2014). Experienced limitation in self-management was related to the "inability to play an active role in self-care because of the limited knowledge of health professionals" (Thomas & Hamilton, 2014, p. 247). Insufficient knowledge of cancer survivorship issues is a barrier to providing best practices for follow-up care by primary HCP including nurses (Dulko et al., 2013). Increased communication between HCPs in the acute stages of cancer treatments and primary HCPs may help facilitate transition of care for BCS (Dulko et al., 2013).

The physical and psychosocial symptoms associated with arm morbidity pose significant challenges for BCS affecting overall quality of life (Hayes et al., 2012; Nesvold et al., 2011; Thomas-MacLean, 2005). Decreased participation in leisure and recreational activities due to physical limitations in addition to changes in meaningful work and family relationships as a result of arm morbidity negatively affects the physical and psychosocial health of BCSs (Hack et al., 2010; Miedema et al., 2011; Quinlan et al., 1011; Thomas et al., 2015). Although many BCS either stop or decrease participation in recreational and leisurely activities because of discomforts and limitations associated with arm morbidity (Karki, Simonen, Mälkiä, & Selfe, 2005; Miedema et al., 2008, 2011), research indicates that regular and continued exercise is vital to improving physical functioning and overall quality of life (McNeely et al., 2006).

5.3.3 Treatments Options for Arm Morbidity. With regard to arm morbidity treatment options, BCS received rehabilitative interventions that were classified as complex decongestive therapy (CDT) (e.g. bandaging, compression garments and manual lymphatic drainage) or non-CDT/unknown interventions (e.g. massage therapy) (International Lymphoedema Framework, 2006). This study found that BCS received rehabilitative interventions from physiotherapists, massage therapists and lymphedema specialists. Few participants reported taking medication prescribed by primary general practitioners (GP) to manage painful lymphedema and sleep difficulties. Medications received were classified as: analgesics, sleep aids and topical creams.

According to the International Lymphoedema Framework (2006), CDT is the gold standard for managing BrCa related lymphedema along with pain and mobility limitations. Several authors have studied the benefits of CDT in arm morbidity management, and report that CDT improves outcomes with ongoing monitoring and early interventions after BrCa surgery (Fu, Deng & Armer, 2014; McNeely et al., 2011; Singh, De Vera, & Campbell, 2013).

Additionally, there is evidence that physiotherapists play an important role in the prevention, early detection and treatment of lymphedema and movement problems in BCS (Engel et al., 2001; Vignes et al., 2007).

Although this study looked at arm morbidity as pain, lymphedema and ROM limitations, this condition encompasses other symptoms such as numbness, axillary cording and heaviness that were not explored. Diagnosis and management of arm morbidity should target clusters of symptoms to improve outcomes. According to Stubblefield and Keole (2014), these symptoms can easily be diagnosed and differentiated with a comprehensive clinical assessment, thorough history and physical examination that assess the lymphovascular systems, the neuromuscular and the musculoskeletal systems. A detailed understanding is necessary to accurately diagnose much of the pathology seen in BCS. Therefore, clinical management of arm morbidity requires ongoing, multidisciplinary approach to monitor symptom change and response to treatment interventions and medications used (Hayes et al., 2012).

This study showed that BCS require treatment interventions from multidisciplinary HCP, however, poor communication between HCP and BCS contributed to poor management of symptoms. In line with other studies, this finding speaks to the need for improved communication in cancer care to ensure survivors' needs are met (Clayton, Dudley & Musters, 2008; Towers, Carnevale, & Baker, 2008; Shaw & Thomas, 2011; Thorne et al., 2009). Effective management of arm morbidity as a chronic condition requires proactive follow up by primary HCP to ensure clinical management utilizes evidence-based guidelines (McCorkle et al., 2011).

5.4 Study Limitations and Strengths

Findings should be interpreted in light of study limitations. First, data were collected from 2005 to 2013. Current clinical practice changes such as the use of sentinel lymph node

dissection (SNLD) instead of axillary lymph node dissection (ALND) are used now to decrease the severity of arm morbidity in clinically node negative BrCa patients (Hack et al., 2010; Mansel et al., 2006). However, the uptake of SNLD in Canada has been slow and therefore SNLD as common practice is not routinely used in all institutions. Furthermore, patients with clinically positive nodes require ALND and radiation therapy, a combination that further increases the risk of arm morbidity (Mansel et al., 2006), rendering finding from this study on self-management practices highly applicable.

Second, the researcher recognizes that conducting a secondary analysis can be a disadvantage due to a lack of control over how the primary study was conducted, generated, or recorded (Szabo & Strang, 1997). In this case, study participants were not interviewed in depth to gain a detailed understanding of self-management practices and treatment options experienced for arm morbidity symptoms. The use of different forms of data from a large population sample across the country strengthens the reliability of findings from a cancer survivor's perspective.

Third, while this thesis focused on self-management of pain, lymphedema and ROM limitations, arm morbidity is a broad term that extends to include many other potential symptoms such as numbness and axillary web syndrome that may develop after BrCa surgery. The side effects of cancer treatments extend into other domains of peoples' lives including employment (Quinlan et al., 2011), family relationships (Thomas – MacLean et al., 2009) leisure and recreational activities (Miedema et al., 2011; Thomas et al., 2015), and overall quality of life (McCorkle et al., 2011; Nesvold et al., 2011).

A secondary analysis design was used to generate new insights from existing data. By utilizing existing data, the researcher saved process steps, which would otherwise be timely and costly to the student researcher (Polit & Beck, 2008). The collection of longitudinal data with a

large sample size would have been unfeasible given the length of the researcher's academic program. Both quantitative and qualitative data increased reliability and trustworthiness of findings. The principal investigator of the primary study (Thomas) was on the thesis committee, and involved in data analysis, confirming accurate interpretations of data and trustworthiness of findings.

5.5 Implications for Nursing

The results of this study have several implications for nursing because they provide valuable insight into the experiences of BCS with arm morbidity (Table 8). Challenges expressed by BCS with self-management of arm morbidity, speak to the need for enhanced supportive care during transition from acute cancer settings to cancer survivorship. Oncology nurses provide care to cancer patients along the cancer trajectory, including survivorship and have a significant role to ensure the needs of BCS are met (Canadian Association of Nurses in Oncology [CANO], 2006). Thus, nurses must be aware of the risk of arm morbidity following BrCa treatments, and need to provide patient information and follow up care with emphasis on self-management strategies and, when necessary, referrals (Burckhardt et al., 2014). Further implications in relation to nursing practice, including the roles of advanced practice nurses, nursing education and nursing research are outlined in Table 9.

Table 9. Implication of Study Findings for Nursing

Context	Strategies
Nursing Practice	– Conduct complete health assessment in cancer survivors, to identify unmet needs (i.e. arm morbidity symptoms in BCS) – Engage BCS in dialogue during assessments, planning, implementation and evaluation of care – Utilize evidence to guide practice in managing symptoms of pain, lymphedema and ROM limitation – Utilize multidisciplinary services available to BCS in managing arm morbidity – Increase awareness of available resources to enhance referral to appropriate specialists/services/resources – Provide referral/information needed by BCS during transition from acute cancer treatments to cancer survivorship – Utilize survivorship care plans to collaborate and coordinate care that meets the needs of cancer survivors
Nursing Education	– Provide educational opportunities for nurses (colleagues and learners) about evidence based cancer symptom management – Facilitate evidence-based nursing approaches within clinical oncology nursing – Engage in continuing education related to caring for cancer patient along their illness trajectory. – Utilize the best available knowledge and resources to facilitate learning
Nursing Research	– Engage nurses in research processes to facilitate translation of findings into practice – Develop and evaluate effective strategies that meet the needs of BCS living with arm morbidity – Further explore the use and implementation of breast cancer survivors supportive care plans in managing symptoms of arm morbidity

5.5.1 Nursing Practice

Nurses provide care to cancer patients along the cancer continuum in different settings (Ferrell, Virani, Smith, & Juarez, 2003). Specifically, oncology nurses are equipped with evidence-based knowledge, clinical skills and understanding of cancer and management of cancer related symptoms (CANO, 2006; Ferrell, Virani, Smith, & Juarez, 2003; Miller, 2008; Schulmeister & Gobel, 2008). In addition to assessing and delivering cancer care, nurses are essential to multidisciplinary teams that plan and implement patient centered care (Canadian Nursing Association [CNA], 2015). In collaboration with multidisciplinary teams (including oncologists, radiation therapists, social workers, physiotherapists, dieticians, family physicians, pharmacists, psychologists and others), oncology nurses work to provide comprehensive care along the cancer continuum (CANO, 2006; Miller, 2008). Therefore, oncology nurses are well situated to play a significant role as advocators in increasing awareness of available resources to enhance referral of BCS to appropriate resources for management of arm morbidity. By building and developing therapeutic and collaborative relationships, nurses can promote and support BCS in self-management of BrCa treatment related arm morbidity (CANO, 2006; CNO, 2009).

Practice standards and competencies for oncology nurses are detailed by CANO (2006), and oncology nurses involved in survivorship care are key to the identification of BrCa treatment related arm morbidity (Miller, 2008). Therefore, based on this study findings, specific examples of nursing practice would involve effective nurse-client communication with emphasis on: patient education on self-management and counseling regarding the use of multidisciplinary resources available to manage arm morbidity (McCorkle et al., 2011). Oncology nurses are well positioned to advocate for women living with or at risk for arm impairments, and encouraging women to discuss new symptoms sooner than later.

To ensure BCS are involved in follow up care, nurses can utilize survivorship care plans as communication tools and surveillance guides for ongoing monitoring and management of arm morbidity (Miller, 2008). The use of survivorship care plans (SCP) could ease some of the challenges associated with transition of care that involve the underuse or overuse of surveillance visits to general practitioners and/or oncologists. A population-based study reported substantial variation in adherence to guideline recommendations, with a considerable number of BCS receiving more than recommended imaging for metastatic disease but fewer than recommended mammograms for detection of local recurrence or new primary cancer (Grunfeld, Hodgson, Del Giudice, & Moineddin, 2010). Additionally, there has not been wide implementation of SCPs in Canada, except for a small number of cancer programs reporting SCP implementation (Jones, 2014). However, despite the challenges of transition in oncology care, SCP documents provides a cancer survivor with a comprehensive follow up plan, clarifies role and responsibility of oncology specialists and primary HCPs, and helps bridge the gap to ensure continuity of care from active treatment to survivorship care (Institute of Medicine, 2006; Jones, 2014; Miller, 2008). The effectiveness of SCPs has been reported in previous studies (Brennan et al., 2013; Jones, 2014).

5.5.2 Roles of Advanced Practice Nurses

According to the Canadian Nurses Association's National Framework for Advanced Nursing Practice (2008), advanced practice nurses (APNs) use competencies in areas of clinical, research, leadership, and consultation and collaboration, to develop and advance nursing practice. APNs in direct clinical practice can improve the experiences of BCS through consistent, comprehensive, and evidence-based symptom assessments and management of arm morbidity symptoms. Through research and leadership, APNs can interpret and implement relevant

empirical findings and evaluate current practices around symptom management of BCS. Finally, APNs can coordinate care with other HCP and connect BCS to resources targeting survivorship concerns through the competencies of collaboration and coordination (Ferrell, Virani, Smith, & Juarez, 2003).

5.5.3 Nursing Education

Although some exposure to cancer care may exist in the undergraduate-nursing curriculum, the curriculum is broad and provides a generalized framework for cancer survivorship care (Ferrell, Virani, Smith, & Juarez, 2003). Nurses have an obligation to share nursing knowledge and expertise with colleagues and learners (CNA, 2009). Through the establishment of supportive learning, nurse educators need to support nurses in clinical practice about the use of evidence-based practice in cancer symptom management (CNA, 2009). The results of this study highlight the importance of ongoing specialty nursing education and training to ensure provision of evidence based care across cancer trajectories. Oncology nurses, as part of the broad health care system, are able to provide information to BCS and implement supportive care planning that facilitates transitions from acute care settings to cancer survivorship outside of a healthcare institution (Miller, 2008). Clear nurse-client communication, using evidence-based information, can facilitate BCS engagement in self-management of long-term side effects of cancer treatments (Jones, 2014; Miller, 2008).

5.5.4 Nursing Research

Nurses have opportunities to engage in research and communicate knowledge gained about cancer symptom management to promote patient and family outcomes (CNA, 2009). Oncology nursing research has progressed in addressing different aspects of cancer survivorship (Ferrell, Virani, Smith, & Juarez, 2003). This study adds to nursing knowledge by exploring self-

management of arm morbidity and treatment options women receive from HCP in managing arm morbidity. Results demonstrated that women continue to report symptoms of pain, lymphedema and ROM limitation months to years after acute treatments, and there is a need for improved support as women attempt to self-manage their arm morbidity (Chapter 4). When symptoms persisted after breast cancer treatment, BCS had discussions with a HCP, suggesting that women need more support and guidance in self-management of their symptoms. Findings further suggest an increased need for implementing effective patient-provider communication to engage BCS in self-management practices during survivorship care.

Based on findings of this study, there are three recommendations for further research. First, conducting a prospective primary mixed methods study to provide a comprehensive understanding of self-management of arm morbidity in BCS is recommended. Second, with the knowledge that symptoms of arm morbidity can occur anytime after acute BrCa treatments, a study focusing on arm morbidity during end-of-life stage would provide insight into the specific needs of palliative patients living with arm morbidity. Third, despite several studies on the benefits of survivorship care planning (Brennan et al., 2013; Jones, 2014; Miller, 2008), implementation and use of survivorship care plans vary because they are intensive and time consuming to develop and implement (Parry et al., 2013; Miller, 2008). Further research is needed to understand how to effectively implement survivorship care plans that include providing evidence-based information to BCS, as well as implementation strategies to facilitate uptake and utilization of survivorship care plans by oncology nurses.

Conclusion

This thesis explored self-management practices performed by breast cancer survivors (BCS) and the treatments women receive from healthcare practitioners in managing symptoms of arm morbidity. The literature review highlighted knowledge gaps in what is known about self-management of arm morbidity and what is communicated to women about self-management (Chapter 2). This secondary data analysis found that a significant number of BCS experienced pain, lymphedema and range of motion (ROM) limitation, 6 to 12 months, 18 to 24 months and 30 to 36 months, post breast cancer surgery (Chapter 4). Quantitative results indicated that the level of symptom severity requiring intervention persisted during survivorship for a big portion of women. Multivariate analysis revealed that self-management practices had small to moderate association with arm morbidity, but necessitates future research to clearly understand breast cancer survivors self-management practiced for arm morbidity. Results shed light on two crucial points: first, BCS continue to live with unresolved arm morbidity symptoms during cancer survivorship. Second, women need more support and guidance as they attempt to self-manage symptoms of arm morbidity through collaborations and discussions with their HCP. Improved communication by nurses could assist in addressing specific survivorship needs, early detection and treatment of arm morbidity symptoms.

Qualitative results revealed that BCSs engaged in self-management of physical symptoms and psychosocial symptom of uncertainty. It was noted that self-management practices may overlap and can occur concurrently for managing multiple symptoms. Results emphasized the complexities associated with arm morbidity, and the significant need for multidisciplinary approaches in managing the condition. Oncology nurses are strategically positioned to advocate for change and ensure BCS are aware of multidisciplinary resources available to them. Further

research is needed to evaluate the necessary requirements for implementing survivorship care planning that would ease transition from acute cancer settings to primary healthcare practitioners.

6.1 References

Boquiren, V. M., Hack, T. F., Thomas, R. L., Towers, A., Kwan, W. B., Tilley, A... Miedema, B. (2016). A longitudinal analysis of chronic arm morbidity following breast cancer surgery. Breast Cancer Research and Treatment, 157 (3), 413–425

Brennan, M., Gormally, J., Butow, P., Boyle, F., & Spillane, A. (2014). Survivorship care plans in cancer: A systematic review of care plan outcomes. *British Journal of Cancer, 111*(10), 1899–908. Doi: 10.1038/bjc.2014.505

Burckhardt, M., Belzner, M., Berg, A., & Fleischer, S. (2014). Living with breast cancer-related Lymphedema: A synthesis of qualitative research. *Oncology Nursing Forum, 41*(4), E220–E237. doi:10.1188/14.onf.e220-e237

Canadian Association of Nurses in Oncology. (2006). Practice Standards and Competencies for the Specialized Oncology Nurse. Retrieved from http://van-cf.cano-acio.ca/~ASSETS/DOCUMENT/CONEP_Standards2006September28_REVISEDFor_20Website.pdf

Canadian Nurses Association. (2008). Advanced nursing practice: a national framework. Ottawa, ON: author. Retrieved from: https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/anp_national_framework_e.pdf

College of Nurses of Ontario. (2009). Professional standards, revised 2002. Toronto, ON: Author. Retrieved from: http://www.cno.org/globalassets/docs/prac/41006_profstds.pdf

Canadian Nurses Association. (2015). Framework for the Practice of Registered Nurses in Canada. Toronto, ON: author. Retrieved from: https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/framework-for-the-pracice-of-registered-nurses-in-canada.pdf?la=en

Clayton, M. F., Dudley, W. N., & Musters, A. (2008). Communication with breast cancer survivors. *Health Communications, 23* (3), 207-21. doi: 10.1080/10410230701808376.

De Groef, A., Meeus, M., De Vrieze, T., Vos, L., Van Kampen, M., Christiaens, M... Devoogdt, N. (2017). Pain characteristics as important contributing factors to upper limb dysfunction in breast cancer survivors at long term. *Musculoskeletal Science and Practice, 29*, 52–59

Dulko, D., Pace, C. M., Dittus, K. L., Sprague, B. L., Pollack, L. A., Hawkins, N. A., & Geller, B. M. (2013). Barriers and facilitators to implementing cancer survivorship care plans. *Oncology Nursing Forum, 40*(6), 575–580. doi:10.1188/13.ONF.575-580

Engel, J., Kerr, J., Schlesinger-Raab, A., Eckel, R., Sauer, H., & Hölzel, D. (2003). Predictors of quality of life of breast cancer patients. *Acta Oncologica, 42*(7), 710–8.

Ferrell, B. R., Virani, R., Smith, S., & Juarez, G. (2003). The role of oncology nursing to ensure quality care for cancer survivors: A report commissioned by the national cancer policy board and institute of medicine. *Oncology Nursing Forum, 30*(1), E1–E11. Doi: 10.1188/03.onf.e1-e11

Fu, M. R., Deng, J., & Armer, J. M. (2014). Putting Evidence Into Practice: Cancer-Related Lymphedema. *Clinical Journal of Oncology Nursing*, *18*(Journal Article), 68–79.

Grunfeld, E., Hodgson, D., Giudice, D., & Moineddin, R. (2010). Population-based longitudinal study of follow-up care for breast cancer survivors. *Journal of oncology practice, 6(4*), 174–81.

Hack, T. F., Kwan, W. B., Thomas-Maclean, R. L., Towers, A., Miedema, B., Tilley, A., & Chateau, D. (2010). Predictors of arm morbidity following breast cancer surgery. *Psycho-Oncology, 19*(11), 1205–1212 8p. https://doi.org/10.1002/pon.1685

Hayes, S. C., Johansson, K., Stout, N. L., Prosnitz, R., Armer, J. M., Gabram, S., & Schmitz, K. H. (2012). Upper-body morbidity after breast cancer: incidence and evidence for evaluation, prevention, and management within a prospective surveillance model of care. *Cancer*, *118*(8), 2237–2249. https://doi.org/10.1002/cncr.27467

Institute of Medicine & National Research Council. (2006). From cancer patient to cancer survivor: Lost in transition. Washington, DC: National Academies Press.

International Lymphedema Framework. (2006). Best practice for the management of Lymphoedema. Retrieved from http://www.lympho.org/portfolio/best-practice-for-the-management-of-lymphoedema/

Jones, J. (2014). Survivorship care plans: where are we now? *Oncology Exchange, 13*(4), 14-17.

Kärki, A., Simonen, R., Mälkiä, E., & Selfe, J. (2005). Impairments, Activity limitations and participation restrictions 6 and 12 months after breast cancer operation. *Journal of Rehabilitation Medicine 37* (3), 180-188.

Langford, D. J., Paul, S. M., West, C., Abrams, G., Elboim, C., Levine, J. D., … Miaskowski, C. (2014). Persistent arm pain is distinct from persistent breast pain following breast cancer surgery. *The Journal of Pain : Official Journal of the American Pain Society*, *15*(12), 1238–1247. https://doi.org/10.1016/j.jpain.2014.08.013

Levy, E., Pfalzer, L., Danoff, J., Springer, B., McGarvey, C., Shieh, C., … Stout, N. (2012). Predictors of functional shoulder recovery at 1 and 12 months after breast cancer surgery. *Breast Cancer Research and Treatment*,*134*(1), 315–24.doi:10.1007/s10549-012-2061-1.

Mansel, R. E., Fallowfield, L., Kissin, M., Goyal, A., Newcombe, R. G., Dixon, J. M., … Ell, P. J. (2006). Randomized multicenter trial of sentinel node biopsy versus standard axillary treatment in operable breast cancer: the ALMANAC Trial.[Erratum appears in J Natl

Cancer Inst. 2006 Jun 21;98(12):876]. *Journal of the National Cancer Institute*, *98*(9), 599–609.

McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L., Lorig, K., & Wagner, E. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians, 61* (1), 50–62. Doi: 10.3322/caac.20093.

McNeely, M. L., Peddle, C. J., Yurick, J. L., Dayes, I. S., Mackey, J. R. (2011). Conservative and dietary interventions for cancer-related lymphedema: a systematic review and meta-analysis. *Cancer*, *117*(6), 1136-1148. Doi: 10.1002/cncr.25513.

Miaskowski, C., Paul, S. M., Cooper, B., West, C., Levine, J. D., Elboim, C., … Aouizerat, B. E. (2014). Identification of patient subgroups and risk factors for persistent arm/shoulder pain following breast cancer surgery. *European Journal of Oncology Nursing, 18* (3), 242–253. Doi: 10.1016/j.ejon.2013.12.002.

Miedema, B., Hamilton, R., Tatemichi, S., Thomas-Maclean, R., Hack, T. F., Quinlan, E., … Kwan, W. (2011). Do breast cancer survivors' post-surgery difficulties with recreational activities persist over time? *Journal of Cancer Survivorship*, *5*(4), 405–412. https://doi.org/10.1007/s11764-011-0190-x

Miedema, B., Hamilton, R., Tatemichi, S., Thomas-MacLean, R., Towers, A., Hack, T. F., … Kwan, W. (2008). Predicting recreational difficulties and decreased leisure activities in women 6-12 months post breast cancer surgery. *Journal of Cancer Survivorship : Research and Practice*, *2*(4), 262–268. https://doi.org/10.1007/s11764-008-0068-8

Miller, R. (2008). Implementing a Survivorship care plan for patients with breast cancer. *Clinical Journal of Oncology Nursing, 12*(3), 479–487. Doi: 10.1188/08.cjon.479-48

Nesvold, I. L., Dahl, A. A., Løkkevik, E., Marit Mengshoel, A., & Fosså, S. D. (2008). Arm and shoulder morbidity in breast cancer patients after breast-conserving therapy versus mastectomy. *Acta Oncologica*, *47*(5), 835–842. Doi: 10.1080/02841860801961257

Nesvold, I. L., Reinertsen, K.V., Fossa, S. D., & Dahl, A. A. (2011) The relation between arm/shoulder problems and quality of life in breast cancer survivors: a cross-sectional and longitudinal study. *Journal of Cancer Survivorship, 5*(1), 62–72. Doi: 10.1007/s11764-010-0156-4.

Ness, S., Kokal, J., Fee-Schroeder, K., Novotny, P., Satele, D., & Barton, D. (2012). Concerns across the survivorship trajectory: results from a survey of cancer survivors. *Oncology Nursing Forum, 40*(1), 35–42. Doi: 10.1188/13.ONF.35-42

Parry, C., Kent, E. E., Forsythe, L. P., Alfano, C. M., & Rowland, J. H. (2013). Can't see the forest for the care plan: A call to revisit the context of care planning. *Journal of Clinical Oncology, 31*(21), 2651–2653. Doi: 10.1200/JCO.2012.48.4618

Polit, D. G. & Beck, C. T. (2008). Nursing research: Generating and assessing evidence for nursing practice, 8th Ed. New York: Lippincott Williams & Wilkins.

Quinlan, E., Maclean, R., Hack, T., Tatemichi, S., Towers, A., Kwan, W., … Tilley, A. (2011). Breast cancer Survivorship and work disability. *Journal of Disability Policy Studies*, *22*(1), 18–27. Doi: 10.1177/1044207310394439

Quinlan, E., Thomas, R., Towers, A., Hack, T., Kwan, W., Miedema, B., Tatemichi, S., Tilley, A. (2015). Improving best practices for diagnosing lymphedema: A proposal to assess limbs according to segment. *Research Perspectives*. Retrieved from http://canadalymph.ca/wp-content/uploads/2015/05/Improving-best-practices.pdf

Schou Bredal, I., Smedy, N.A., Ottesen, S., Warncke, T., & Schlichtin, E. (2014). Chronic pain

in breast cancer survivors: comparison of psychosocial, surgical and medical characteristic between survivors with and without pain. *Journal of Pain and Symptom Management, 48* (5), 852–862

Shaw, R., & Thomas, R. (2011). Role of GPs in breast cancer- related arm morbidity care. *Journal of Lymphoedema*, *6*(2), 10–19.

Stubblefield, M. D. & Keole, N. (2014). Upper body pain and functional disorders in patients with breast cancer. *Physical Medicine and Rehabilitation, 6*(2), 170-83. http://dx.doi.org/10.1016/j.pmrj.2013.08.605

Thomas, R., Hack, T., Quinlan, E., Tatemichi, S., Towers, A., Kwan, W., … Morrison, T. (2015). Loss, adaptation and new directions: The impact of arm morbidity on leisure activities following breast cancer. *Canadian oncology nursing journal*, *25*(1), 49–59.

Thomas, R., & Hamilton, R. (2014). Illustrating the (in)visible: Understanding the impact of loss in adults living with secondary lymphedema after cancer. *International Journal of Qualitative Studies on Health and Well-being, 9*, 24354 - http://dx.doi.org/10.3402/qhw.v9.24354

Thomas-Maclean, R. Spriggs, P., Quinlan, E., Towers, A., Hack, T., Tatemichi, S., Miedema, B., Kwan, W. & Andrea Tilley, A. (2010). Arm morbidity and disability in Canada: Reporting the current status from Canada. *Journal of Lymphoedema,* 5(2), 33-38.

Thomas-MacLean, R., Towers, A., Quinlan, E., Hack, H., Winkle Kwan, W., Miedema, B. & Graham, P. (2009). “This is a kind of betrayal”: A qualitative study of disability after breast cancer. *Current Oncology*, *16*(3), 26-32.

Towers, A., Carnevale, F. A., & Baker, M. E. (2008). The psychosocial effects of cancer-related lymphedema. *Journal of Palliative Care, 24*(3), 134-143.

Thorne, S., Armstrong, E. A., Harris, S. R., Hislop, T. G., Kim-Sing, C., Oglov, V., Oliffe, J. L., & Stajduhar, K. I. (2009). Patient real-time and 12-month retrospective perceptions of difficult communications in the cancer diagnostic period. *Qualitative Health Research, 19* (10), 1383-1394. Doi: 10.1177/1049732309348382.

Ridner, S. H., Dietrich, M. S., & Kidd, N. (2011). Breast cancer treatment-related lymphedema self-care: Education, practices, symptoms, and quality of life. *Supportive Care in Cancer, 19*(5), 631–637. Doi: 10.1007/s00520-010-0870-5

Schulmeister, L., & Gobel, B. (2008). Symptom management issues in oncology nursing. *The Nursing Clinics of North America, 43*(2), 205–20. Doi: 10.1016/j.cnur.2008.02.004.

Singh, C., De Vera, M., & Campbell, K. L. (2013). The effect of prospective monitoring and early Physiotherapy intervention on arm morbidity following surgery for breast cancer: A pilot study. *Physiotherapy Canada, 65*(2), 183–191. Doi: oi: 10.3138/ptc.2012-23

Szabo, V. & Strang, V.R. (1997). Secondary analysis of qualitative data. *Advances in Nursing Science, 20*(2), 66-74.

Vignes, S., Porcher, R., Arrault, M., & Dupuy, A. (2006). Long-term management of breast cancer-related lymphedema after intensive decongestive physiotherapy. *Breast Cancer Research and Treatment, 101*(3), 285–290. Doi: 10.1007/s10549-006-9297-6

Wonghongkul, T., Dechaprom, N., Phumivichuvate, L., & Losawatkul, S. (2006). Uncertainty appraisal coping and quality of life in breast cancer survivors. *Cancer Nursing, 29*(3), 250–7.

Appendices

7.1 Appendix A – Search Strategy

	Medline	**CINAHL**	**PubMed**
Self-management	**Subject heading(s)** exp Self Care/ exp Self-Assessment/ **Free-text** self management.ti,ab. (self adj5 manage).mp.	**Subject heading(s)** (MH "Self Care+") (MH "Self Assessment") **Free-text** ("self" N4 ("manage* or care)) ((TI (("self" N4 (manage* OR care)))) OR (AB (("self" N4 (manage* OR care)))))	**Subject heading(s)** Search ((self management[MeSH Terms])) OR self care[MeSH Terms])) OR self assessment[MeSH Terms])
Arm morbidity	**Subject heading(s)** Axilla/ or Breast Neoplasms/ or Lymph Node Excision/ or Lymphedema/ or Sentinel Lymph Node Biopsy/ or Arm/ exp Shoulder Joint/ or exp Treatment Outcome/ **Free-text** arm morbidity.ti,ab.	**Subject heading(s)** (MH "Arm Injuries+") OR (MH "Arm Exercises") OR (MH "Shoulder Pain") OR (MH "Lymphedema+") OR (MH "Range of Motion") OR (MH "Shoulder Pain")	**Subjecti heading(s)** Search ((limited range of motion[MeSH Terms]) OR shoulder disability[MeSH Terms]) OR arm morbidity[MeSH Terms]
Breast cancer survivors	**Subject heading(s)** exp Survivors/ or exp Breast Neoplasms/ **Free-text** survivors.ti,ab. Breast cancer survivor$.ti,ab. cancer survivors.ti,ab.	**Subject heading(s)** MH "Cancer Survivors") AND (MH "Breast Neoplasms") **Free-text** TI "breast cancer survivors" OR AB "breast cancer survivors"	**Subjecti heading(s)** Search ((breast cancer) OR breast neoplast[MeSH Terms]) OR cancer survivors[MeSH Terms]
Results	**71 articles**	**116 articles**	**84 articles**
Notes		Subject: Major Heading: breast neoplasms, survivors, exercise, lymphedema, therapeutic exercise, self care, symptoms, health behavior	

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Roanne Thomas, PhD
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October 7, 2015

Office of Research Ethics and Integrity
University of Ottawa
550 Cumberland, room 154
Ottawa, Ontario

Re: Secondary Analysis of Data for Vicky Rosine Samuel

Dear Research Ethics Board

I am the principal investigator of the primary study *Disability after Breast Cancer* in which data will be used for this secondary analysis.

I was a professor at the University of Saskatchewan when the data was collected with ethical approval from all participating sites. As a professor at the University of Ottawa, the data is now securely stored at the Creative Practice Center, Roger Guindon Hall, room 1125, 451 Smyth Road, Ottawa, ON. There is no identifying information on the data.

I hereby provide access to Vicky Rosine Samuel, Masters of Science in Nursing student from the University of Ottawa (supervised by Dr. Wendy Gifford) to access this data to conduct a secondary analysis for her Master's thesis.

Sincerely,

Roanne Thomas, PhD

7.3 Appendix C – Variable Selection and Coding

Demographic Characteristics

Variable	Data Type	Responses coded/recoded	Notes
Age	Continuous	Birth dates Assessment dates	Rounded years calculated from given birthday years subtracted from year of assessment
Race	Categorical	White Non-white	**SIAM Q8** Original question had 9 categories. Categories were collapsed due to 89.9% of respondents indicated they were white. Black (e.g. African, Caribbean etc.), South Asian (e.g., Indian, Pakistani etc.), East Asian (e.g., Chinese, Japanese, Korean etc.), Southeast Asian (e.g., Thai, Filipino, Vietnamese etc.), West Asian (e.g., Arabian, Iranian etc.), South or Central American, Aboriginal, Caucasian/White and Other
Education	Categorical	Less or equal to High school Some college to university undergraduate degree Graduate degrees	**SIAM Q37** Original question had 6 categories: Finished primary or elementary school, Finished junior high school or middle school, Finished high school, Finished community college, Finished undergraduate degree at university, and finished graduate degree at university
Marital Status	Categorical	Single, Married, Divorced, Separated, Widow and Common law	**SIAM Q38** Same categories as original
Income	Categorical	Less than 40,000 40,001 – 80,000 80,001 or over Did not answer	**SIAM Q34** Original question had 9 categories: less than 20,000, 20,001-30,000, 30,001-40,000, 40,001-50,000, 50,001-60,000, 60,001-70,000, 70,001-80,000, 80,001 or over, and Do not wish to answer

Clinical Characteristics

Variable	Data Type	Responses coded/recoded	Notes
Tumor Stage	Categorical	Stage I Stage II Stage III	Same categories as original
Type of Surgery	Categorical	Radical mastectomy Modified radical mastectomy Partial mastectomy or lumpectomy	
Radiation	Categorical	No Yes	
Chemotherapy	Categorical	No Yes	
Hormonal Therapy	Categorical	No Yes	

Independent Variables from Items of the SIAM Questionnaire (Arranged by SIAM Question #)

Independent Variables	SIAM item	Data Type	Responses coded/recoded	Notes
Dialogue with HCP	Q15	Categorical	1. No 2. Yes	0. Does not apply (Removed from analysis) 1. No (explain:)_____ 2. Yes
	Q21	Categorical	1. No 2. Yes	0. Does not apply (Removed from analysis) 1. No (explain:)_____ 2. Yes
	Q23	Categorical	1. No 2. Yes	0. Does not apply (Removed from analysis) 1. No (explain:)_____ 2. Yes

Independent Variables	SIAM item	Data Type	Responses coded/recoded	Notes
Treatment by HCP	Q16	Categorical	1. No 2. Yes	0. Does not apply (Removed from analysis) 1. No (explain:)_____ 2. Yes
	Q17	Categorical	0. Does not apply 1. Type of professional	0. Does not apply (No HCP) 1. Type of professional (Yes; had a HCP)
	Q22	Categorical	1. No 2. Yes	0. Does not apply (Removed from analysis) 1. No 2. Yes
	Q24	Categorical	1. No 2. Yes	0. Does not apply (Removed from analysis) 1. No (explain:)_____ 2. Yes (Profession)_____
	Q25	Categorical	1. No 2. Yes	0. Does not apply (Removed from analysis) 1. No (explain:)_____ 2. Yes (Type of medication)_____
	Q26	Categorical	1. No 2. Yes	0. Does not apply (Removed from analysis) 1. No (explain:)_____ 2. Yes
Change in Leisure Activities	Q28	Categorical	1. No 2. Yes	0. Does not apply (Removed from analysis) 1. No (explain:)_____ 2. Yes (Explain:)_____
	Q29	Continuous	Responses 0 to 7	Responses of 0 to 7: for days in a week exercised arm

Dichotomized Outcome Variables

Outcome Variable	Tools Used to Collect data	Data Type	Responses coded	Notes
Pain	MPQ Present Pain Index	Categorical	0 = no pain 1 = Some pain	Original question had 6 answers: 0 = no pain 1 = mild 2 = discomforting 3 = distressing 4 = horrible 5 = excruciating Recoded variables to indicate presence (for answers 1 to 5) or absence of pain (for answers 0)
Lymphedema	Clinical assessments obtained measurements of arm circumference.	Categorical	0 = <=5% no lymphedema 1 = >5% Lymphedema	Originally continuous data collected from seven sequential circumferential arm measurements of the: metacarpophalangeal (MCO) joint, thumb base, wrist crease, and wrist crease + 10, 20, 30, and 40 cm up the arm. Methods chapter details data collection and percentage calculations
Range of motion limitation	Clinical assessments measured shoulder abduction and external rotation angles using a goniometer	Categorical	0 = no ROM problem 1 = Some ROM problem	Originally continuous data was collected to measure shoulder abduction and external rotation angles. Using a goniometer, shoulder abduction and external rotation angles were measured to the point of pain sensation. Shoulder abduction and external rotation were regarded as restricted if less than 170 or 80 degrees, respectively. See methods chapter for details on data collection

7.4 Appendix D – Qualitative Interview Questions

(3 out of 10 used in the primary study)

1) Could you please describe the physical symptoms associated with the arm problems you are experiencing?

2) What does it the affected area [hand, arm, shoulder, armpit] feel like? Is there anything that relieves your symptoms? Anything that makes your symptoms worse? What do you believe caused the problems you just described?

3) Are you being treated for theses symptoms? If so, what type of treatment are you receiving? If not, what have you tried to get treatment for these problems?

7.5 Appendix E – Research Ethics Approval

File Number: H10-15-28 **Date (mm/dd/yyyy)**: 01/12/2016

Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

First Name	Last Name	Affiliation	Role
Wendy	Gifford	Health Sciences / Nursing	Supervisor
Vicky Rosine	Samuel	Health Sciences / Nursing	Student Researcher

File Number: H10-15-28

Type of Project: Master's Thesis

Title: Women's self-management of arm morbidity after breast cancer treatment: a secondary

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
01/12/2016	01/11/2017	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:
N/A

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File Number: H10-15-28 **Date (mm/dd/yyyy):** 01/12/2016

Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

During the course of the project, the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the project (e.g., change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, including consent and recruitment documentation, should be submitted to the Ethics Office for approval using the "Modification to research project" form available at: http://research.uottawa.ca/ethics/submissions-and-reviews.

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: http://research.uottawa.ca/ethics/submissions-and-reviews.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Hoda Shawki
Protocol Officer for Ethics in Research
For Daniel Lagarec, Chair of the Health Sciences and Sciences REB

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7.6 Appendix F – Predictor Variable Frequencies

T1 (6 to 12 months after surgery)

Q15 Discussed treatment for swelling - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	547	73.9	85.1	85.1
	No	31	4.2	4.8	89.9
	Yes	65	8.8	10.1	100.0
	Total	643	86.9	100.0	
Missing	System	97	13.1		
Total		740	100.0		

Q16 Received treatment for swelling - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	548	74.1	85.2	85.2
	No	53	7.2	8.2	93.5
	Yes	42	5.7	6.5	100.0
	Total	643	86.9	100.0	
Missing	System	97	13.1		
Total		740	100.0		

Q17 Provider of swelling treatment - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	598	80.8	93.3	93.3
	Answer given	43	5.8	6.7	100.0
	Total	641	86.6	100.0	
Missing	System	99	13.4		
Total		740	100.0		

Q20 Any swelling in armpit, chestwall, breast - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	392	53.0	53.4	53.4
	Yes	342	46.2	46.6	100.0
	Total	734	99.2	100.0	
Missing	System	6	.8		
Total		740	100.0		

Q21 Discussed treatment for movement problems - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	366	49.5	49.9	49.9
	No	227	30.7	30.9	80.8
	Yes	141	19.1	19.2	100.0
	Total	734	99.2	100.0	
Missing	System	6	.8		
Total		740	100.0		

Q22 Received treatment from physiotherapist - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	366	49.5	49.9	49.9
	No	268	36.2	36.5	86.4
	Yes	100	13.5	13.6	100.0
	Total	734	99.2	100.0	
Missing	System	6	.8		
Total		740	100.0		

Q23 Discussed treatment for pain - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	186	25.1	25.4	25.4
	No	304	41.1	41.5	66.8
	Yes	243	32.8	33.2	100.0
	Total	733	99.1	100.0	
Missing	System	7	.9		
Total		740	100.0		

Q24 Received treatment for pain - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	189	25.5	25.7	25.7
	No	455	61.5	62.0	87.7
	Yes	90	12.2	12.3	100.0
	Total	734	99.2	100.0	
Missing	System	6	.8		
Total		740	100.0		

Q25 Medication taken for pain - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	186	25.1	25.3	25.3
	No	326	44.1	44.4	69.8
	Yes	220	29.7	30.0	99.7
	No, but is on regular anti-inflammatory for hip problem	1	.1	.1	99.9
	Yes, taking meds for other problem, may be helping with pain from breast/armpit area	1	.1	.1	100.0
	Total	734	99.2	100.0	
Missing	System	6	.8		
Total		740	100.0		

Q26 Treatment adequate relief of pain - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	496	67.0	67.6	67.6
	No	32	4.3	4.4	71.9
	Yes	198	26.8	27.0	98.9
	Does not know	8	1.1	1.1	100.0
	Total	734	99.2	100.0	
Missing	System	6	.8		
Total		740	100.0		

Q28 Change in leisure activities - T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	44	5.9	6.0	6.0
	No	479	64.7	65.3	71.3
	Yes	211	28.5	28.7	100.0
	Total	734	99.2	100.0	
Missing	System	6	.8		
Total		740	100.0		

Recode Q29 Exercise into 2 variables_T1

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	182	24.6	24.8	24.8
	2.00	551	74.5	75.2	100.0
	Total	733	99.1	100.0	
Missing	System	7	.9		
Total		740	100.0		

T3 (18 to 24 months after surgery)

Q15 Discussed treatment for swelling - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	332	44.9	77.0	77.0
	No	55	7.4	12.8	89.8
	Yes	44	5.9	10.2	100.0
	Total	431	58.2	100.0	
Missing	System	309	41.8		
Total		740	100.0		

Q16 Received treatment for swelling - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	346	46.8	80.3	80.3
	No	47	6.4	10.9	91.2
	Yes	38	5.1	8.8	100.0
	Total	431	58.2	100.0	
Missing	System	309	41.8		
Total		740	100.0		

Q17 Provider of swelling treatment - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	388	52.4	90.4	90.4
	Answer given	41	5.5	9.6	100.0
	Total	429	58.0	100.0	
Missing	System	311	42.0		
Total		740	100.0		

Q20 Any swelling in armpit, chestwall, breast - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	493	66.6	76.8	76.8
	Yes	149	20.1	23.2	100.0
	Total	642	86.8	100.0	
Missing	System	98	13.2		
Total		740	100.0		

Q21 Discussed treatment for movement problems - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	407	55.0	63.3	63.3
	No	155	20.9	24.1	87.4
	Yes	81	10.9	12.6	100.0
	Total	643	86.9	100.0	
Missing	System	97	13.1		
Total		740	100.0		

Q22 Received treatment from physiotherapist - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	412	55.7	64.2	64.2
	No	183	24.7	28.5	92.7
	Yes	47	6.4	7.3	100.0
	Total	642	86.8	100.0	
Missing	System	98	13.2		
Total		740	100.0		

Q23 Discussed treatment for pain - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	259	35.0	40.3	40.3
	No	217	29.3	33.7	74.0
	Yes	167	22.6	26.0	100.0
	Total	643	86.9	100.0	
Missing	System	97	13.1		
Total		740	100.0		

Q24 Received treatment for pain - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	267	36.1	41.5	41.5
	No	306	41.4	47.6	89.1
	Yes	70	9.5	10.9	100.0
	Total	643	86.9	100.0	
Missing	System	97	13.1		
Total		740	100.0		

Q25 Medication taken for pain - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	229	30.9	35.8	35.8
	No	276	37.3	43.2	79.0
	Yes	134	18.1	21.0	100.0
	Total	639	86.4	100.0	
Missing	System	101	13.6		
Total		740	100.0		

Q26 Treatment adequate relief of pain - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	495	66.9	77.1	77.1
	No	26	3.5	4.0	81.2
	Yes	116	15.7	18.1	99.2
	Does not know	5	.7	.8	100.0
	Total	642	86.8	100.0	
Missing	System	98	13.2		
Total		740	100.0		

Q28 Change in leisure activities - T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	222	30.0	34.5	34.5
	No	318	43.0	49.5	84.0
	Yes	103	13.9	16.0	100.0
	Total	643	86.9	100.0	
Missing	System	97	13.1		
Total		740	100.0		

Recode Q29 Exercise arm into 2 variables_ T3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	128	17.3	20.0	20.0
	2.00	513	69.3	80.0	100.0
	Total	641	86.6	100.0	
Missing	System	99	13.4		
Total		740	100.0		

T5 (30 to 36 months after surgery)

Q15 Discussed treatment for swelling - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	46	6.2	30.9	30.9
	No	65	8.8	43.6	74.5
	Yes	38	5.1	25.5	100.0
	Total	149	20.1	100.0	
Missing	System	591	79.9		
Total		740	100.0		

Q16 Received treatment for swelling - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	78	10.5	52.7	52.7
	No	35	4.7	23.6	76.4
	Yes	35	4.7	23.6	100.0
	Total	148	20.0	100.0	
Missing	System	592	80.0		
Total		740	100.0		

Q17 Provider of swelling treatment - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	113	15.3	76.9	76.9
	Answer given	34	4.6	23.1	100.0
	Total	147	19.9	100.0	
Missing	System	593	80.1		
Total		740	100.0		

Q20 Any swelling in armpit, chestwall, breast - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	421	56.9	81.4	81.4
	Yes	96	13.0	18.6	100.0
	Total	517	69.9	100.0	
Missing	System	223	30.1		
Total		740	100.0		

Q21 Discussed treatment for movement problems - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	356	48.1	68.1	68.1
	No	129	17.4	24.7	92.7
	Yes	38	5.1	7.3	100.0
	Total	523	70.7	100.0	
Missing	System	217	29.3		
Total		740	100.0		

Q22 Received treatment from physiotherapist - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	363	49.1	69.4	69.4
	No	138	18.6	26.4	95.8
	Yes	22	3.0	4.2	100.0
	Total	523	70.7	100.0	
Missing	System	217	29.3		
Total		740	100.0		

Q23 Discussed treatment for pain - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	240	32.4	46.0	46.0
	No	180	24.3	34.5	80.5
	Yes	102	13.8	19.5	100.0
	Total	522	70.5	100.0	
Missing	System	218	29.5		
Total		740	100.0		

Q24 Received treatment for pain - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	249	33.6	47.4	47.4
	No	221	29.9	42.1	89.5
	Yes	55	7.4	10.5	100.0
	Total	525	70.9	100.0	
Missing	System	215	29.1		
Total		740	100.0		

Q25 Medication taken for pain - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	250	33.8	48.0	48.0
	No	148	20.0	28.4	76.4
	Yes	122	16.5	23.4	99.8
	Yes, taking meds for other problem, may be helping with pain from breast/armpit area	1	.1	.2	100.0
	Total	521	70.4	100.0	
Missing	System	219	29.6		
Total		740	100.0		

Q26 Treatment adequate relief of pain - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	389	52.6	74.4	74.4
	No	12	1.6	2.3	76.7
	Yes	112	15.1	21.4	98.1
	Does not know	10	1.4	1.9	100.0
	Total	523	70.7	100.0	
Missing	System	217	29.3		
Total		740	100.0		

Q28 Change in leisure activities - T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Does not apply	198	26.8	37.8	37.8
	No	231	31.2	44.1	81.9
	Yes	95	12.8	18.1	100.0
	Total	524	70.8	100.0	
Missing	System	216	29.2		
Total		740	100.0		

Recode Q29 Exercise into 2 variables_T5

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1.00	124	16.8	23.7	23.7
	2.00	399	53.9	76.3	100.0
	Total	523	70.7	100.0	
Missing	System	217	29.3		
Total		740	100.0		

7.7 Appendix G – Bivariate Results Tables

Demographics, Clinical characteristics and Self-Management Variable Bivariate Analyses, 6 to 12 months post surgery (T1)

Variable	Pain (sig)	Lymphedema (sig)	ROM limitation (sig)	Statistical test
Age	– 0.12 (*p* = .001)	.116 (*p* = .002)	0.04	Point biserial correlations
Race	.125	.15	.12	Cramers' *V*
Education	.05	.11	.16 (*p* =. 003)	Cramers' *V*
Marital status	.07	.12	.13 (*p* =. 039)	Cramers' *V*
Income	.103 (*p* =. 05)	.1	.06	Cramers' *V*
Tumor stage	.03	.14 (*p* =. 001)	.04	Cramers' *V*
Type of surgery	.04	.13 (*p* =. 002)	.1 (*p* =. 028)	Cramers' *V*
Radiation	–.04	.003	–. 06	Phi coefficient
Chemotherapy	.04	–. 06	–. 03	Phi coefficient
Hormone therapy	–.06	.04	–. 01	Phi coefficient
Self-management Variables				
Q28	.21 (*p* <. 001)	.047	.138 (*p* <. 001)	Phi coefficient
Q29	.115(*p* =. 001)	.003	.034	Point biserial correlation
Q15	.16	–. 002	.186	Phi coefficient
Q20	.18 (*p* <. 001)	.086 (*p* =. 020)	.13 (*p* <. 001)	Phi coefficient
Q21	.14 (*p* =. 006	.01	.075	Phi coefficient
Q23	.19 (*p* <. 001)	.009	.07	Phi coefficient
Q16	.06	–0.214 (*p* =. 038)	.206 (*p* =. 044)	Phi coefficient
Q17	.086 (*p* =. 029)	.271 (*p* <. 001)	.13 (*p* =. 001	Phi coefficient
Q22	.12 (*p* =025)	–. 04	–. 034	Phi coefficient
Q24	.19 (*p* <. 001)	–. 003	.112 *p* =. 009)	Phi coefficient
Q25	.26 (*p* <. 001)	–. 004	.15 (*p* <. 001)	Phi coefficient
Q26	–. 06	.01	–. 007	Phi coefficient

- Significance at the 0.05 level (2 tailed)
- *p* -values included for significant variables only

Multicollinearity Assessment of Independent Variables using Chi square, Phi coefficient and Point-biserial Correlation coefficient (T1)

	Q28	Q29	Q15	Q20	Q21	Q23	Q16	Q17	Q22	Q24	Q25	Q26
Q28	1											
Q29	.02	1										
Q15	-.02	.1	1									
Q20	.18 *p* <.001	.01	.145	1								
Q21	.24 *p* <.001	.11 *p* =.037	.304 *p* =.018	.16 *p* =.003	1							
Q23	.23 *p* <.001	0.08	.26 *p* =.019	.17 *p* <.001	.52 *p* <.001	1						
Q16	-0.05	.21 *p* =.046	.56 *p* <.001	0.16	.30 *p* =.017	0.16	1					
Q17	.08 *p* =.048	.11 *p* =.008	.64 *p* <.001	.16 *p* <.001	.13 *p* =.015	0.07	.89 *p* <.001	1				
Q22	.14 *p* =.007	.14 *p* =.007	.25 *p* =.041	.19 *p* <.001	.60 *p* <.001	.31 *p* <.001	.31 *p* =.012	.20 *p* <.001	1			
Q24	.20 *p* <.001	.09 *p* =.030	.29 *p* =.010	.13 *p* =.002	.46 *p* <.001	.39 *p* <.001	0.36	.16 *p* <.001	.48 *p* <.001	1		
Q25	.23 *p* <.001	.03	.019	.14 *p* =.001	.23 *p* <.001	.29 *p* <.001	0.04	.09 *p* =.046	.123 *p* =.027	.24 *p* <.001	1	
Q26	.02	.09	-.076	-.05	.02	-.06	-.04	-.016	.04	-.03	.137 *p* =.039	1

- Significance at the 0.05 level (2 tailed)
- *p* -values included for significant variables only

Demographics, Clinical characteristics and Self-Management Variable Bivariate Analyses, 18 to 24 months post surgery (T3)

Variable	**Pain (sig)**	**Lymphedema (sig)**	**ROM limitation (sig)**	
Age	-.07	.06	.153 *p* <.001	Point biserial correlations
Race	.14	.14	.1	Cramers' *V*
Education	.08	.08	.14 (*p* =. 024)	Cramers' *V*
Marital status	.12	.13	.08	Cramers' *V*
Income	.06	.11	.1	Cramers' *V*
Tumor stage	.06	.17 (*p* <. 001)	.08	Cramers' *V*
Type of surgery	.11(*p* =. 028)	.17 (*p* <. 001)	.13 (*p* =. 004)	Cramers' *V*
Radiation	-.05	.07	-.01	Phi coefficient
Chemotherapy	.02	-.003	.001	Phi coefficient
Hormone therapy	-.01	-.014	-.02	Phi coefficient
Self-management Variables				
Q28	.19 (*p* <. 001)	-.05	.08	Phi coefficient
Q29	-.01	-.06	-.06	Point biserial correlation
Q15	.16	.05	.15	Phi coefficient
Q20	.19 (*p* <. 001)	.1 (*p* =. 015)	.16 (*p* <. 001)	Phi coefficient
Q21	.23 (*p* <. 001)	-.09	.05	Phi coefficient
Q23	.22 (*p* <. 001)	-.01	-.02	Phi coefficient
Q16	.19	-.34	.12	Phi coefficient
Q17	.18 (*p* <. 001)	.32 (*p* <. 001)	.11 (*p* =. 024)	Phi coefficient
Q22	.12	.04	.13	Phi coefficient
Q24	.21 (*p* <. 001)	.15 (*p* =. 004)	.18 (*p* <. 001)	Phi coefficient
Q25	.33 (*p* <. 001)	-.03	.2 (*p* <. 001)	Phi coefficient
Q26	-.05	.01	-.11	Phi coefficient

- Significance at the 0.05 level (2 tailed)
- *p* -values included for significant variables only

Multicollinearity Assessment of Independent Variables using Chi square, Phi coefficient and Point-biserial Correlation coefficient (T3)

	Q28	Q29	Q15	Q20	Q21	Q23	Q16	Q17	Q22	Q24	Q25	Q26
Q28	1											
Q29	-.08	1										
Q15	.19	.08	1									
Q20	.12 *p* =.013	-.05	.16	1								
Q21	.21 *p* =.002	.12	.4 *p* =. 007	0.1	1							
Q23	.19 *p* <.001	.02	.4 *p* <.001	0.05	.47 *p* <.001	1						
Q16	.17	.16	.79 *p* <.001	0.09	.41 *p* =.009	.35 *p* =.003	1					
Q17	.13 *p* =.027	.06	.79 *p* <.001	.18 *p* <.001	.2 *p* =.012	.18 *p* =.004	.93 *p* <.001	1				
Q22	.14 *p* =.036	.1	.23	0.06	.5 *p* <.001	.23 *p* =.002	.34 *p* =.032	.2 *p* =.010	1			
Q24	.09	-.01	.43 *p* <.001	.14 *p* =.009	.41 *p* <.001	.28 *p* <.001	.39 *p* =.002	.33 *p* <.001	.55 *p* <.001	1		
Q25	.25 *p* <.001	-.1	.19	.2 *p* <.001	.18 *p* =.014	.12 *p* =.18	.01	.16 *p* =.030	-.04	.2 *p* <.001	1	
Q26	-.18 *p* =.039	.08	-.004	.08	.01	-.02	.03	-.06	.09	-.03	.19 *p* =.023	1

- Significance at the 0.05 level (2 tailed)
- *p* -values included for significant variables only

Demographics, Clinical Characteristics and Self-Management Variable Bivariate Analyses, 30 to 36 months post surgery (T5)

Variable	Pain (sig)	Lymphedema (sig)	ROM limitation (sig)	statistical test
Age	-.03	.01	.26(p<.001)	Point biserail correlations
Race	.16	.12	.14	Cramers' *V*
Education	.05	.06	.16 (*p* =.027)	Cramers' *V*
Marital status	.07	.08	.08	Cramers' *V*
Income	.06	.12	.06	Cramers' *V*
Tumor stage	.11(*p* =.036)	.15 (*p* =.003)	.06	Cramers' *V*
Type of surgery	.07	.11 (*p* =.042)	.1	Cramers' *V*
Radiation	.03	.08	-.01	Phi coefficient
Chemotherapy	.09 (*p* =.038)	.02	-.02	Phi coefficient
Hormone therapy	-.01	-.05	.11 (*p* =.012)	Phi coefficient
Self-management Variable				
Q28	.09	.01	.04	Phi coefficient
Q29	.1(*p* =.023)	.02	.02	Point biserial correlation
Q15	.004	.24(*p* =.015)	.01	Phi coefficient
Q20	.24(*p* <.001)	.14(*p* =.002)	.13(*p* =.003)	Phi coefficient
Q21	.27(*p* <.001)	-.01	-.07	Phi coefficient
Q23	.08	.08	-.02	Phi coefficient
Q16	.08	-.2	.13	Phi coefficient
Q17	.14	.27(*p* =.001)	.19(*p* =.024)	Phi coefficient
Q22	.17(*p* =.028)	.13	-.11	Phi coefficient
Q24	-.005	.05	.07	Phi coefficient
Q25	.19(*p* =.002)	.01	.22(*p* <.001)	Phi coefficient
Q26	-.07	.06	.01	Phi coefficient

- Significance at the 0.05 level (2 tailed)
- *p*-values included for significant variables only

Multicollinearity Assessment of Independent Variables using Chi square Phi coefficient and Point-biserial Correlation coefficient (T5)

	Q28	Q29	Q15	Q20	Q21	Q23	Q16	Q17	Q22	Q24	Q25	Q26
Q28	1											
Q29	-.08	1										
Q15	.2	-.04	1									
Q20	.24 *p* <.001	.06	.19	1								
Q21	.14	.05	.42 *p* =.005	.09	1							
Q23	.07	.02	.38 *p* =.002	.02	.58 *p* <.001	1						
Q16	.29 *p* =.015	.03	.69 *p* <.001	.18	.05	.31 *p* =.026	1					
Q17	.21 *p* =.018	.15	.68 *p* <.001	.38 p <.001	.18	.21 *p* =.04	.83 *p* <.001	1				
Q22	.09	.07	.35 *p* =.24	.03	.60 *p* <.001	.34 *p* <.001	.22	.43 *p* =.001	1			
Q24	.06	.08	.44 *p* <.001	.03	.51 *p* <.001	.52 *p* <.001	.42 *p* =.003	.42 *p* <.001	.42 *p* <.001	1		
Q25	.16 *p* =.012	.003	-.08	.15 p =.014	.06	.17 *p* =.011	-.15	-.07	.04	.18	1	
Q26	-.04	.1	-.18	.06	-.13	-.07	-.15	.16	.09	.09	.2 *p* =.027	1

- Significance at the 0.05 level (2 tailed)
- *p* -values included for significant variables only

7.8 Appendix H – Multivariate Logistic Regression Results Tables

Pain, T1

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	39.116	12	.000
	Block	39.116	12	.000
	Model	39.116	12	.000

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	392.368[a]	.118	.157

a. Estimation terminated at iteration number 4 because parameter estimates changed by less than .001.

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	Any swelling in armpit, chestwall, breast	-.544	.261	4.338	1	.037	.580	.348	.968
	Discussed treatment for movement problems	.412	.344	1.432	1	.231	1.510	.769	2.966
	Received treatment from physiotherapist	.061	.356	.029	1	.864	1.063	.529	2.137
	Discussed treatment for pain	-.520	.304	2.916	1	.088	.595	.328	1.080
	Received treatment for pain	-.403	.361	1.250	1	.264	.668	.329	1.355
	Medication taken for pain	-.665	.255	6.802	1	.009	.514	.312	.848
	Change in leisure activities	-.257	.262	.963	1	.326	.774	.463	1.292
	Days per week exercise involving arms	.047	.044	1.153	1	.283	1.048	.962	1.143
	Years of age at assessment	-.020	.012	3.071	1	.080	.980	.958	1.002
	Family Income Categories T1 (Did not answer – referent)			5.312	3	.150			
	Family Income Categories T1 (Under $40,000)	.368	.374	.969	1	.325	1.444	.695	3.004
	Family Income Categories T1 ($40,001 – 80,000)	-.112	.364	.094	1	.759	.894	.438	1.824
	Family Income Categories T1 (Over $80,001)	-.506	.415	1.490	1	.222	.603	.268	1.359
	Constant	2.095	.798	6.891	1	.009	8.122		

a. Variable(s) entered on step 1: Any swelling in armpit, chestwall, breast - T1, Discussed treatment for movement problems - T1, Received treatment from physiotherapist - T1, Discussed treatment for pain - T1, Received treatment for pain - T1, Medication taken for pain - T1, Change in leisure activities - T1, Days per week exercise involving arms - T1, Years of age at assessment - T1, Family Income Categories: 4 Levels - T1.

Lymphedema, T1

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	15.600	7	.029
	Block	15.600	7	.029
	Model	15.600	7	.029

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	99.458[a]	.161	.222

a. Estimation terminated at iteration number 20 because maximum iterations has been reached. Final solution cannot be found.

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	Received treatment for swelling	.955	.508	3.532	1	.060	2.598	.960	7.030
	Years of age at assessment	.056	.023	5.876	1	.015	1.058	1.011	1.107
	Tumor Stage - T1 (Stage 3 –referent)			1.778	2	.411			
	Tumor Stage - T1 (Stage 1)	-.292	.694	.177	1	.674	.747	.192	2.909
	Tumor Stage - T1 (Stage 2)	.495	.659	.565	1	.452	1.641	.451	5.969
	Type of Surgery - T1 (Radical mastectomy – referent)			.001	2	1.000			
	Type of Surgery - T1 (Partial mastectomy or lumpectomy)	-24.177	40192.970	.000	1	1.000	.000	.000	.
	Type of Surgery - T1 (Modified radical mastectomy)	-.013	.542	.001	1	.981	.987	.341	2.856
	Any swelling in armpit, chestwall, breast	.545	.583	.873	1	.350	1.725	.550	5.411
	Constant	-3.171	1.462	4.702	1	.030	.042		

a. Variable(s) entered on step 1: Received treatment for swelling - T1, [Rounded Down] Years of age at assessment - T1, Tumor Stage - T1, Type of Surgery - T1, Any swelling in armpit, chestwall, breast - T1.

ROM limitation, T1

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	31.275	16	.012
	Block	31.275	16	.012
	Model	31.275	16	.012

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	55.887[a]	.327	.489

a. Estimation terminated at iteration number 20 because maximum iterations has been reached. Final solution cannot be found.

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	Change in leisure activities	-1.013	.910	1.237	1	.266	.363	.061	2.164
	Any swelling in armpit, chestwall, breast	-2.402	1.003	5.739	1	.017	.091	.013	.646
	Received treatment for swelling	-.122	.872	.020	1	.889	.885	.160	4.885
	Received treatment for pain	-1.094	1.095	.998	1	.318	.335	.039	2.864
	Medication taken for pain	-.830	.837	.983	1	.321	.436	.085	2.248
	Highest level of education - T1 (Graduate degree – referent)			5.689	3	.338			
	Highest level of education - T1 (High school and below)	20.289	40192.969	.000	1	1.000	647865232.000	.000	.
	Highest level of education - T1 (Some college – university undergraduate degree)	1.715	1.801	.907	1	.341	5.555	.163	189.371
	Current marital status - T1 (With partner-referent)			4.521	1	.477			
	Current marital status - T1 (No partner)	1.884	1.672	1.269	1	.260	6.579	.248	174.450
	Type of Surgery - T1	3.001	1.083	7.681	1	.006	20.107	2.408	167.908
	Constant	.744	1.580	.222	1	.638	2.105		

a. Variable(s) entered on step 1: Change in leisure activities - T1, Any swelling in armpit, chestwall, breast - T1, Received treatment for swelling - T1, Received treatment for pain - T1, Medication taken for pain - T1, Highest level of education - T1, Current marital status - T1, Type of Surgery - T1.

Logistic Regression Analyses Results, 18 to 24 months post-surgery (T3)

Pain, T3

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	23.640	8	.003
	Block	23.640	8	.003
	Model	23.640	8	.003

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	207.146[a]	.132	.176

a. Estimation terminated at iteration number 20 because maximum iterations has been reached. Final solution cannot be found.

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	Type of Surgery - T1 (Stage 3 – referent)			.998	2	.607			
	Type of Surgery - T1 (Stage 1)	-20.806	28193.268	.000	1	.999	.000	.000	.
	Type of Surgery - T1 (Stage 2)	.382	.383	.998	1	.318	1.466	.692	3.104
	Change in leisure activities	-.211	.388	.297	1	.586	.810	.379	1.731
	Any swelling in armpit, chestwall, breast	.039	.352	.012	1	.912	1.040	.521	2.073
	Discussed treatment for movement problems	-.182	.396	.211	1	.646	.833	.383	1.812
	Discussed treatment for pain	-.944	.385	6.020	1	.014	.389	.183	.827
	Received treatment for pain	-.067	.420	.026	1	.873	.935	.410	2.131
	Medication taken for pain	-.741	.350	4.492	1	.034	.477	.240	.946
	Constant	1.229	.466	6.962	1	.008	3.419		

a. Variable(s) entered on step 1: Type of Surgery - T1, Change in leisure activities - T3, Any swelling in armpit, chestwall, breast - T3, Discussed treatment for movement problems - T3, Discussed treatment for pain - T3, Received treatment for pain - T3, Medication taken for pain - T3.

Lymphedema, T3

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	23.727	6	.001
	Block	23.727	6	.001
	Model	23.727	6	.001

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	338.864[a]	.064	.101

a. Estimation terminated at iteration number 4 because parameter estimates changed by less than .001.

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	Type of Surgery - T1 (Radical mastectomy –referent)			6.030	2	.049			
	Type of Surgery - T1 (Partial mastectomy or lumpectomy)	.249	1.156	.047	1	.829	1.283	.133	12.364
	Type of Surgery - T1 (Modified radical mastectomy)	.764	.311	6.028	1	.014	2.146	1.167	3.949
	Tumor Stage - T1 (Stage 3– referent)			5.671	2	.059			
	Tumor Stage - T1 (Stage 1)	-.986	.427	5.338	1	.021	.373	.162	.861
	Tumor Stage - T1 (Stage 2)	-.791	.388	4.142	1	.042	.454	.212	.971
	Any swelling in armpit, chestwall, breast	-.120	.287	.173	1	.677	.887	.505	1.558
	Received treatment for pain	-.626	.319	3.840	1	.050	.535	.286	1.000
	Constant	-.277	.465	.354	1	.552	.758		

a. Variable(s) entered on step 1: Type of Surgery - T1, Tumor Stage - T1, Any swelling in armpit, chestwall, breast - T3, Received treatment for pain - T3.

ROM limitation, T3

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	37.740	7	.000
	Block	37.740	7	.000
	Model	37.740	7	.000

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	454.421[a]	.101	.134

a. Estimation terminated at iteration number 4 because parameter estimates changed by less than .001.

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	Years of age at assessment	.027	.011	6.024	1	.014	1.028	1.005	1.050
	Highest level of education - T1	-.173	.102	2.916	1	.088	.841	.689	1.026
	Type of Surgery - T1 (Radical mastectomy-referent)			4.117	2	.128			
	Type of Surgery - T1 (Partial mastectomy or lumpectomy)	.032	.836	.001	1	.970	1.032	.201	5.315
	Type of Surgery - T1 (Modified radical mastectomy)	.548	.270	4.105	1	.043	1.729	1.018	2.937
	Any swelling in armpit, chestwall, breast	-.436	.246	3.132	1	.077	.647	.399	1.048
	Received treatment for pain	-.781	.309	6.363	1	.012	.458	.250	.840
	Medication taken for pain	.533	.244	4.772	1	.029	1.704	1.056	2.747
	Constant	-.583	.906	.415	1	.520	.558		

a. Variable(s) entered on step 1: Years of age at assessment - T3, Highest level of education - T1, Type of Surgery - T1, Any swelling in armpit, chestwall, breast - T3, Received treatment for pain - T3, Medication taken for pain - T3.

Logistic Regression Analyses Results, 30 to 36 months post-surgery (T5)

Pain, T5

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	10.706	8	.219
	Block	10.706	8	.219
	Model	10.706	8	.219

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	132.853[a]	.098	.131

a. Estimation terminated at iteration number 4 because parameter estimates changed by less than .001.

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	Tumor Stage - T1 (Stage 3 – referent)			.416	2	.812			
	Tumor Stage - T1(Stage 1)	.497	.788	.399	1	.528	1.645	.351	7.699
	Tumor Stage - T1(Stage 2)	.429	.744	.332	1	.564	1.535	.357	6.603
	Chemotherapy - T1	-.453	.524	.750	1	.387	.635	.228	1.774
	Any swelling in armpit, chestwall, breast	-.650	.466	1.950	1	.163	.522	.209	1.300
	Discussed treatment for movement problems	-.426	.571	.556	1	.456	.653	.213	2.000
	Received treatment from physiotherapist	-.321	.688	.217	1	.642	.726	.188	2.798
	Medication taken for pain	-.758	.447	2.880	1	.090	.469	.195	1.125
	Days per week exercise involving arms	.082	.086	.919	1	.338	1.085	.918	1.284
	Constant	.632	.922	.469	1	.493	1.881		

a. Variable(s) entered on step 1: Tumor Stage - T1, Chemotherapy - T1, Any swelling in armpit, chestwall, breast - T5, Discussed treatment for movement problems - T5, Received treatment from physiotherapist - T5, Medication taken for pain - T5, Days per week exercise involving arms - T5.

Lymphedema, T5

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	17.203	6	.009
	Block	17.203	6	.009
	Model	17.203	6	.009

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	117.759[a]	.160	.214

a. Estimation terminated at iteration number 20 because maximum iterations has been reached. Final solution cannot be found.

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	Tumor Stage - T1 (Stage 3 –referent)			3.593	2	.166			
	Tumor Stage - T1 (Stage 1)	-1.387	.733	3.587	1	.058	.250	.059	1.050
	Tumor Stage - T1 (Stage 2)	-.709	.594	1.427	1	.232	.492	.154	1.575
	Type of Surgery - T1 (Radical mastectomy)			1.895	2	.388			
	Type of Surgery - T1 (Partial mastectomy or lumpectomy)	22.022	40192.969	.000	1	1.000	3663599611.000	.000	.
	Type of Surgery - T1 (Modified radical mastectomy)	-.726	.528	1.895	1	.169	.484	.172	1.361
	Discussed treatment for swelling	-.816	.482	2.861	1	.091	.442	.172	1.138
	Any swelling in armpit, chestwall, breast	-1.283	.508	6.372	1	.012	.277	.102	.751
	Constant	2.667	.790	11.393	1	.001	14.401		

a. Variable(s) entered on step 1: Tumor Stage - T1, Type of Surgery - T1, Discussed treatment for swelling - T5, Any swelling in armpit, chestwall, breast - T5.

ROM limitation, T5

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	31.743	5	.000
	Block	31.743	5	.000
	Model	31.743	5	.000

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	322.099[a]	.116	.155

a. Estimation terminated at iteration number 4 because parameter estimates changed by less than .001.

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B) Lower	Upper
Step 1[a]	Years of age at assessment	.044	.014	10.496	1	.001	1.045	1.018	1.074
	Highest level of education - T1	-.169	.118	2.051	1	.152	.845	.670	1.064
	Hormonal Therapy - T1	.570	.327	3.033	1	.082	1.767	.931	3.355
	Any swelling in armpit, chestwall, breast	-.308	.306	1.010	1	.315	.735	.403	1.340
	Medication taken for pain	.821	.270	9.227	1	.002	2.273	1.338	3.862
	Constant	-4.032	1.121	12.944	1	.000	.018		

a. Variable(s) entered on step 1: Years of age at assessment - T5, Highest level of education - T1, Hormonal Therapy - T1, Any swelling in armpit, chestwall, breast - T5, Medication taken for pain - T5.

7.9 Appendix I – Examples of Codes, Categories and Themes from Qualitative Data

The following tables outline examples of codes, categoeries, sub-themes and themes that emerged from qualitative interviews (*n* = 40). Study objectives are also shown to match with findings

Objective 2: How do women self-manage symptoms of arm morbidity?

Codes	Categories	Sub-themes	Themes
I worse elastic bandage every day	Bandaging	Complex Decongestive Therapy (CDT)	Self-management of physical symptom
I always wear my elastic bandage when I know I will need it			
She is trying to teach me how to bandage			
if it gets a little more swollen, it does help to have the sleeve on	Compression garments		
When I am working or during the day I am wearing the sleeve			
I learned a bit how to do the compressive bandages by myself			
I just relax, you know, and massage it a little	Self-massaging		
I started doing like a massage and going up the arm and stuff like that			
Symptoms are relived if I massage my arm in an upward motion			
I do myself a little bit of therapeutic touch, you know, I do that…ya, I think it soothes it a bit…in my mind			
Well I do exercises for the arm and the upper body, um every morning when I wake up	Exercising	Physical Activity	
I use very small weights on my arm and some of the exercises that we do in the classes			
I am doing a lot of exercises that were recommended. Those exercises were given by the therapist			

Codes	Categories	Sub-themes	Themes
I try to make it a regular routine where I do my exercises every morning		Physical Activity	Self-management of physical symptom
I've tried to stretch it. I've tried to stretch the tendons to see if that will ease it up and it does for a short time	Stretching		
And a little body stretch and that's how I start my day			
She just said stretch			
She's kind of … stretched it to the point where I can do daily work			
I swam all the time…I was swimming and that I had such complete mobility in my arm.	Swimming		
when I don't have my swim… it swells up … and so the swims… have been very helpful			
the water is the best way for me to do that….I'm part of a group, uh lymphodema aqua therapy			
I've done a lot of walking and I've really tried to be consciously healthy about everything	Walking		
sometimes I walk along for a little while with my arm above my head			
I just made sure I didn't lift things, or try to remember not to lift things with that arm. But no, I just had to make adjustments	Being cautious	Increased Self-Awareness	
I am cautious about not carrying as much weight in my left arm…I'm more cautious about protecting it			
I've done some minor adjustments…really its trial and error			
I try to watch the positioning at night to make sure that I'm not doing something awkward that might be producing the numbness	Changing positions		
raise the arm over my head and open and close my hand, about as often as I can during the day			
I put my arm up on the chesterfield with a pillow on top of it and that does relieve the pain an awful lot			

Codes	Categories	Sub-themes	Themes
I have to rest it a day or two then it's back to normal	Resting		
I kind of overdo it …but I just talk to my boss and take a day off and kind of rest	Resting	Increased Self-Awareness	
Then I rest it, and then I start doing a little bit more exercise			
I do have pain in my shoulder from time to time, and I'm not sure whether that is because of the imbalance from not having a breast there	Reflecting on Causes	Uncertainty	Self-management of psychosocial Uncertainty
I was fine one day and I got up the next morning and I had pain in my arm and I couldn't put my bra on. My breast swelled up overnight…..it was really worrisome			
I don't think there was anything that triggered it that I noticed. I hadn't done anything, out of the ordinary			
I said, what do I do next because I can't seem to get any cooperation from Dr [Name]'s office. The other thing was their lack of interest and knowledge			
Sometimes it resolves over time, sometimes it doesn't			
What did I do, you know?...well it persisted and it got worse…I went to see my GP and she said I've never seen anything like that			
I have little bit of lymphedema, and I am wondering if it will stop or continue			
It seems like everyone will look at me with that [compression sleeve]. So there is a lot of anxiety			
Emotionally, I've been a lot better.			
You shouldn't be doing this kind of exercise and that kind of exercise but, what can I be doing?			
It's just heavy… why does this one feel like that? He didn't give me any medicine, all he said, its urn, it's from the treatment	Reflecting on Treatments		
I decided, nobody referred me anywhere, I found myself the information. I decided to go for lymphatic drainage			

Codes	Categories	Sub-themes	Themes
But the surgeon…found it funny [going for lymphatic drainage], to her, she wasn't seeing that it will do anything	Reflecting on Treatments	Uncertainty	Self-management of psychosocial Uncertainty
I tried going to, having acupuncture for it and I didn't see that that was helping at all			
It's your responsibility to look for care and the right person to look after you. Because if you don't, you can fall through the cracks			
There is a lot of guilt. I'm thankful that I've survived….i have to try to get myself back together and figure out why God let me stay			
The family physician is the first person you go to of course, but then you can't expect your family physician to do everything. You have to take it upon yourself			
I was just carrying a little bit too much. Plus I think it was just the stress of just worry.			
I try not to think [about] what's happening to me and sometimes I do think about it… it's sometimes, kind of frustrating			
I have to keep my health up, if I keep on worrying about, about my health and my cancer, I'm going to get worse, but I, I'm a, I think I'm a strong woman and I like to keep my (laugh) my attitude to stay alive yet for a while so ah.			
I was feeling [numbness]….didn't necessarily mean that there was a tumor back pressing more nerves…which was my biggest concern			

Objective 3: To explore treatment options experienced for managing arm morbidity

Codes	Categories	Sub-themes	Themes
along with the manual massage, the compression did help and it never came back	Lymph drainage/ manual drainage	Complex Decongestive Therapy (CDT)	Rehabilitation
Lymphatic drainage, compression and then the sleeve			
It moves the fluid, the excess fluid around to reposition it in my lymph notes [nodes].			
I will move my arm to encourage the draining to go to a different place			
They showed me just how to, reroute the river, kind of thing, like change the drainage in it.			
every few months for a manual massage of my arm			
I've gone to see some um, lymphodema massage… I'm improving drainage and circulation in my arm.			
I had experienced movement problems with my arm and I went to physio with [name] at St. Joseph's…. and we did get the arm moving, it is moving properly	Physiotherapy		
I decided to go and have a physiotherapy assessment done which I did, and they gave us some exercises to do			
[name] suggested that I come in for some of her physio, well it certainly has made a difference in my movement			
I'm feeling better, because since then I've had some physio and resolved some of the issues with my shoulder			
so I went to see a physiotherapist and um , that was between the surgery and the radiation			
having seen a physiotherapist I know exactly what I should be doing			
the physiotherapist in the breast center clinic there….She showed me her exercises she gave me a lot of information			

Codes	Categories	Sub-themes	Themes
I went to a massage therapist who used to work a lot under my arm	Massage Therapy	Non-CDT/other	
I still have massage therapy every three weeks and that has made a big difference.	Massage Therapy	Non-CDT/other	
She's trying to massage some of the muscles, and then my motion gets a little better.			
She did the massage and everything, but other than that- that's been the extent of my treatment.			
She massages my arm and that seems to help a lot.			
massage for about a half an hour, it was relaxing and it just feel, I felt so good for the, you know 4 or 5 days			
..not by anyone that's, has a medical background…she massages my arm and that seems to help a lot			
Ibuprophin, that seems to help	Analgesics	Medications	
I was popping ibuprofen quite regularly to try to, um , 'cause it has an anti-inflammatory effect… he suggested that I should possibly just take an aspirin			
sometimes just an extra strength Tylenol….you know I rest my arm then and then the pain goes away so,			
I do put the cream on in the morning and at night. This keeps it under control…I can function.	Topical cream/ointment		
Two other medications that I put on up to three times a day when it's really bad.			
Take sleeping pills so I can sleep. My sleeping difficulties, …I have right since the whole process of radiation	Sleep aids		