

**Breast Cancer Rehabilitation:
A Mixed Method Inquiry of Physical Recovery
and Lived Experiences**

by

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ABSTRACT

The purpose of this mixed method study was to determine the extent of physical problems, rehabilitation needs, and cancer rehabilitation experiences after breast cancer treatment. Women diagnosed with breast cancer were surveyed to examine physical morbidities, disability, and quality of life. An interpretive descriptive approach was used in the conduction of a focus group. The percentage of women experiencing physical problems after breast cancer treatment was high, physical disability was low and there was a moderately high quality of life. Despite the high report of physical problems, less than half received physical rehabilitation. Themes from the focus group data were difficulty in finding clear/consistent information, financial issues and the need for integration of cancer rehabilitation services. This research adds to the better understanding of cancer rehabilitation needs and practices and may be used to improve the delivery of cancer rehabilitation services to address the physical needs of breast cancer survivors.

Key Words: Breast Cancer, Cancer Rehabilitation, Rehabilitation Usage, Rehabilitation Experiences.

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1.0 INTRODUCTION

Advances in breast cancer treatment over the past few decades have resulted in an increased number of breast cancer survivors in Canada. Statistics from the Canadian Cancer Society (2012) estimates an 88% survival rate 5 years past breast cancer diagnosis, which has increased by 14% since 1984 (Canadian Cancer Society, 2012a; National Cancer Institute of Canada, 1993). In Manitoba, 800 women are diagnosed each year with breast cancer and a majority of them endure surgery, chemotherapy, radiation therapy, and hormonal therapy (Canadian Cancer Society, 2012b). These invasive and lengthy treatments have prolonged women's lives, but have come at a cost. This increasing number of breast cancer survivors¹ means there are a growing number of women living with the physical short-term, long-term, and late effects of breast cancer treatments. These effects of cancer treatment can compromise functional ability, independence, and quality of life. They are alive and have survived, but do they thrive? To be a survivor should not just mean the absence of disease or dysfunction, but also the presence of optimal physical, psychological, and socioeconomic health and productivity. Survivors of cancer need to attain and maintain an ideal quality of life for the remainder of their lives.

1.1 Statement of the Problem

The increasing survival rates, and the unfavourable treatment effects to health and quality of life, point to the increasing need for rehabilitation after cancer treatment. In broad terms, rehabilitation refers to helping individuals attain the maximum physical,

¹ A breast cancer survivor is considered to be any individual that has been diagnosed with breast cancer from the time of diagnosis to the end of life.

social, psychological, and vocational functioning. Unfortunately, the physical rehabilitation needs of many breast cancer survivors are overlooked during treatment and more certainly once they have completed their primary treatment. Even if there are identified physical problems amenable to rehabilitation, there is not any routine referral system nor is there an inclusion of services responsive to these needs. In addition to the lack of organized or integrated cancer rehabilitation services, there are few specialized personnel to whom cancer patients can be referred. It is evident that efficient systems are needed to identify the rehabilitation needs, to provide rehabilitation services, and to facilitate evidence-based rehabilitation outcomes for breast cancer survivors (M. Hewitt, Greenfield, & Stovall, 2006; Vargo, 2008).

To facilitate the effective implementation of cancer rehabilitation for breast cancer survivors, the accurate identification of the physical effects of cancer treatment and the rehabilitation requirements is paramount (Gamble, Gerber, Spill, & Paul, 2011; Ganz, 1990; M. Hewitt, Maxwell, & Vargo, 2007). As an initial step, a rehabilitation needs-assessment is vital to identify the adverse physical effects of cancer treatment and to provide timely and appropriate cancer rehabilitation. If this first step is lacking, then there will be a missed opportunity to address these issues and to improve the quality of life for breast cancer survivors. One of the principle problems impeding the timely provision of cancer rehabilitation is the inadequate identification of those who need rehabilitation services (Dalton, Bidstrup, & Johansen, 2011; Lehmann et al., 1978).

There is an interest in, and a genuine need for, rehabilitation services amongst breast cancer survivors. Studies have reported that up to 87% of the cancer patients surveyed had physical limitations for which they wanted rehabilitation management

(Cheville, Beck, Petersen, Marks, & Gamble, 2009; Kim et al., 2011; Thorsen et al., 2011; van Harten, van Noort, Warmerdam, Hendricks, & Seidel, 1998). Many women have expressed the desire and the need for early rehabilitation as well as advice for exercise after surgery (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002a; Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002b; Springer et al., 2010; Torres Lacomba et al., 2010). In a study of prostate, breast, colorectal and lung cancer survivors, the desire for physical activity counseling, a component of rehabilitation, is reported to be as high as 84% (Jones & Courneya, 2002). This interest and need for cancer rehabilitation, including physical activity interventions, indicates that needs-assessments and rehabilitation services should be routinely incorporated into cancer care delivery. Presently, most cancer centres do not provide this service as a standard part of care.

In contrast, there is a segment of the breast cancer population that is not aware of the role of cancer rehabilitation and the potential benefits to their quality of life. They do not realize that their physical difficulties can be treated and also do not know how to express their concerns to cancer care providers. Some may even feel that these “minor” troubles are normal after cancer treatment and are not worth mentioning when they have lived through all the treatment and survived this major threat to their life (Binkley et al., 2012). An evident challenge here is to not only increase patients’ awareness of the benefits and availability of rehabilitation, but also to assist patients to avail themselves of these services (Guadagnoli & Mor, 1991). This lends additional credence to the need for systematic assessments of the physical rehabilitation needs of breast cancer survivors to determine their rehabilitation requirements and to arrange appropriate referrals. This lack

of knowledge of the role, potential benefits, and the entire rehabilitative process is a predicament facing cancer rehabilitation (Paul & Buschbacher, 2011).

In Manitoba, some strides have been made in the provision of rehabilitation with a focus on physical activity interventions and also in meeting the psychosocial needs of cancer survivors. However, there is a gap in meeting all the physical rehabilitation needs. In addition, the awareness of cancer patients about cancer rehabilitation and the role it occupies in survivorship is unknown. The purpose of this inquiry is to examine the physical needs of breast cancer survivors, the use of routine physical needs-assessments for breast cancer survivors, the existence of formalized referral systems to rehabilitation interventions, the provision of sufficient and accessible cancer rehabilitation services, and women's experiences in relation to cancer rehabilitation.

2.0 REVIEW OF LITERATURE

2.1 Introduction

A review of the literature establishes a background to examine cancer rehabilitation and the physical rehabilitation needs of breast cancer survivors. The areas of this review include the following: 1) breast cancer treatment physical effects and efficacy of rehabilitation, 2) definition and description of cancer rehabilitation, 3) physical needs-assessments and breast cancer survivors, 4) cancer rehabilitation services, models and delivery, and 5) limitations in the literature. This chapter concludes with the purpose of the study, the research questions, the assumptions underlying the study, and the significance of the study.

2.2 Summary of the Literature

2.2.1 Breast Cancer Treatment Physical Effects and Efficacy of Rehabilitation

A majority of women undergoing treatment for breast cancer, such as mastectomy, lumpectomy, sentinel node biopsy, axillary lymph node dissection, chemotherapy, and high-dose radiation, experience life-saving results. These treatments, however, also come with a myriad of short-term, long-term, and late-effects that can impact the mobility, function and quality of life of the survivor. Even up to 6 years after diagnosis, as many as 60% of women have at least one functional limitation, impairment, or lingering physical effect of treatment that could be improved or managed by physical rehabilitation interventions (Baker, Denniston, Smith, & West, 2005; Ganz et al., 1996; Johansen, 2007; Lehmann et al., 1978; Schmitz, Speck, Rye, Disipio, & Hayes, 2012; R. Thomas-Maclean et al., 2009).

The short-term effects of cancer treatment for those diagnosed with breast cancer generally include acute or transient complications following surgery, chemotherapy, and radiation treatment. These effects are typically short-lived and last from a few weeks to 6 months (B. Smoot, Wampler, & Topp, 2009). Long-term effects refer to persistent or permanent side effects for which the cancer patient must compensate, and can begin during treatment and continue well beyond the end of treatment. The late effects of cancer treatment are any side effect that appears months to years after the completion of treatment. Both long-term and late effects of treatment can be persistent, may worsen over time, and also carry significant potential to adversely affect the overall health and well-being of survivors (Aziz & Rowland, 2003; Aziz, 2007).

Recommendations for evidence-based clinical practice guidelines for the management of physical impairments related to cancer treatment have been synthesized in a supplement to *Cancer* (Harris, Schmitz, Campbell, & McNeely, 2012), and include guidelines for upper extremity rehabilitation, lymphedema management, cancer-related pain, cancer-related fatigue, chemo-induced peripheral neuropathy, bone health and weight management.

Shoulder and arm morbidities are a common occurrence following surgical procedures and radiation therapy in breast cancer. The life-saving and prognostic value of mastectomies, lumpectomies, axillary lymph node dissections, sentinel node biopsies, and radiation therapy is evident. The physical after-effects of pain, numbness, weakness, impaired shoulder mobility, and limited upper-limb function, however, are often the unfortunate consequences (Fleissig et al., 2006; Rietman et al., 2003; Shamley et al., 2007). The prevalence of these complaints after surgery, depending on the surgical

procedure, are reported to range from 5% to 63% for arm-shoulder pain and sensory changes, 17% to 40% for arm weakness, and 9% to 34% for limited arm mobility (Barranger et al., 2005; Bosompra, Ashikaga, O'Brien, Nelson, & Skelly, 2002; Maunsell, Brisson, & Deschenes, 1993; Tasmuth, von Smitten, Hietanen, Kataja, & Kalso, 1995; Ververs et al., 2001). In addition, interference with work, leisure activities and other physical functioning was reported in 29% to 68% of breast cancer survivors (Miedema et al., 2008; Quinlan et al., 2009). These shoulder and arm morbidities are not always short-term and can persist for many months to several years after surgery and radiation treatments. In a study by Hack et al (1999), 31% of breast cancer patients reported arm/shoulder pain, 18% reported weakness, and 63% reported numbness, with 73% assessed to have limited shoulder range of motion at least 6 months after the end of their cancer therapies (Hack, Cohen, Katz, Robson, & Goss, 1999). Other studies have reported persistent residual impairments of the arm, shoulder, and upper body at one year and even up to 5 years post-surgery (Engel, Kerr, Schlesinger-Raab, Sauer, & Holzel, 2003; Karki, Simonen, Malkia, & Selfe, 2005; Rietman et al., 2006; Tasmuth, von Smitten, & Kalso, 1996; Warmuth et al., 1998). These common shoulder and arm morbidities have an impact on quality of life for the breast cancer survivor and can be one of the greatest sources of distress after breast cancer treatment (Kuehn et al., 2000). The arm-shoulder pain, and limited mobility following breast cancer treatments, has a significant association with sleep disturbances and is often a predictor of long-term insomnia (Dahl, Nesvold, Reinertsen, & Fossa, 2011) which is an added negative effect to the breast cancer survivor's quality of life. The evidence-based beneficial impact of physical rehabilitation interventions is recognized for the reduction of pain, restoring of

movement and strength, and returning patients to optimal function (Beurskens, van Uden, Strobbe, Oostendorp, & Wobbles, 2007; Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002b; L. Gerber et al., 1992; Ghazinouri, Levy, Ben-Porat, & Stubblefield, 2005; Lauridsen, Torsleff, Husted, & Erichsen, 2000; Lauridsen, Christiansen, & Hesso, 2005; McNeely et al., 2010; Springer et al., 2010; Wise, Kepics, & Lattanzi, 2009). In addition, evidence exists for the value of pre-operative assessments or screening and education in preventative measures for minimizing shoulder morbidities (Flores & Hodges, 2004; Lauridsen et al., 2000; Lauridsen et al., 2005; Springer et al., 2010). Considering both the short-term and long-term sequelae to shoulder and arm function following breast cancer therapies, there is an urgent need for developing systematic rehabilitation protocols and integrating screening and interventions into routine cancer care.

Secondary lymphedema is a significant and common complication of breast cancer and its therapies. There is a wide range of the reported prevalence of secondary lymphedema, varying from 6% to 80% (S. Hayes, 2008). The prevalence reported varies with the diagnostic method and criteria that have been used, the timing of measurement and the type of cohort evaluated (S. C. Hayes et al., 2012). Lymphedema is a life-long phenomenon and can have a significant impact on the lives of survivors and their long-term adjustment (Erickson, Pearson, Ganz, Adams, & Kahn, 2001; Gartner et al., 2010; Kornblith et al., 2003). The manifestation of lymphedema is usually within 3 years after initial treatment; however, it can also be a late-effect of surgery and radiation many years later (Petrek, Senie, Peters, & Rosen, 2001). Lymphedema can result in much physical and physiological morbidity which can include infection, skin changes, altered sensation, pain, and decreased range of motion and strength and overall limited function (McNeely

et al., 2012). The presence of lymphedema in the arm also affects activities of daily living, recreational activities, employment, sleep, and body image (Gartner et al., 2010; R. L. Thomas-Maclean et al., 2008). These effects result in a significantly lower health-related quality of life in breast cancer survivors with lymphedema compared to survivors without lymphedema (Ahmed, Prizment, Lazovich, Schmitz, & Folsom, 2008; Jeong, Sim, Hwang, & Kim, 2011). Evidence exists that lymphedema in breast cancer survivors can be successfully managed with complete decongestive therapy, which includes manual lymphatic drainage, compression bandaging and garments, exercises, skin and nail care, and education in self-management (Badger, Preston, Seers, & Mortimer, 2004; Erickson et al., 2001; Hamner & Fleming, 2007; Kligman, Wong, Johnston, & Laetsch, 2004; Rockson, 2008; Williams, Vadgama, Franks, & Mortimer, 2002). This treatment has been effective in reducing and maintaining limb volume, lessening pain in the upper-limb and maintaining function for the breast cancer survivor (Hamner & Fleming, 2007; Williams et al., 2002). Pre-operative screening, baseline measurements, education in risk-minimizing strategies and regular post-operative follow-up assists in prevention for those at risk, enables early identification and more timely interventions for those that do develop lymphedema (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002a; Stout Gergich et al., 2008; Torres Lacomba et al., 2010). The provision of lymphedema treatment services, specifically preventative measures, pre- and post-op screening, early diagnosis and on-going intervention, is a vital component of cancer rehabilitation for management of this common physical effect of breast cancer treatment.

Cancer-related fatigue is one of the most prevalent and often debilitating effects of breast cancer treatment and may be a significant problem for over a third of breast

cancer survivors for at least a year and even up to seven years past diagnosis (Bower et al., 2006; Cavalli Kluthcovsky et al., 2011). This persistent lack of energy and chronic tiredness does not usually respond to rest and can have negative effects on mood, daily function, and quality of life. There is much evidence that a multi-faceted approach to fatigue management is efficacious, which includes pharmacologic interventions, psychological counseling, stress management, enhancing sleeping hygiene, energy conservation techniques and both aerobic and resistance exercise (Cheville, 2009; Lawrence, Kupelnick, Miller, Devine, & Lau, 2004; Winningham, 2001). The overall positive effect of aerobic activity and resistive exercise on symptom management, specifically fatigue, in breast cancer survivors is recognized both during and after active cancer treatment (McNeely et al., 2006; Mock et al., 2005; Stricker, Drake, Hoyer, & Mock, 2004). This multi-dimensional nature of cancer-related fatigue has been further examined and an intervention of exercise, sports, information, and psychoeducation has significantly reduced cancer-related fatigue (van Weert et al., 2005). In view of the prevalence of fatigue and the benefit of rehabilitation strategies in the management of cancer-related fatigue, it is recommended that routine screening, evaluation and interventions are incorporated into all cancer care programs (Mock, 2003).

The effect from surgery and radiation treatments to the soft tissues can be profound for some breast cancer survivors. The exact prevalence of this myofascial dysfunction is unknown, but it may be as high as 21% (Cheville & Tchou, 2007). Trigger points, hypertonicity, radiation fibrosis, muscle imbalances, and postural disturbances all interplay to contribute to myofascial dysfunction of the chest wall, scapular region, head, neck and back. Many manual therapy techniques offered by physiotherapists can be

effective in treating and managing this dysfunction. Myofascial release, sustained trigger point compression, gentle stretching, and progressive resisted exercises to address the myofascial dysfunction, muscle imbalances and strength deficits have all been helpful to ameliorate this often painful and debilitating condition (Crawford, Simpson, & Crawford, 1996; Gugliotti, 2011; Lauridsen et al., 2000; Lauridsen et al., 2005).

Following breast or axillary surgery, lymphatic disruption may result in tightened fibrotic bands or “cords” which is referred to as axillary web syndrome (AWS). These cords may be confined to the axilla, or may extend distally to the medial or anterior arm as far as the palm and can be a main contributor to pain and restricted mobility after surgery. AWS usually develops between 1 to 5 weeks post-surgery and the incidence may be as high as 72% particularly in those after axillary clearance of lymph nodes (Lauridsen et al., 2005; Leidenius, Leppanen, Krogerus, & von Smitten, 2003; Moskovitz et al., 2001). Although AWS is reported to be self-limiting (most of the cording spontaneously resolves by 3 to 6 months post-surgery), it can be a painful and distressing condition for women for those few months after surgery (Leidenius et al., 2003; Moskovitz et al., 2001). The effective treatment of AWS is not well documented; however, physiotherapy treatments of manual soft tissue techniques, modified skin-rolling techniques, gentle stretching and self-mobilization have provided some positive outcomes for decreased pain, increased shoulder range of motion and an earlier return to functional activities (Fourie & Robb, 2009; Kepics, 2004; Lauridsen et al., 2005).

The concern with body image for breast cancer survivors is common and has an integral role in feelings of being unattractive and inadequate. Body image concerns are also associated with decreased sexual activity, poorer psychological adjustment and

decreased overall functioning (Alfano & Rowland, 2006). These body image disturbances have been reported in 25% and even up to 67% of breast cancer survivors, particularly in those that have had mastectomies (Shimozuma, Ganz, Petersen, & Hirji, 1999; Sneeuw et al., 1992). Physical activity has been shown to have a positive influence in improving body image (Mehnert et al., 2011; Mock et al., 1997; Pinto, Clark, Maruyama, & Feder, 2003; Pinto & Trunzo, 2004). This further identifies the essential role of physical activity interventions in the rehabilitation of the breast cancer survivor especially those with body image concerns.

In addition to the altered body image as the result of surgery, greater than 50% of women experience weight gain after adjuvant chemotherapy and hormonal therapy (Demark-Wahnefried, Campbell, & Hayes, 2012; Shimozuma et al., 1999). The plausible factors for this weight gain could be related to premature menopause, hormonal therapies, decreased physical activity, increased dietary intake, and psychological issues (Demark-Wahnefried, Winer, & Rimer, 1993). Being overweight or obese has been linked to the prevalence of other morbidities for the breast cancer survivor, such as lymphedema, fatigue, and arthralgias, and in addition, cardiovascular disease, type 2 diabetes, chronic back pain, and asthma (Demark-Wahnefried et al., 2012). Weight management for women diagnosed with breast cancer is not only important for the cancer treatment-associated sequelae, but also for the prevention and management of comorbidities. A 3-fold approach is recommended for any weight management strategy: diet, exercise and behaviour therapy. Many weight management interventions have shown success amongst breast cancer survivors (Demark-Wahnefried et al., 2012; Winningham, MacVicar, Bondoc, Anderson, & Minton, 1989), with greater improvements seen in those

interventions that utilize the 3-fold strategies. The important role of physical activity and exercise in the rehabilitation of breast cancer survivors is evident not only for weight management, but also for all areas of well-being.

The overall effect of surgery, chemotherapy, and radiation treatments for breast cancer survivors can result in a deconditioned physical status, limitations with daily functioning, and impaired physical performance (Campbell et al., 2012; Ganz et al., 2004). While the incidence of decline in function and physical performance is greatest in the first year after cancer therapies, 40% may experience functional decline even up to 5 years later (Lash & Silliman, 2002). This deconditioned status and functional decline can in turn result in greater fatigue, weight gain, concerns with body image, increased psychological distress, and poorer quality of life. There is now strong evidence of the beneficial role of physical activity and exercise to attenuate these effects for breast cancer survivors both during active treatment and upon completion of treatment (Courneya, Mackey, & Jones, 2000; Courneya, 2001; Courneya, Mackey, & McKenzie, 2002; Courneya et al., 2003; Dimeo, Fetscher, Lange, Mertelsmann, & Keul, 1997; Spence, Heesch, & Brown, 2010; Young-McCaughan & Sexton, 1991; Young-McCaughan et al., 2003). In addition to the evidentiary benefits of improved psychological well-being and enhanced quality of life, the addition of an exercise program for breast cancer survivors increases physical fitness, physical function, and overall muscular strength (Courneya & Friedenreich, 2007; Pinto et al., 2003; Pinto, Frierson, Rabin, Trunzo, & Marcus, 2005; Segal et al., 2001; Young-McCaughan et al., 2003). A sedentary lifestyle, in contrast, may prolong the physical deconditioning, delay recovery from cancer treatments, exacerbate fatigue, and increase the risk for other chronic conditions such as obesity,

cardiovascular disease, diabetes, and osteoporosis (Courneya & Friedenreich, 2007; Demark-Wahnefried et al., 2003; Demark-Wahnefried, Pinto, & Gritz, 2006; Dimeo et al., 1997). Most breast cancer survivors do realize the importance of physical activity as part of a healthy lifestyle; however, they are uncertain of how to safely and effectively resume or begin an exercise program during or after their cancer treatments (Young-McCaughan et al., 2003). The surveillance of the breast cancer survivor's level of function and physical status should ideally start in the pre-operative phase, and follow with early post-operative evaluations and ongoing surveillance. Interventions can then be implemented as early as needed. The role of the cancer rehabilitation professional in these interventions is essential in providing personal instruction, training, and education for structured evidence-based exercise programs. It is imperative that cancer rehabilitation professionals are aware of the potential negative effects of cancer treatments in order to provide exercise interventions that are safe for the breast cancer survivor with individual adjustments in the exercise prescription that considers these effects. The ongoing surveillance of function and physical status and the provision of physical activity interventions should be a vital component in cancer care initiatives and should be made available to all breast cancer survivors.

Post-mastectomy pain syndrome has a varying prevalence ranging from 4% to 56% depending on the diagnostic criteria (Gartner et al., 2009; Smith, Bourne, Squair, Phillips, & Chambers, 1999; Wallace, Wallace, Lee, & Dobke, 1996), and can persist for more than 5 years after breast cancer treatments (Peuckmann et al., 2009). This severe, persistent neuropathic pain following surgery has the obvious effects to daily function and has been associated with poorer quality of life (Macdonald, Bruce, Scott, Smith, &

Chambers, 2005; Peuckmann et al., 2009). Any rehabilitative measures and analgesic modalities aimed at reducing and managing pain, and preserving flexibility, strength and function are imperative. The use of acupuncture, transcutaneous nerve stimulation, topical heat and cold therapy, manual therapies and other analgesic modalities utilized in rehabilitation have much value in the management of pain, however, caution must be exercised with the use of some modalities in the breast cancer population (Franklin, 2007; J. Silver & Mayer, 2007; Wise et al., 2009).

Chemotherapy-induced peripheral neuropathy (CIPN) is an unfortunate result from damage or dysfunction of the peripheral nerves, and can range from mild to severe. The incidence of CIPN is not well established, but it is estimated that up to 83% of breast cancer patients after chemotherapy may have some form of peripheral neuropathy (Stubblefield, McNeely, Alfano, & Mayer, 2012). Some patients unfortunately face long-term problems with a variety of symptoms ranging from sensory neuropathies of numbness, tingling, cold sensitivity, pain, burning, and freezing sensations, to motor neuropathies of weakness, limited range of motion and function. These symptoms can lead to neuropathic pain, serious limitation of activities of daily living and severe decrease in quality of life. It is recommended that breast cancer patients are assessed before, during, and after chemotherapy especially to identify those at greater risk for developing CIPN, and for early recognition and treatment of CIPN (Stubblefield et al., 2012). The rehabilitation strategies for the treatment and management of CIPN if it develops include: general exercise and physical activity; therapeutic exercise; functional restoration and maximizing self-care for activities of daily living; pain management; balance retraining; provision of gait aids and assistive devices; and education for

reduction of risk of injury and falling, compensation strategies for maintaining balance, proper skin care and improved safety (Harris et al., 2012; Stubblefield et al., 2012; Visovsky, Collins, Abbott, Aschenbrenner, & Hart, 2007).

Many women who have undergone radical mastectomies choose to have breast reconstruction surgery. While this is not a direct effect of breast cancer treatment this procedure can have significant physical sequelae requiring rehabilitation for the breast cancer survivor. Morbidity can occur not only at the chest and upper body but also at the donor site from where the tissue is harvested. The donor sites for autologous tissue transfers, namely transverse rectus abdominis muscle (TRAM) flap, deep inferior epigastric perforator (DIEP) flaps and latissimus dorsi harvesting can have considerable disabling effects. Weakness and imbalance of the truncal flexors and extensors, compromised proprioceptive innervation to the abdominal musculature resulting in altered “righting” reflexes and dynamic balance, and an increased risk of low back pain can all be the unfortunate consequences of abdominal muscle harvesting (Alderman, Kuzon, & Wilkins, 2006; Cheville & Tchou, 2007). For latissimus dorsi harvesting, shoulder morbidity and stability is a concern, and as well, the potential myofascial dysfunction post-operatively from any surgery is always a notable worry. Implant-based reconstruction can potentially lead to decreased pectoral muscle strength and increased breast pain (de Haan, Toor, Hage, Veeger, & Woerdeman, 2007). Early post-operative rehabilitation is recommended and the aim of rehabilitation following breast reconstructive surgery can include restoring of truncal muscle balance and stability, optimizing proprioceptive acuity, and reducing myofascial dysfunction. Rehabilitation would also include postural alignment, education in proper body mechanics and back

protection management, and regaining of optimal range of motion, strength and function (McNeely et al., 2012; Monteiro, 1997).

This literature review demonstrates that women treated for breast cancer can experience a substantial number of physical side effects that may be permanent or that persist for years after their primary treatment. It is also evident that most of these physical effects can be successfully avoided, ameliorated, or managed by rehabilitation services and exercise interventions. In addition, the prevalence of the varied physical rehabilitation problems and needs among breast cancer survivors point to the need for rehabilitation efforts that are comprehensive in nature, identifying problems and implementing interventions as early as possible, including attention to life style, health promotion activities, and overall wellness.

2.2.2 Definition and Description of Cancer Rehabilitation

A definition of cancer rehabilitation, in circulation since the 1990's, refers to a process that assists the individual with a cancer diagnosis in obtaining optimal physical, social, psychological, and vocational function within the limits created by the disease and its treatment (Watson, 1990). This definition can encompass a broad range of services including psychosocial support and counseling, physical therapy and rehabilitation, physical activity interventions, vocational and occupational therapy, lifestyle and health promotion education, as well as additional specific treatment of numerous clinical problems. Any approaches to cancer rehabilitation should take into consideration the strong connections between the physical, psychological and social dimensions of the survivor, and that psychosocial rehabilitation is most effective with simultaneous physical rehabilitation (Ronson & Body, 2002). The multidimensional cancer

rehabilitation approach seen in the definition has been shown to be preferred by cancer survivors, feasible and clinically effective for a wide range of cancer types and stages regardless of time since diagnosis (van Weert et al., 2005). This cancer rehabilitation definition supports coordinated and comprehensive multidisciplinary team involvement.

Four categories of cancer rehabilitation have been described: 1) Preventative – potential disability is expected and rehabilitation measures are designed to reduce the severity or shorten its duration by improving physical functioning and reducing morbidity and disability; 2) Restorative – minor disability is expected and rehabilitation measures are designed to control, circumvent or eliminate residual cancer disability; 3) Supportive – permanent disability is expected and rehabilitation measures are designed to lessen disability and other associated problems to improve functional status; and, 4) Palliative – advanced disease is present and disability is increasing and irreversible and rehabilitation measures are designed to optimize functional status, physical independence and quality of life (Dietz, 1974).

Based on these categories, cancer rehabilitation should be recognized as an evolving process and a seamless continuum which responds to the needs of the survivor at all stages of their disease and treatment. It should run in parallel with traditional cancer care services for the entire continuum of care from diagnosis to survivorship and end-of-life (David, 1993; Hellbom et al., 2011). This approach to cancer rehabilitation would require the assessment of the rehabilitative needs through all phases of cancer treatment, timely referral to appropriate therapies, and evaluation of the outcomes to determine the effectiveness of the interventions.

In the preventative phase, cancer rehabilitation and an integrated needs-assessment should be introduced early in the cancer treatment trajectory to optimize the health outcomes for cancer survivors (Gamble et al., 2011). Introducing the patient to the concept of cancer rehabilitation soon after cancer has been diagnosed, or before or immediately after surgery, chemotherapy or radiation, gives an opportunity to present risk management strategies, provide education concerning the potential effects of cancer treatment, and promote the role of cancer rehabilitation. Additionally, this preventative approach can reduce the post-treatment morbidities and prepare the cancer patient so that they are aware of the possible functional limitations and the available rehabilitation interventions (Ganz, 1990).

The restorative and supportive phases of cancer rehabilitation involve systematic needs-assessments, evaluating and controlling the physical effects of treatment, preserving and restoring function, developing supportive programs for both psychosocial and physical care, promoting healthy lifestyles and continuing instruction in self-management (Okamura, 2011; Watson, 1990). The palliative category of cancer rehabilitation includes many of the previously mentioned objectives; however, there would be more focus on optimizing quality of life and independence in activities of daily living, in addition to being attentive to comfort and symptom control (Okamura, 2011; Yoshioka, 1994).

In all these phases of cancer rehabilitation, the focus on optimal functioning is the essence and core concept that should be addressed before, during, and after primary cancer treatment (Watson, 1992). Optimal functioning should encompass achieving the best possible outcomes in the physical, psychological, social, emotional, vocational, and

spiritual aspects of the survivor's life. When a person is functioning optimally in all areas of life, they are experiencing the best quality of life. Further, the rehabilitation objectives should harmonize with the patient's goals for optimal functioning and should be incorporated with the cancer treatment goals regardless of the phase of cancer treatment. This patient-focused strategy and the incorporation of the patient's rehabilitation goals require individualized evaluations and rehabilitation plans at every stage of the cancer treatment course.

In summary, cancer rehabilitation can be described by these defining attributes: 1) Cancer rehabilitation is concerned with quality of life and not quantity of life, although it may affect the quantity of life. 2) The rehabilitation measures are governed by the survivor's rehabilitation needs and goals, a patient-focused approach. 3) Cancer rehabilitation is concerned with optimal function and independence in all aspects of life. 4) Cancer rehabilitation is dynamic and continuous, should be preventative, restorative, supportive, and palliative, starting at diagnosis and continuing through treatment, remission, recurrence, and end-of-life (Hunter, 1998).

2.2.3 Physical Needs-assessments and Breast Cancer Survivors

The process of understanding and responding to the physical effects after breast cancer treatment for survivors begins with an assessment of their physical needs. A physical needs-assessment allows for the identification of specific physical problems or issues of physical concern to the breast cancer survivor. In this context, a physical need can be defined as the requirement of some action or resource that is necessary, desirable, or useful to attain optimal physical well-being (Foot, 1996; Sanson-Fisher et al., 2000).

The advantage of a needs-assessment is that it enables the direct assessment of the survivors' self-reported perceived needs for help, indicates the rehabilitation service that is required and allows for earlier referral to these services (Bonevski et al., 2000). Breast cancer survivors may have easily managed or treated rehabilitation problems which unfortunately go unrecognized and then often worsen and cause a further deterioration in quality of life. This lack of recognition points to the need for routine identification of the physical rehabilitation needs, which would lead to earlier referral to rehabilitation services and provision of rehabilitation at the readily treatable stage of many physical problems.

In addition, the assessment of needs can enable cancer service providers to identify gaps in existing services, present information regarding the actual services required, lead to redesign of rehabilitation services and the improved allocation of valuable rehabilitation resources (Carr & Wolfe, 1976; Hodgkinson et al., 2007; Sanson-Fisher et al., 2000). If gaps in rehabilitation services are not identified, then the reasons for these gaps also cannot be recognized and, in turn, optimal rehabilitation interventions cannot be developed to meet the needs of breast cancer survivors. This further indicates the crucial role of the needs-assessment for breast cancer survivors (Lehmann et al., 1978).

In research and clinical practice, the assessment of quality of life and physical needs in cancer survivors has utilized numerous validated and reliable multidimensional self-report instruments. It is important that instruments with sound psychometric properties are used which can capture both the immediate post-treatment problems as well as the longer-term health outcomes (Pearce, Sanson-Fisher, & Campbell, 2008). In

addition, a general measure that includes all aspects of life affected by cancer and its treatment including physical, psychological, social and spiritual domains is useful to understand the survivor and their needs as a “whole” person.

Even though these quality of life or physical needs-assessment measures exist, many cancer care centres do not routinely or systematically assess the needs of breast cancer survivors. A strategy to enhance the role of cancer rehabilitation and the quality of life for breast cancer survivors is the implementation of a regular and methodical quality of life measure including a physical rehabilitation needs-assessment. A needs-assessment on its own does not automatically lead to improved patient outcomes. The information gathered from a needs-assessment must be used for appropriate rehabilitation goal setting and care planning (Richardson, Medina, Brown, & Sitzia, 2007). This on-going surveillance of the breast cancer survivors quality of life and physical needs should also include preventative measures, education in management strategies, proactive health promotion, and of course early interventions for identified needs. These needs-assessments should occur at the time of diagnosis, at the beginning and completion of all treatments - surgery, chemotherapy and radiation treatments, in the event of a recurrence, and in palliation. In other words, they should be ongoing at regular intervals through all time points of treatment and follow-up care (Richardson et al., 2007).

The current model of care for women with breast cancer focuses on the treatment of the cancer and then follow-up for detection of recurrence. There is little long-term surveillance for the survivor’s physical and functional well-being and their need for rehabilitation. A prospective surveillance model (PSM) for rehabilitation for women with breast cancer has been proposed (Stout et al., 2012). The goals of the PSM are to

promote surveillance, to provide education, to introduce rehabilitation and exercise interventions, and to promote and support improved lifestyle behaviours. This model also seeks to make certain that any impairment is managed proactively and surveillance is periodic and ongoing throughout treatment and recovery. This model proposes not only the use of self-report instruments, but also the use of tests and measures to identify physical impairments. While this prospective surveillance model is promising, the feasibility of the cost and other resources required to incorporate it into survivorship care is unknown (Cheville, Nyman, Pruthi, & Basford, 2012; Stout, Pfalzer et al., 2012).

The early and on-going identification of the physical needs of breast cancer survivors and the implementation of the appropriate intervention may prevent or lessen long-term morbidity and reduce continuing health-care costs. In addition to the improved quality of life, survivors with morbidities that are successfully managed may require fewer invasive tests, may have less hospital admissions, shorter length of stays, less disablement and dependence in activities and a reduced need for assistive devices (Cheville, Kornblith, & Basford, 2011).

In summary, the assessment of the physical needs and quality of life should be seen as an essential component of the continuing health of all breast cancer survivors. The goal of this surveillance is to acquire information about various health outcomes that are relevant to assisting in improved function and quality of life and the reduction of cancer-related morbidity. Needs-assessments should be integral and continuous in cancer care, which will facilitate the provision of rehabilitation interventions for optimal function and quality of life. The physical needs-assessment is a key element of

prevention, early detection, and effective management of the adverse effects of cancer treatment for breast cancer survivors.

2.2.4 Cancer Rehabilitation Services, Models and Delivery

Survivors of cancer are considered to be living with a chronic disease that requires ongoing support for prevention, surveillance, interventions and coordination of care (L. H. Gerber, 2001; Phillips & Currow, 2010). This view of cancer as a chronic disease along with the many cancer survivors living with significant disability and lasting effects of cancer treatment indicates the need for comprehensive cancer rehabilitation services. Cancer rehabilitation should be viewed as an essential service for cancer survivors just as cardiac rehabilitation is an essential component of treatment after a myocardial infarction.

Models of comprehensive cancer rehabilitation centres have identified these key objectives of rehabilitation services: 1) to meet the physiological and functional needs of cancer patients; 2) to address the psychological, social, emotional and spiritual needs of cancer patients; 3) to provide ongoing education to reduce cancer risks and increase early detection; and, 4) to provide administrative support to plan, coordinate, and oversee rehabilitative activities for cancer patients (J. Clark, Ford, & Hegedus, 2004). Key elements should be considered when planning a comprehensive cancer rehabilitation centre: 1) the program is located in the proximity of other cancer treatment services, 2) the creation of a dedicated space for all rehabilitation components, 3) the presence of a coordinated multidisciplinary team approach, and 4) the provision of convenient and accessible services in a healing environment. In addition, models for cancer rehabilitation

services include a physician referral, with provision of all medical information; effective baseline assessments with relevant, measurable parameters; determination of the rehabilitation goals, recommendations, and precautions; development of an individualized exercise and rehabilitation program; and, reassessments and evaluation of the effectiveness of the rehabilitation program (Schneider, Dennehy, Roozeboom, & Carter, 2002). The multidisciplinary team involved in cancer rehabilitation programs should ideally include physiatrists, physiotherapists, certified lymphedema therapists, occupational therapists, social workers, rehabilitation oncology nurses, dietitians, art/music therapists, speech-language pathologists, certified fitness instructors, psychologists, vocational counselors, and chaplains.

Some cancer care institutions may not have the resources or space for comprehensive rehabilitation services and offer community-based cancer rehabilitation group interventions. Group interventions help to maximize personal resources while still providing expert guidelines for cancer survivors. These programs are multifaceted, vary in their objectives and most usually include an education and psychosocial component, tailored strengthening and aerobic exercises, peer-support, and a wellness focus (Gaskin, LoBuglio, Kelly, Doss, & Pizitz, 1989; Gordon, Battistutta, Scuffham, Tweeddale, & Newman, 2005; Johnson & Kelly, 1990). The recognition of the value of health promotion behaviours and life-style changes in the rehabilitation of breast cancer survivors is reflected in these comprehensive programs.

While no national cancer rehabilitation program exists in Canada, some cancer rehabilitation programs have emerged (Chasen & Dippenaar, 2008; Segal et al., 1999; Ward, Doll, Ristovski-Slijepcevic, Kazanjian, & Golant, 2010). These, and similar cancer

rehabilitation programs conducted in the United States, have reported significant improvements in functional capacity, range of motion, and health-related quality of life, and a reduction in fatigue and depression among cancer survivors (Schneider et al., 2002; Segal et al., 1999).

Breast cancer survivors and cancer care centres face a multitude of barriers when it comes to accessing and providing comprehensive cancer rehabilitation services. These barriers may include the following: 1) a lack of knowledge amongst oncologists and cancer survivors regarding available rehabilitation services and benefits; 2) a lack of established relationships between oncologists and rehabilitation specialists leading to poor coordination amongst cancer care professionals; 3) a lack of appropriate and routine screening of physical rehabilitation needs and referral to rehabilitation; 4) the fact that the services which have been deemed beneficial are not widely available or easily accessible; 5) few professionals with expertise in cancer rehabilitation; 6) a lack of exercise and rehabilitation facilities; and, 7) a lack of fiscal support for cancer rehabilitation services (Cheville & Tchou, 2007; J. K. Silver & Gilchrist, 2011). In addition, there may be many personal obstacles for the breast cancer survivor which can act as a barrier to the actual performance in rehabilitation programs. These barriers mostly relate to the physical effects of cancer treatment, such as fatigue, deconditioning, loss of range of movement, compromised immunity and comorbidities (Blaney et al., 2010). Barriers related to the side effects of cancer treatment suggest that survivors would benefit from rehabilitation and exercise programs that are provided by trained health care professionals who are knowledgeable regarding cancer treatment and its effects who can then tailor the

programs to the individual according to abilities, age, and cancer-related medical variables.

To summarize, cancer rehabilitation interventions, both therapeutic and healthy lifestyle promotion carry the potential to manage or ameliorate most of the physical effects of cancer treatment. These rehabilitation services, models, and delivery should be developed based on the successful evidence-based outcomes of established programs. The development of cancer rehabilitation services should consider the screening for need, coordination and referral of services, cost and accessibility of services, availability of trained professionals, and the establishment of rehabilitation and exercise facilities. Cancer rehabilitation services should be available to all breast cancer survivors throughout their cancer treatment and beyond to help them in the management of this chronic disease.

2.3 Limitations in the Literature

Cancer rehabilitation has been receiving more attention in the recent few years, both in the research arena and in clinical practice. The entire issue of the April 15, 2012 supplement of the journal *Cancer* featured numerous articles on breast cancer rehabilitation, survivorship, and a prospective surveillance model for breast cancer survivors (Schmitz, Stout, Andrews, Binkley, & Smith, 2012). The articles in the supplement were commissioned based on presentations and deliberations at a *Roundtable Meeting on a Prospective Model of Care for Breast Cancer Rehabilitation* held in February, 2011 in Georgia, USA. The objective of this supplement was to stimulate discussion regarding the importance of rehabilitation interventions and to promote the

inclusion of prospective surveillance and cancer rehabilitation services into survivorship care.

Despite the growing interest in and value of cancer rehabilitation, there is a scarcity of research in Manitoba in the area of cancer rehabilitation, and in addition, no comprehensive cancer rehabilitation program exists. Two multi-centre studies have included Manitoba and have examined the status of arm morbidity and disability in breast cancer survivors (R. L. Thomas-Maclean et al., 2008; R. L. Thomas-Maclean et al., 2010), and a third study examined recreational and leisure activities post-surgery (Miedema et al., 2008). There is a gap that remains in the literature regarding the awareness, accessibility, and availability of cancer rehabilitation services for breast cancer survivors in Manitoba. The need and desire for cancer rehabilitation amongst breast cancer survivors, the value of rehabilitation services in meeting these needs and the success of existing cancer rehabilitation models have been revealed in this literature review. The determination of the physical rehabilitation needs after cancer treatment and the insight into the lived experience of breast cancer survivors in Manitoba will help facilitate the development of much needed comprehensive cancer rehabilitation services in Manitoba.

2.4 Purpose of the Study

The purpose of this study is to explore the physical rehabilitation needs of breast cancer survivors, to gain new insights into their understanding and awareness of the role of cancer rehabilitation, and to determine the availability and accessibility of cancer rehabilitation services for breast cancer survivors.

2.5 Research Questions

The central questions for this study are as follows:

1. What are the physical rehabilitation problems and needs of breast cancer survivors in Manitoba?
2. What are breast cancer survivors' understandings of the role of cancer rehabilitation?
3. What is the current availability of physical rehabilitation services for breast cancer survivors in Manitoba and what has been the experience in accessing these services?
4. What are the recommendations and strategies for improved future provision of physical rehabilitation services for breast cancer survivors in Manitoba?

2.6 Assumptions Underlying the Study

The study is founded on the following assumptions:

1. The physical rehabilitation needs are not routinely identified for breast cancer survivors.
2. The physical effects of cancer treatment can be successfully managed by physical rehabilitation therapies.
3. Despite the provision of psychosocial rehabilitation services in Manitoba, there is a lack of physical rehabilitation services for breast cancer survivors.
4. Many women with breast cancer desire and need cancer rehabilitation services.

2.7 Significance of the Study

This research project provides vital information to further enhance the understanding of the physical effects of cancer treatment and the rehabilitation needs of breast cancer survivors. This study identifies the gaps that exist in the identification of

the physical rehabilitation needs and the adequate provision of cancer rehabilitation.

Further, recommendations are provided for improved cancer rehabilitation services in the Province of Manitoba. The findings of this study will be disseminated in an endeavour to open the dialogue with all stake-holders to advance the role and delivery of cancer rehabilitation in Manitoba and ultimately improve the lives of cancer survivors.

3.0 METHODOLOGY AND PROCEDURES

3.1 Introduction

The methodology and procedures are presented in this chapter. The rationale for a mixed method approach is explained. The outcome measures, inclusion criteria, procedure for data collection and the recruitment results are described, followed by details of the data analysis, the ethical considerations, and finally the setting and context of breast cancer care and services in Manitoba.

3.2 Methodology

This study used a mixed methods approach of collecting and analyzing a combination of both quantitative and qualitative data. The rationale of using a mixed methods research design is that this combined methodology can provide broader and deeper insights into understanding the complexities of the physical effects of cancer treatment, the availability and accessibility of cancer rehabilitation, and the experiences of breast cancer survivors. In addition, these methods complement each other and provide a wider focus than a single method for a more complete analysis of the data (Sale, Lohfeld, & Brazil, 2002). Quantitative survey data was collected utilizing validated surveys for measuring quality of life and physical morbidities related to cancer treatment. The qualitative component is based on the interpretive description methodology (S. E. Thorne, 2008; S. Thorne, Kirkham, & MacDonald-Emes, 1997). The aim of interpretive description is to provide a comprehensive summary of the phenomena in everyday terminology (Sandelowski, 2000). In this study, a focus group and targeted questions were used to obtain interview data regarding breast cancer survivors' awareness and

understanding of the role of cancer rehabilitation and their experiences with accessing the available rehabilitation services in Manitoba.

3.3 Outcome Measures

A participant information form was designed specifically for this study, and included demographic and clinical information such as: age, date of cancer diagnosis, cancer stage, cancer treatment received or currently receiving, number of lymph nodes removed, subscription to private health insurance, education level, occupational status, physical problem checklist, and rehabilitation services received (Appendix A).

Health-related quality of life (HRQL) and the impact of arm morbidity on breast cancer survivors were measured utilizing the Functional Assessment of Cancer Therapy-Breast version 4 (FACT-B+4) (Appendix B). The FACT-B+4 is a 44-item self-report instrument designed to measure multidimensional quality of life in breast cancer survivors. The FACT-B+4 is comprised of the FACT-General plus the Breast Cancer Subscale (BCS), which complements the general scale with items specific to HRQL for breast cancer survivors. There are six subscales: Physical Well-Being (PWB) (score range 0-28), Social Well-Being (SWB) (score range 0-28), Emotional Well-Being (EWB) (score range 0-24), Functional Well-Being (FWB) (score range 0-28), Breast Cancer Subscale (BCS) (score range 0-36) and the Arm Subscale (score range 0-20) which includes additional items related to arm morbidity such as swelling, painful arm movement, arm range of motion and stiffness, and arm numbness. A five-point scale is used to indicate the degree to which each statement has applied over the past seven days, with 0 being not at all, and 4 being very much. The total FACT-B score ranges from 0 to 144, with higher scores reflective of a greater quality of life. The α coefficient (internal

consistency) for the FACT-B+4 total score ranged from 0.62 to 0.90, with a subscale α coefficient ranging from 0.63-0.86. The test-retest reliability for the BCS is from 0.88 to 0.97. The FACT-B+4 demonstrates ease of administration, brevity, reliability, validity and sensitivity to change and is appropriate for use in oncology clinical trials as well as in clinical practice (Brady et al., 1997; Coster, Poole, & Fallowfield, 2001).

Upper-limb symptoms and functional status was measured using the Disabilities of Arm, Shoulder, and Hand Questionnaire (DASH) (Appendix C). The DASH outcome measure is a 30-item self-report questionnaire that duplicates the FACT-B+4 questions related to pain, weakness, stiffness, and sensory changes, and has the added self-report of physical functioning of the upper-limb. Participants score the DASH items on a scale from 1 to 5, where a score of 1 indicates no limitation and 5 indicates significant to extreme limitation. Scores are calculated and range from 0 (no disability) to 100 (extreme disability). Total DASH scores between the 25 and 75 quartiles are considered to indicate some degree of disability; scores below the 25th quartile indicate minimal or no disability; and scores over the 75th quartile are considered high disability (R. L. Thomas-Maclean et al., 2008). The individual DASH items 1 to 23 are related to activity limitations and participation restrictions, and items 24 to 29 are related to symptoms and impairments. The validity, test-retest reliability (ICC=0.96), and responsiveness of DASH has been demonstrated (Beaton et al., 2001; Roy, MacDermid, & Woodhouse, 2009). Numerous authors have utilized the DASH in breast cancer research to measure upper-limb dysfunction deeming it to be an appropriate tool for this population (Jeong et al., 2011; Swisher, Davison, Aranda, Eye, & Erickson, 2010; R. L. Thomas-Maclean et al., 2008; Velloso, Barra, & Dias, 2011). Additionally, the DASH scale has been used in

conjunction with the FACT-B+4 in breast cancer survivors in a longitudinal study exploring upper-body function, symptoms and fatigue (Schmitz et al., 2012), objective and subjective upper body function (S. Hayes, Battistutta, & Newman, 2005), and in examining the change in quality of life measures and upper-body disability over time (Gordon et al., 2005).

The qualitative aspect of this study utilized interpretive description methodology to gather the lived experiences of breast cancer survivors through a focus group. Focus groups have demonstrated clear usefulness and practicality in the collection of qualitative data (D. Morgan, 1996) and have been utilized as a rich source of information allowing breast cancer survivors to share their experiences, perceptions and opinions (Bruner & Boyd, 1999; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Korstjens, Mesters, Gijzen, & van den Borne, 2008; Wyatt, Kurtz, & Liken, 1993). Focus groups “aim to promote self-disclosure among participants by explicitly capitalizing on group dynamics in discussion” (Freeman, 2006). Basche (1987) further describes the focus group as a “qualitative research technique used to obtain data about feelings and opinions of small groups of participants about a given problem, experience, service or other phenomenon” (Basch, 1987). Focus groups can effectively foster group interaction and provide a wealth of descriptive information to explore the complexities of attitudes, priorities, language, framework and experiences (Kitzinger, 1994). By employing interpretive description, this study was able to ascertain the breast cancer survivor’s awareness of cancer rehabilitation and its availability and accessibility in Manitoba, explore the breast cancer survivor’s perceived physical needs and experience with cancer rehabilitation, and to gather the breast cancer survivor’s overall opinions, beliefs, and attitudes about cancer

rehabilitation. The open-ended focus groups questions and a detailed focus group script were generated for this purpose (Appendix D). It was proposed that two focus groups of 6 to 8 breast cancer survivors who fell within the inclusion criteria be conducted; however, the recruitment numbers for the focus group was seven women. Therefore, only one focus group was conducted.

3.4 Participants and Data Collection

Inclusion criteria for the participants for this study were as follows:

- 1) Women age 18 and older with a diagnosis of first primary invasive breast cancer during or after completion of surgery, chemotherapy and/or radiation treatments.
- 2) Participants diagnosed or treated for breast cancer within the last three years.
- 3) Participants who reside in the Province of Manitoba.
- 4) Participants that are able to understand, read, and communicate in English, and are competent to provide informed consent.

This excludes women diagnosed with ductal carcinoma in situ (DCIS) as this does not usually require chemotherapy or radiation treatment, thus resulting in a less complex treatment course. Women with metastatic breast cancer have also been excluded from the study as metastatic disease can result in multifarious physical effects outside of the scope of this study.

In Manitoba, it is estimated that there are 800 new diagnoses of breast cancer each year and 210 deaths from breast cancer per year (Canadian Cancer Society, 2012b), giving a potential population size of 1,770 breast cancer survivors over the past 3 years.

A target sample size for a survey depends on the resources available, the aim of the study, and the statistical quality needed for the survey (Kelley, Clark, Brown, & Sitzia, 2003). With this in mind, the minimum sample size of this population of breast cancer survivors is 115. This sample size for collection of the data considers a response rate of mailed surveys of <20%, a margin of error of 3% and a population size of 1,770 (Bartlett, Kotrlik, & Higgins, 2001).

Recruitment and data collection was performed by the researcher and commenced after approval from the Research Resource Ethics Committee (RRIC) of CancerCare Manitoba (Appendix E) and the Health Research Ethics Board (HREB) of the University of Manitoba (Appendix F).

Recruitment for the survey participants was done by the mailing of letters of invitation and survey packages from the Manitoba Cancer Registry. Based on the inclusion criteria, 1,130 recruitment letters were mailed. These packages included a recruitment cover letter from the Manitoba Cancer Registry, a letter of invitation to participate, the participant information form, Functional Assessment of Cancer Therapy-Breast version 4 (FACT-B+4), and the Disabilities of Arm, Shoulder, and Hand Questionnaire (DASH) questionnaires (Appendices A, B, C, G, and H), and a postage-paid return envelope. The completion of the surveys and the return of them to the researcher indicated implied consent to participate allowing their responses to the surveys to be included in this study. There were 1,130 recruitment packages mailed, with seven returned due to the potential participants moving or having died. There were 474 survey respondents, which was a response rate of 42%.

Purposive sampling was implemented according to the inclusion criteria for the recruitment of the focus group participants. Posters advertising the proposed study were placed in various departments within CancerCare Manitoba, including chemotherapy and radiation treatment areas, the Breast Cancer Centre of Hope, and psychosocial oncology departments (Appendix I). Focus group recruitment was also done through distribution of letters of invitation in the breast cancer clinics and by the psychosocial professionals at CancerCare (Appendix J). Additionally, any participants that provided their email in response to the survey letter, or potential participants known to the researcher through previous contact, received an email invitation to participate in the focus group. On the posters and in the letter of invitation, potential participants were asked to contact the researcher either via telephone or e-mail to indicate their interest to participate in the study. The potential participants that contacted the researcher were qualified for the study. All women recruited for the focus groups were contacted and a date, time and location for the focus group session were arranged. Ten women responded to the invitation and seven women were qualified and available to participate in the focus group. Two of these women were previously known to the researcher.

Each focus group participant signed an informed consent document (Appendix K), which was obtained by the researcher in person prior to the focus group. The data was collected via the participant information form (demographic questionnaire) and a focus group interview with targeted questions. The participant information form (Appendix A) was designed specifically to capture demographic and medical characteristics about the participant, their reported physical problems after cancer diagnosis and their receipt of any cancer rehabilitation services. The semi-structured interview guide (Appendix D)

was drafted to ask targeted questions in an effort to explore the breast cancer survivors experience with cancer rehabilitation and the gaps and barriers they experienced in accessing these services, as well as their recommendations for improved future provision of cancer rehabilitation. The focus group was conducted by an experienced and independent facilitator, and was attended by the research advisor and the researcher who took field notes. The focus group was audio recorded, and was 110 minutes in length.

3.5 Data Analysis

The aim of the study was to gain an understanding of the physical effects of cancer treatment and the rehabilitation needs of breast cancer survivors in Manitoba, to explore their perspectives on the role of cancer rehabilitation, and to determine the current availability and access of physical rehabilitation services for breast cancer survivors in Manitoba.

There were 474 survey respondents. All the data was included in the analysis; however, there were 32 incomplete surveys which had an incomplete demographic (n=4), FACT-B (n=15), and DASH (n=13) forms. Descriptive statistics were used to characterize the participants and the distribution of variables. Mean values and standard deviations and frequencies and percentages summarized the continuous and categorical variables for the socio-demographic and medical characteristics, physical problems after cancer diagnosis and the receipt of any cancer rehabilitation services. Statistical analysis was carried out to examine the distribution of scores, mean and standard deviation on the 6 subscales and the total score of the FACT-B+4. Even those with insufficient data for a total FACT-B analysis some subscales were complete and therefore have been included in the analysis. For easier comparison and to present the subscales using the same metric,

the FACT-B subscales were also rescaled using a simple linear transformation to have a possible range of 0-100. The PWB, SWB and FWB subscales were multiplied by 100/28, the EWB was multiplied by 100/24, the BCS was multiplied by 100/36, the Arm Subscale was multiplied by 100/20 and the total FACT-B was multiplied by 100/144 (the Arm Subscale is not included in the calculation of the total FACT-B score). To convert back to the raw scores, a simple reversal of the linear transformation can be applied. Further analysis took place to determine the mean and range of the total DASH score, and the frequency and severity of activity limitations and participation restrictions (items 1 to 23) and symptoms and impairments (items 24 to 29) from the scores on the DASH questionnaire.

An inductive content analysis was undertaken for the focus group data. Content analysis is a systematic and objective means of describing and understanding the data (Elo & Kyngas, 2008). Its purpose is to provide knowledge, new insights, a representation of the facts and a practical guide to action (Krippendorff, 1980). This inductive analysis was deemed to be the best method of analysis and was chosen based on the purpose of the study. The process of the analysis included a detailed and systematic coding of the data, identification of categories and themes and a linking of the issues addressed in the focus group. The audio recording of the focus group interview was transcribed verbatim. The transcript was read thoroughly and repeatedly, and open coding was done to organize the data. Open coding refers to a line by line review of the transcript with the identification of concepts (short phrases or sentences) that describe all the aspects of the content. Notes and headings are then marked in the margin of the text. The transcript was thoroughly re-read and the concepts were reviewed to compile the

concepts into categories. The categories were reviewed thoroughly and three themes were identified. The categories and themes were also reviewed by the focus group facilitator and the research advisor to collaborate the findings. A descriptive summary of the qualitative data was written identifying the themes. This summary was e-mailed to each focus group participant as a method of member checking (Appendix L) to validate the accuracy of the data analysis. No participants identified any disagreement or concern with the findings presented in this summary.

3.6 Ethical Considerations

This study was approved by the Health Research Ethics Board (HREB) of the University of Manitoba, and the Research Resource Ethics Committee (RRIC) of CancerCare Manitoba.

The decision to participate in this study was based on an understanding of the purpose of the research and the potential risks and benefits. Each participant was given the opportunity to ask questions or seek clarification about the study prior to their participation in the study. The informed consent document outlined the purpose of the study, research procedures, and participant expectations and indicated their right to participate or withdraw from the study. Potential participants that were not interested in participating in the study were not further pursued. The participants were given the opportunity to receive a written summary of the study findings upon completion of the research.

Participant confidentiality and anonymity was safeguarded. No identifying information appeared on any collected data for this study. Questionnaires, transcripts

from the focus groups and all other research data was kept in a locked cabinet and/or secured in an encrypted computer file to which only the researcher has access. The focus group participants were instructed to keep all comments within the group confidential.

Possible psychological distress related to the identification of physical problems after cancer treatment for these survivors has been recognized as a potential harmful effect of this study. The identification of physical problems related to cancer treatment may have been new and distressing information for the breast cancer survivor. They may not have realized that their physical limitations, their pain, or other symptoms possibly occurred as a result of cancer treatment and that these problems could have been successfully treated or managed by rehabilitation services. In an effort to minimize or manage this distress, any participant that expressed any distress was asked to contact Patient and Family Support Services at CancerCare Manitoba for referral for psychosocial support. Those that expressed a need for treatment for a physical problem amenable to rehabilitation were asked to contact their primary physician or oncologist for a referral to the appropriate rehabilitation service.

An additional possible risk in this study was the perceived invasion of privacy in the recruitment of participants through a third party – the mailings from the Manitoba Cancer Registry. Potential participants may have perceived that their privacy had been invaded when a researcher has gained access to private information without their consent. To minimize this risk of invasion of privacy, the researchers did not know who was invited to participate in the study, nor did the Manitoba Cancer Registry know who agreed or did not agree to participate in the study. The participants were informed of this

in the recruitment cover letter. The potential participant was allowed to make a free and autonomous choice about their participation in the study.

There were no obvious intrinsic benefits for participants other than their role in the expansion of the existing body of knowledge concerning cancer rehabilitation and the detailed understanding of cancer rehabilitation needs and services in Manitoba. The benefit of this study to participants was their valuable contribution to the advancement of cancer rehabilitation knowledge and services for future breast cancer survivors.

3.7 Setting and Context of Breast Cancer Care and Services in Manitoba

It is important for the reader to understand the context of breast cancer care in Manitoba in which this inquiry took place. CancerCare Manitoba (CCMB) is the provincial cancer agency in Manitoba that is

charged by an act of the legislature of Manitoba with responsibility for cancer prevention, detection, care, research and education for the people of Manitoba.

CancerCare Manitoba is dedicated to enhancing the quality of life for those living with cancer and blood disorders, and improving control of cancer for all Manitobans. (CancerCare Manitoba, 2013)

CCMB is located in three sites in Winnipeg, and has a shared model of cancer care in 17 communities in rural Manitoba (CCMB Community Cancer Program Network), including Cancer Hubs that are currently under development. Multidisciplinary coordinated breast cancer care is provided by oncology surgeons, plastic surgeons, medical oncologists and radiation oncologists who specialize in breast cancer.

CancerCare Manitoba's Patient and Family Support Services provides breast cancer specific support groups, information sessions, individual and family counseling, peer

support, and the Breast Cancer Centre of Hope which provides information and support specific to breast cancer including a Breast Cancer Patient Navigator.²

The Winnipeg Regional Health Authority Breast Health Centre

has a multi-disciplinary team of experts who specialize in breast health. The Centre's focus is serving women and men of all ages who have breast problems or signs and symptoms of breast cancer. The Breast Health Centre coordinates clinical assessment, diagnostic tests, treatment, education and support through a variety of specialized programs. (Winnipeg Regional Health Authority, 2013)

Pre-and-post operative group instruction is offered to all undergoing surgery in collaboration with the Breast Health Centre and the Breast Cancer Centre of Hope. Throughout primary cancer treatments and afterwards, those diagnosed with breast cancer and their families have access to and may self-refer for support programs and services through CCMB's Patient and Family Support Services and/or the Breast Health Centre and/or oncology programs in Winnipeg Community hospitals or through the rural Cancer Hubs, and/or the Community Cancer Programs. Lymphedema management is available through the Breast Health Centre and, currently, the wait time for accessing lymphedema services is generally one week with a physician referral. Those receiving

² A Breast Cancer Patient Navigator refers to a "trained individual who facilitates timely access to appropriate health care and resources for patients and their families, a skilled communicator who provides holistic care, empowering patients with education and knowledge about their illness, and an individual who is knowledgeable of the cancer system". (Pedersen & Hack, 2010)

treatment for lymphedema at the Breast Health Centre are provided bandaging supplies. Compression garments are not covered by Manitoba Health and are the responsibility of the individual; however, some funding may be available through “Helping Hands”, a non-profit organization who provide financial support to breast cancer patients in need.

There are some specific post-treatment rehabilitation programs offered in Winnipeg. An 8-week physical activity, psychosocial and nutritional program - Eat Well, Get Fit - is available for breast cancer survivors through the Breast Health Centre. CCMB offers: “Moving Forward After Breast Cancer”, Art Therapy, Yoga, Pilates, Cancer Transitions, bone health/osteoporosis education session, cognitive enhancement (Brain Fog) sessions, and Mindfulness based sessions, among others. Information about these programs can be found in CancerCare Manitoba’s *The Navigator* and *Our Voice* newsletters and on notices posted in treatment centres throughout Manitoba. Those diagnosed with breast cancer that require physiotherapy and/or occupational therapy could receive these services through the Regional Health Authorities at publicly funded Manitoba hospitals. Privately funded services such as physiotherapy, occupational therapy, lymphedema treatment, and massage therapy are available through private health insurance. Many community-based physical activity programs are available throughout the Province and are the responsibility of the individual.

4.0 RESULTS

4.1 Quantitative Data

4.1.1 Description of Participants

Survey and demographic data was collected from 474 participants (representing a response rate of 42.2%). The mean age of the participants was 60.8 years, with a range of 27 to 83 years (SD = 11.1). The mean time since diagnosis was 21.3 months with a range of 4 to 45 months (SD=7.6). The majority reported stage 1 or 2 breast cancer (62.8%), and the most common surgery was a lumpectomy (59.9%). Radiation therapy was received by 81.2% and 55.5% had undergone chemotherapy. The mean number of lymph nodes removed was 6.9 with a range of 0 to 38 (SD=8.1). The majority had private health insurance (67.7%) and lived in the urban area (63.3%). A sizeable number had completed college or university (49.0%). The demographic and medical characteristics are reported in Table 2.

4.1.2 Quantitative Results

At least one physical problem after breast cancer diagnosis was self-reported on the participant information form by 87.9% of the participants; 73.8% reported having more than one physical problem. The most commonly reported problem was fatigue (62.0%), followed by scar tightness (47.5%), pain (46.0%), numbness and tingling (45.4%), being out of shape (41.6%), shoulder stiffness and general weakness (both 33.2%), shoulder weakness (30.8%) and lymphedema (20.5%) (Figure 1). A rehabilitation service, such as physiotherapy, occupational therapy, massage therapy, lymphedema treatment, or a physical activity program was received by 42.6% of the participants. For those that reported one or more physical problem, 47.2% reported

receiving a rehabilitation service. Figure 2 illustrates the percentage of participants who received a specific rehabilitation service. Massage therapy (17.7%) and physiotherapy (17.3%) were the most commonly reported rehabilitation service, followed by a physical activity program in the community (16.5%), and lymphedema treatment (12.9%).

The FACT-B survey was returned by 474 participants and the total FACT-B score was calculated on 459 surveys that had complete data. Even those with insufficient data for a total FACT-B analysis some subscales were complete and therefore have been included in the analysis. The mean total FACT-B+4 score was 110.3 with a range of 38 to 143 (SD=20.5). A higher quality of life is indicated as the score moves toward the maximum score of 144. The mean scores for each subscale have been converted to percentages for ease of comparison. The lowest mean quality of life score was for the breast cancer subscale (68.9%) and the highest was for the physical well-being (81.8%). The mean quality of life scores on the subscales of physical well-being, social well-being, emotional well-being, functional well-being, breast cancer concerns, the arm subscale, and the total FACT-B are shown in Table 3.

There were 461 DASH surveys completed and scored. The mean overall DASH score was 17.1, with a range of 0 to 77.6 (SD=16.4), indicating a 17% overall disability of the arm, shoulder and hand. The individual DASH items 1 to 23 are related to activity limitations and participation restrictions and 38.7% of participants reported some limitation with their arm, shoulder or hand. The severity of those indicating activity limitations and participation restrictions are presented in Figure 3.

Fifty-one percent of the participants reported at least a mild severity on the DASH items that relate to symptoms and impairments (items 24 to 29), indicating a majority had at least one perceived symptom or impairment of the arm, shoulder or hand. The most commonly reported symptom or impairment was pain in the upper limb with activity (58.5%), and weakness of the upper limb (58.3%), followed by stiffness (54.1%) and pain (53.4%) of the upper limb. The severity of those indicating mild to extreme symptoms and impairments, such as pain, pins and needles, weakness, stiffness and sleep disturbance are presented in Figure 4.

4.2 Qualitative Data

4.2.1 Description of Participants

A purposive sample of women was recruited from various CancerCare Manitoba sites including the Breast Cancer Centre of Hope, MacCharles CancerCare site and St. Boniface CancerCare site with the use of posters and letters of invitation, and via email letters of invitation to other contacts as previously described. One focus group consisting of seven women with an average age of 52 years (range 41 – 60 years) was conducted. All participants were ambulatory and communicated in English. All but one was diagnosed with stage 2 breast cancer and they were an average of 27 months since diagnosis. Six of the seven women reported at least one physical problem after their breast cancer diagnosis, with lymphedema, fatigue, pain and being out of shape the most commonly reported (71.0%). Only one woman reported not receiving any kind of rehabilitation service; all those that reported lymphedema received lymphedema treatment; three reported receiving physiotherapy. Four women had attended a physical

activity program either within CancerCare, or the community or both. Demographics of the focus group participants are listed in Table 4.

4.2.2 Qualitative Results

During the focus group session discussion took place around cancer rehabilitation for the physical effects of cancer treatment. It was observed that the women had a difficult time separating the physical aspect of their cancer recovery from the emotional and mental components. The discussion had to be repeatedly brought back to the physical effects of cancer treatment. They shared that a cancer diagnosis affected all aspects of their lives and it was difficult for the participants to separate just the physical side. They referred to a cancer diagnosis being “life-changing” with an impact to all spheres of their lives and that these areas were all interconnected. When discussing the meaning of cancer rehabilitation, it was also shared that this was “rehabilitation” for every life domain. One woman referred to cancer rehabilitation as something that could help her move forward in life:

I guess trying to find a way to get to a place where you can really move forward and kind of leave some of this stuff behind, and it's never going to be gone forever, but to get to a place moving forward where you can have fun again and laugh again...reclaim a little bit of life, you know. That's what it is for me.

With this encompassing holistic point of view of cancer rehabilitation, the participants were asked to list all the cancer rehabilitation services that they were aware of or that they utilized after their breast cancer diagnosis. Multiple physical activity programs (Healthy Eating Active Living, Eat Well Get Fit Program, restorative yoga,

swimming, Pilates, Running Room, Dragon boat team), psychosocial programs and supports (psychosocial counseling, brain fog sessions, mindfulness sessions, Moving Forward, Look Good Feel Better, art therapy), and information support and resources (lending library, Breast Centre of Hope, booklets/information sheets, workshops, support groups, Guardian Angel Caring Room, The Navigator newsletter, dietary support, peer support program) were shared. The only two treatment services that were revealed were lymphedema treatment and physiotherapy.

After reviewing all these services, the participants felt that there were many rehabilitation services and resources available to breast cancer survivors compared to other types of cancer. “I think that with breast cancer there are so many more resources than with other cancers...there are so many positive things and it’s just amazing.”

Additionally, they expressed that, overall, CancerCare was presenting a unified message when supporting those diagnosed with breast cancer. They felt that the message they received during and after cancer treatment was one that instilled confidence in their care team. One woman stated:

I would have to say that I think collectively CancerCare does a really good job of pulling together...And I did know that numerous times, I heard it here, and heard it here, and it all supported the same philosophy and I think that’s really important when it comes to being confident in your treatment, and then moving forward.

Women had a lot of praise for the breast cancer resource centre, both for the professional staff and the printed resources. They conveyed they found the centre “very helpful during the different pivotal points and changes in therapies.” The professional

staff was readily available to share and discuss some of the support programs: “She’d say here are the programs, and just keep yourself busy with that if you want. It’s true she (the nurse) was very good that way.” Another woman appreciated the time that was taken to review some of the programs: “The nurse took the time and said you know and here’s this (information booklet) and she showed me a few things.”

Despite the identification of the available services and support and some of the positive experiences, three themes emerged from the data relating to the challenges faced regarding cancer rehabilitation. While the women felt that they did receive information, support, and some rehabilitation services, they also felt that there were many gaps and challenges within the system that posed as barriers to them receiving adequate or timely cancer rehabilitation. The three themes were: 1) Difficulty in finding clear and consistent information; 2) The need for integration of cancer rehabilitation services; and, 3) Financial challenges related to cancer rehabilitation services.

4.2.2.1 THEME: Difficulty in Finding Clear and Consistent Information.

A majority of the women interviewed in the focus group reported at least one physical concern after breast cancer treatment. Lymphedema, fatigue, pain in the area of surgery and being out of shape was reported by 5 of the participants, and 4 reported shoulder weakness or stiffness, scar tightness, numbness and tingling, and general muscle weakness. These physical issues raise significant concerns and can create new or on-going questions about managing these problems, not only during primary treatment, but also for several years after completion of treatment. Many women were not sure where to go when they had questions and expressed frustration and even confusion: “I don’t know who to go to. Oh, my doctor, oh I’ve never seen that before. My oncologist, oh, that’s

kind of funny... But where do you go to ask those questions?" Several women had difficulty finding answers regarding lymphedema: "...like the question is where to go when you have these issues (with lymphedema)? So, where do you go to just confirm your new normal, because you're still not familiar with it."

Women also reported receiving conflicting information about how to deal with some of these issues such as exercising post-operatively, or how to care for their shoulder or arm. Some women were told one thing by their surgeon and later received different advice from the nurse. They expressed that this conflicting information was not helpful in their recovery. One participant recalled her frustration in receiving inconsistent information about the post-operative care of her arm:

And sometimes the information is conflicting. I remember someone saying 'don't ever, ever, ever, sleep on the side that you've had surgery'. Oh, then what am I going to do now...and then later I found out that no, once your healed, don't spend the whole night there, but I think it's okay, just be careful and support yourself. So, yeah, you get conflicting messages too.

Additionally, the women conveyed that they had the need for clear and consistent information from knowledgeable sources. They felt that there should be an experienced and trained person they could go to with questions that could give them reassurance and guidance regarding their physical concerns. One woman explained that "having someone that is knowledgeable about breast cancer survivors and to give people reassurance... having someone that is really aware, somebody who understands, somebody who has the knowledge would be a big help physically and mentally."

Although they didn't use the exact word 'navigator', some women referred to a mentor, or guide to help them through the cancer care system. One woman referred to a "lifeline to tie into". They felt that this would certainly be a big help to them when they had questions about treatment, side-effects of treatment, and any on-going concerns. Another woman referred to an umbrella mentor: "Like being assigned to a mentor, right, sort of to overlook and say this is the package that encapsulates breast cancer and these are all the things that plug into it and I'm your umbrella."

4.2.2.2 THEME: The Need for Integration of Cancer Rehabilitation Services.

The frustration and confusion in trying to find clear and consistent answers to questions about the physical effects they were experiencing led most women to conclude that there was a gap in the cancer care system concerning the integration and coordination of cancer rehabilitation after a breast cancer diagnosis. Most women expressed that their surgeons, medical oncologists, and radiation oncologists were excellent during their treatment phase. However, even during their treatments and certainly after their treatments, they felt that there was no-one in charge of directing their rehabilitation, whether it was for lymphedema care, physiotherapy or physical activity programs. They expressed that there should be knowledgeable professionals within the cancer care system that are responsible for overseeing rehabilitation care, and that some system should be in place to coordinate rehabilitation services. One woman expressed this gap in the coordination of rehabilitation services:

Whose responsibility is it to continue to care for you post treatment and I don't know that I got a really good clear picture of that, so whose role is it to be

vigilant? Where's the follow through for that and how do you pull that through? I think there's a real gap in being able to pull those things together.

Another woman reported a similar sentiment and felt that she needed "(somebody that) can help me through that, that I can see on a regular basis and have that ongoing support in that fashion, someone who understands, somebody who has the knowledge..."

Despite the prevalence of some of the physical effects the participants experienced after cancer treatment, some did not receive any kind of cancer rehabilitation service. All but one of the participants reported at least one physical effect after cancer treatment, yet only 43% received a rehabilitation service such as physiotherapy. One woman reported being unaware of any rehabilitation services and relayed: "I didn't know anything about any of this stuff (rehabilitation services), like I really, really didn't." There were others who wanted a rehabilitation service, but were not offered anything: "See, I didn't get a referral to physiotherapy at all, and I would have liked it, but there was nothing that came through the lymphedema clinic or through my doctor". Still others felt that they had no guidance as to how to obtain a referral for rehabilitation. One woman questioned, "Who would offer it? Like this is the question I have too, like who's offering you like any kind of rehab? Right, like where is it supposed to come from?" Finally, women expressed that they were not given direction on how to access rehabilitation: "Nobody said, oh, by the way, if you need this (treatment)...this is where you go".

Even though the integration and coordination of rehabilitation services was described as inadequate, some participants did receive therapy and other support

services, or attended physical exercise programs within CancerCare or in the community. Six of the seven women sought out and participated in physical activity programs after their cancer treatment. They expressed that they had to “do their own homework” if they wanted to join some of these programs, and that there wasn’t anyone coordinating the use of these services. One woman commented: “...they said there’s different programs and stuff. So I did go and find it because I wanted to do something about it, so, I think if I needed or wanted something (a rehabilitation service) I sought it out.”

Of the focus group participants, 5 of the 7 women reported having lymphedema. They stated that this had a huge impact on their lives. Because of this, women felt that there should be more information, education, support, and coordination of services for those with lymphedema. All of the women with lymphedema did receive treatment; however, they expressed frustration at the difficulty in obtaining a referral and accessing lymphedema treatment. One woman relayed her experience:

I had a terrible time getting diagnosed with almost everything with my lymphedema; it was just a gong show. It was ridiculous. My doctors didn’t know what it was. I said this is what I’ve got, send me to this person, do this, do that...

The women with lymphedema expressed that it affected every aspect of their lives on a daily basis and that it needed to be properly managed from very early on. One woman communicated the impact of lymphedema on quality of life and the importance of proper management:

I certainly would double star the lymphedema in terms of actual physical impact in terms of recuperation and how it can blow any sense of well-being if it’s not

well handled...so like, it's huge in my estimation and what I've experienced with others too, that's a really, really big thing.

The women who participated in the focus group were self-motivated, asked questions, sought answers and usually found what they needed in terms of cancer rehabilitation. They discussed, however, that there are many women that are not self-motivated and do not seek or receive the appropriate rehabilitation in a timely manner. They further discussed that some women may be in a more disadvantaged situation, such as not being able to speak English, and don't ask questions, don't know how to find what they need, and don't know how to access rehabilitation services. One woman stated: "We're missing 70% of who walk that line (as a breast cancer patient) and who would benefit from this kind of resource". Another participant further explained:

And I keep thinking to myself that I'm one of the fortunate ones, I pay attention, I ask questions, and I can get it, but what about the poor little woman who's 70 years old, and maybe doesn't even have English as her first language and maybe doesn't have someone that goes with her. What does she do?

The lack of a routine and universal management for all breast cancer survivors with insufficient integration of rehabilitative services led to agreement by all the participants that a solution might include the offering of systematic post-diagnosis physical assessments. The women described that this could include the provision of preventative measures, instruction in self-care, and the identification of any physical rehabilitation needs for all breast cancer patients. They also agreed that this assessment of needs should take place pre-operatively, post-operatively, and periodically throughout cancer treatment and in follow-up care. Rehabilitation services would then be coordinated

and offered to each woman with any identified rehabilitation needs after breast cancer diagnosis. One woman explained that this kind of surveillance of the physical needs and integration of rehabilitation services would take care of the physical side after cancer treatment, which she felt had been neglected:

...someone that would coordinate rehab care because that would take care of a different piece of you. There's the medical piece, there's the surgical piece, there's the drugs, the radiation, but then there's that whole other part of you that you just kind of carry on and I think that (someone to coordinate rehabilitation) would be awesome.

Women also felt that the routine assessments of physical needs should be automatically included for all breast cancer patients, with the offering of rehabilitation services being “all part of the package”. One woman stated: “But I think if it (assessment of rehabilitation needs) was not... elective. It's part of the package for this person, this person and this person, and this person... That would be great.” Another participant explained this integration of rehabilitation: “(Cancer rehabilitation) would be like a no choice. Here is your diagnosis, here is your diagnostic testing, here is your chemotherapy, here is your radiation, here is your rehabilitation... it's all part of the package.”

With the incorporation of universal physical needs surveillance into standard cancer care, women felt that those less self-motivated and more disadvantaged would not be “lost in the system”. They also felt even with this routine assessment and offering of rehabilitation services, that individuals could still choose to receive that service at that time or at later time, as explained by one woman:

Maybe some people who don't want it (a rehabilitation service), or they're not ready for it, or whatever, but that it would be just automatically offered, and then if they didn't want it at that particular time there might be an option to have it another time, or whatever, so you're not lost in the system.

In addition to routine and universal assessment of rehabilitation needs, the participants expressed the need for a complete care package for whole body health – a coordination of all the therapies, both physical and psychosocial. One woman relayed her thoughts on this coordination of whole body health:

Whole body health is exactly that, that my experience with the combination of treatments that are available in general, whether it's chiropractic, or massage therapy, or lymphedema or lymph drain massage...or physiotherapy, if you can work together with the therapies you have whole body health, and I think essentially what we try to get back together is a body that we are not quite familiar with and that we want it to be as healthy as it can be and we realize that there are parts that won't. If you can work together with the therapies you have whole body health. If we can get a complete care package addressing each of those issues, you know a consolidation of the therapies, respective of what each one can offer.

Associated with the need for integrated and coordinated cancer rehabilitation is the poor continuity of care that women feel exists after completion of their primary treatment. At the completion of primary treatment, women are followed in oncology for a short time period and then they are transitioned to care with their family physicians. If they have further concerns or questions about any post-treatment issue they feel that they

are not getting the attention or answers they need. One woman expressed her frustration: “So, if you had questions about your health and your physical function you’re not getting answers...once treatment is done, it’s over.” They also felt that they were being a nuisance or reactionary when they had unusual concerns, and that these concerns were not being adequately addressed. One woman shared her experience:

For example I had a large issue with some swelling that was going in my neck and in my face, which terrified me. And so I initially called the oncology office and so they were like so when is your next chemo? And I’m like, oh, no no no, I’m like all done. Bye... they’re done with you. You’re just dropped, and literally you could hear ‘click’. Well, now who do I go to?

They described poor transition to care with their family physicians and inadequate follow-up to deal with some of the new or recurring concerns they encountered. They reflected that not all family physicians are necessarily knowledgeable enough about cancer treatment, or that they do not always know the specifics of the cancer treatment that was received, the follow-up care that is necessary or the side-effects of treatment for which to screen. One woman shared her thoughts on her family physician:

Like he’s not that knowledgeable, right, I mean that’s not his specialty. So, I don’t have the confidence, I guess, that I get a knowledgeable answer from (him)... And that’s no disservice to him, because I’ve had every confidence in him in terms of his care, but just in terms of a knowledge base.

Another woman further explained the lack of continuity of care in the transition to family physicians: “I think that’s there’s a lot of doctors out there that haven’t a clue what to do with you when you get returned (after cancer treatment)”.

Women experience the effects of cancer treatment during, immediately and long after they are finished primary treatment. A woman explained it this way: “And CancerCare cares for you when you’re in the treatment and the responsibility goes far beyond the treatment because it doesn’t just leave you...” These on-going effects of treatment led the participants to feel they should be able to access cancer care professionals beyond the treatment phase.

One consequence of this gap in continuity of care and inadequate coordination of rehabilitation services is the feeling of abandonment for many women. This feeling of abandonment is common after the completion of radiation, as one woman explains: “I find that interesting, ‘cause then you’re done with the radiation guy, but you’re going to get worse for two weeks, but you’re done... But they’re done... Yah, it’s over, we’re done with you, done with you. “ Another woman was puzzled how you can go from a very busy and controlled schedule during the treatment phase to very little contact with cancer care once you are finished that phase. She shared: “And it’s just like, wow, how do you get from an agenda that had every day – go here, go here, do this, do this – and there were people around me forever to, you’re on your own.”

4.2.2.3 THEME: Financial Challenges Related to Rehabilitation Services.

Even with adequate information and clear and consistent answers to questions, integrated assessment of physical needs and the timely coordination of rehabilitation

services, a major financial barrier exists to accessing rehabilitation services. The women shared that there is a lack of funding for rehabilitation services such as physiotherapy and lymphedema management. Many cancer rehabilitative services are not included in the Provincial Health Plan and those that are may have long waiting lists, with a limited number of treatment sessions allowed. The Provincial Health Plan also does not cover the cost of compression garments for those with lymphedema. The expenses related to garments for managing lymphedema can be high, as one woman explained: “I have a little bit of insurance and it pays for 80% of so many garments and I went way over. Now we haven’t even started talking about the wrapping supplies and all the other stuff, right?”

Those that do have private health insurance soon realize that the coverage is very limited for physiotherapy, lymphedema therapy, supplies and garments. Private physiotherapy and costly and intensive lymphedema management often results in many out-of-pocket expenses. Those that do not have private insurance are very frustrated, as one woman explains: “If you don’t have insurance or if you don’t have the resources, you’re not going, you’re going to sit on that waiting list and you’re going to wait for that.”

Despite the need for these essential rehabilitation services or components to manage lymphedema, some women report that they just go without physiotherapy, lymphedema treatment, or garments, simply because they can’t afford it. These financial challenges pose a large barrier to accessing rehabilitation services or the needed lymphedema management supplies. One woman shared her concern:

Finances are a big deal, then everything stops short, because most of us live by what our finances allow us to do. So if we don't have the finances we don't give ourselves the opportunity to access physiotherapy if we don't have coverage for it. We're not going to go.

Another woman further explained her challenge when she considered buying garments for her lymphedematous arm: "So I didn't have the financial resources to go and buy it (the garment), there's no way... it's prohibitively expensive."

There was an overwhelming agreement among the participants that more funding is needed under the Provincial Health Plan for physical rehabilitation such as physiotherapy, lymphedema treatment, bandaging supplies and compression garments. They felt that there should be improved access and affordability for rehabilitation services for all women diagnosed with breast cancer in Manitoba. They sensed that many women need rehabilitation services, especially lymphedema management, which if not properly managed has many unfortunate consequences. They shared that the provision of adequate funding for rehabilitation after breast cancer would certainly alleviate many fears and concerns for breast cancer survivors.

5.0 DISCUSSION

5.1 Introduction

This chapter will discuss both the quantitative and qualitative study findings related to the research questions and the applicable empirical literature. A synthesis of the findings and recommendations for cancer rehabilitation in Manitoba will be identified followed by the limitations of this study, future directions, and knowledge translation.

5.2 Discussion of Quantitative Findings

5.2.1 Study Sample

The mean age of the sample was 60.8 years, which is very similar to the average age of women diagnosed with breast cancer. In Canada, 52.0% of women diagnosed with breast cancer are between the ages of 50 and 69 (Canadian Breast Cancer Foundation, 2013), and the average age of those diagnosis with breast cancer in Manitoba in 2010 and 2011 was 61.3 years (Epidemiology and Cancer Registry, CancerCare Manitoba., 2013) . The age of the study sample could have influenced the number of those not in the workforce (homemaker or retired – 52.7%). Forty-nine percent of the sample had completed college or university, which could reflect the higher number of those with private health insurance and those possibly receiving a rehabilitation service. It is established that well-educated citizens are often more actively engaged in their health care and generally have higher incomes (The Conference Board of Canada, 2013). In Canada, the percentage of those who have completed post-secondary education is 53.0% (Human Resources and Skills Development in Canada, 2012b); therefore, the study sample had a similar educational attainment to that of

Canada's general population. In Manitoba, 71.7% of the general population live in the urban area (Human Resources and Skills Development in Canada, 2012a), and of those diagnosed with breast cancer in 2010 and 2011, 64.9% lived in an urban area (Epidemiology and Cancer Registry, CancerCare Manitoba., 2013), which is quite comparable to the study sample (63.3% reported to live in either Winnipeg or Brandon). It is reported that women in urban areas have a higher incidence rate of breast cancer than those in rural or remote areas of Canada (Canadian Partnership Against Cancer, 2012), which is possibly related to breast cancer screening usage and the distribution of risk factors (Borugian, Spinelli, Abanto, Xu, & Wilkins, 2011). The direct comparison regarding those who subscribe to private health insurance is difficult, as the percentage is unknown. However, in the study sample, 67.7% of the participants had private health insurance, which is higher than reported in another Canadian study of a similar cohort where 53.0% subscribed to private health insurance (Gray et al., 2000).

The medical characteristics of the study sample were compared to the medical profiles reported in the 2012 Breast Cancer Special Focus Report by the Canadian Partnership Against Cancer (CPAC) (Canadian Partnership Against Cancer, 2012). CPAC report that 78.0% of diagnosed breast cancer cases in Manitoba were diagnosed with early stage (1 or 2) disease. In the current study sample, 63.0% reported stage 1 or 2 breast cancer. In regard to the surgical procedures for women diagnosed with breast cancer, CPAC reports that 36.0% in Manitoba undergo mastectomies and 64.0% have breast conserving surgery. This is similar to the study sample as 38.0% had mastectomies and 60.0% had breast conserving surgery. CPAC further reports that radiation therapy is received by 56.0% of Manitoba women with a breast cancer

diagnosis and chemotherapy is received by 38.0%. In the current study sample, 81.0% received radiation therapy, and 56.0% underwent chemotherapy. The average number of lymph nodes removed in women diagnosed with breast cancer in Manitoba in 2010 and 2011 was 3.1 (range=0-74, SD=7.2) (Epidemiology and Cancer Registry, CancerCare Manitoba., 2013). This average is lower than was reported in the study sample (mean=6.9, range=0-38, SD=8.1), which relied on self-report, and is possibly an overestimation of the actual number of lymph nodes removed.

Taken as a whole, the study sample was approximately 61 years of age, was in the vicinity of 21 months since diagnosis of stage 1 or 2 breast cancer, had undergone primarily lumpectomies with 5 or less lymph nodes removed, and had typically received radiation treatment with just over half receiving chemotherapy treatment. The women were typically well-educated, urban-dwelling, subscribers of private health insurance and either homemakers or retired from the workforce. While this study sample may have some similarities to the target population (age, education level, place of residence, and surgical procedure), this study sample is not completely representative of the target breast cancer population in Manitoba. Exact comparisons to the breast cancer population in Manitoba are difficult as some of the specific demographic characteristics of those diagnosed with breast cancer are unknown.

5.2.2 Self-report of Physical Problems

Based on this sample of breast cancer survivors, there is a high self-report of physical problems after diagnosis, which is consistent with the literature. On the participant information form, only 12.1% of the participants denied a physical problem such as lymphedema, shoulder weakness or stiffness, fatigue, numbness or tingling, scar

tightness, pain, general weakness or deconditioning. For the items that related to symptoms and impairments of the arm, shoulder and hand on the DASH survey, 51.0% reported at least one physical problem such as sleep disturbance, stiffness, weakness, pins and needles, pain, or pain with activity. The most commonly reported physical problem was fatigue (62.0%), which is not a surprising finding as the prevalence rates for fatigue are high not just in the breast cancer population, but for all cancer types (Ashbury, Findlay, Reynolds, & McKerracher, 1998; Barton-Burke, 2006; Howell et al., 2013; Lawrence et al., 2004). Overall, the high prevalence of physical problems and upper limb impairments such as the ones described above, have been confirmed repeatedly by numerous authors, both by self-report and through objective measures in the months and years following breast cancer treatment (Bosompra et al., 2002; Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002b; Cheville, Troxel, Basford, & Kornblith, 2008; Devoogdt et al., 2011; Engel et al., 2003; Ghazinouri et al., 2005; Hack et al., 1999; Hack et al., 2010; S. Hayes, Battistutta, & Newman, 2010; S. C. Hayes et al., 2012; Karki et al., 2005; Kim et al., 2011; Kwan et al., 2002; Miedema et al., 2011; Swisher et al., 2010; Tengrup, Tennvall-Nittby, Christiansson, & Laurin, 2000). Additionally, the report of one or more physical problems, which in the current study was reported by 73.8% of the participants, is a common finding in many cancer patients, especially in those with more advanced disease (Cheville et al., 2011).

Lymphedema was reported by 20.5% of the participants. The prevalence of lymphedema after breast cancer treatment varies widely in the literature, with reports from 5% to over 70% (Bosompra et al., 2002; Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002a; B. Clark, Sitzia, & Harlow, 2005; Erickson et al., 2001; S. Hayes,

2008; Kornblith et al., 2003; Petrek et al., 2001). The reason for this wide variation of the reported prevalence relates to whether it is self-reported or objectively measured, the definition of lymphedema used, and the diagnostic method and timing of the assessment (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002a; S. C. Hayes et al., 2012; Williams, Franks, & Moffatt, 2005). In the current study, the true incidence of lymphedema may be underestimated as it relied on self-report.

For activity limitations and participation restrictions reported on DASH (items 1 to 23), 38.7% of participants reported some limitation or restriction, with 85.6% of those being mild or moderate. The women reported that most of their difficulties were with opening a tight jar, pushing a heavy door, doing heavy housework and carrying heavy objects. These women reported having ongoing mild or moderate difficulty with activities that require upper body force or strength at close to 2 years post-diagnosis. It is unknown if these difficulties were related solely to the breast cancer experience or if they were age-related or related to other comorbid conditions. Normative age-related differences have been reported in employed men and women. These authors reveal greater disability and higher mean DASH score with increasing age, and those age 50 to 65 years had the highest impairment and activity limitation (Jester, Harth, & Germann, 2005). The findings in the current study echo similar reports on activity limitations and participation restrictions in the breast cancer population (Devoogdt et al., 2011; Karki et al., 2005; Miedema et al., 2008; Swisher et al., 2010; R. L. Thomas-Maclean et al., 2010). Miedema et al. (2008) further identified that participants had difficulty with activities that required some force or impact (49.0%) or activities that involved moving their arm freely (44.0%), and reported that 29% of the women had a decreased level of

participation in leisure activities since their breast cancer diagnosis. Pain, range of motion and arm morbidity had a significant relationship with the recreational and leisure activities ($p \leq 0.011$). The current study relied on self-report of arm morbidities; however it would be worthwhile to examine the relationship of these variables and the activity limitations and participation restrictions captured on the DASH.

5.2.3 Receipt of Rehabilitation Services

Eighty-eight percent of the participants reported at least one physical problem after their breast cancer diagnosis, and 73.8% reporting more than one, yet only 42.6% had reported having received one or more type of rehabilitation service. Consistent with the current study, other authors reveal a great disparity between the high incidence of physical problems, the need for rehabilitation and the receipt of cancer rehabilitation services (Cheville et al., 2008; Cheville et al., 2009; Guadagnoli & Mor, 1991; Kim et al., 2011; Ross, Petersen, Johnsen, Lundstrom, & Groenvold, 2011; Thorsen et al., 2011). This is an unfortunate finding, as there is much evidence that rehabilitation services such as physiotherapy, occupational therapy, lymphedema treatment and exercise programs are effective in addressing physical problems after breast cancer treatment (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002a; Cheville & Tchou, 2007; Cheville et al., 2008; Ghazinouri et al., 2005; Lauridsen et al., 2005; McNeely et al., 2006; McNeely et al., 2010; J. K. Silver & Gilchrist, 2011).

The need for rehabilitation services among cancer survivors has been explored by several authors, and in one study by Thorsen et al. (2011), they described that 63.0% of their participants reported a need for at least one rehabilitation service, with physical therapy and physical training being the most frequent need reported (43.0% and 34.0%

respectively). The authors further account that the need for these rehabilitation services remained unmet for 40.0% of the participants (Thorsen et al., 2011).

The most commonly reported rehabilitation services in the current study were massage therapy and physiotherapy. Lymphedema treatment was received by 12.9% of the participants, yet 20.5% reported lymphedema. A study by Clark, Sitzia and Harlow (2005) reports similar findings: 20.7% of the participants had lymphedema, yet only half of them had received lymphedema treatment (B. Clark et al., 2005). In the current study, the type of practitioner that provided the lymphedema treatment is unknown, which may have typically been provided by a massage therapist as most certified lymphedema therapists in Manitoba are massage therapists. It appears, though, that not all of those who report lymphedema receive the treatment to manage the lymphedema.

In the current study, there were 67.7% of the participants that had private health insurance, which indicates that they may have had better access to rehabilitation services; however, even though the majority of participants had private health insurance, this was not reflected in the percentage that received rehabilitation services. The percentage of those with private health insurance, while higher in the current study, is comparable to a Canadian study by Gray et al (2000). The authors described that 53.0% of the participants had private health insurance, and only 31.0% reported utilizing at least one professional service, with the highest utilization being physiotherapy (Gray et al., 2000). A study by Lin and Pan (2012) examined the use of rehabilitation among breast cancer survivors and report that 39.6% had utilized an insurance-covered rehabilitation service at least once over a 5-year period. They report that physical therapy was the most commonly used (84.2%). The authors point out that the

prevalence of rehabilitation usage was far lower than the rate of complications (Lin & Pan, 2012). The reason for the disparity between the high prevalence of physical problems, despite those that have private coverage for rehabilitation treatment, and the receipt of a rehabilitation service, may be the low reporting of a physical problem to physicians, inadequate screening for need or referral to cancer rehabilitation services, a lack of awareness of the role and potential benefits of cancer rehabilitation and the treatment options, personal or physical barriers, the limited number of trained cancer rehabilitation health professionals, and the poor availability of cancer rehabilitation services (Bachmann-Mettler et al., 2011; Cheville & Tchou, 2007; Cheville et al., 2009; Gray et al., 2000; Lehmann et al., 1978; Lin & Pan, 2012; Schmitz, Stout et al., 2012; J. K. Silver & Gilchrist, 2011; R. L. Thomas-Maclean et al., 2008; Thorsen et al., 2011). All of these factors could apply to this disparity in Manitoba; however, further clarification as to why cancer rehabilitation services are poorly utilized in Manitoba, and the associations and predictors of rehabilitation utilization is warranted.

5.2.4 Quality of Life: FACT-B

The mean FACT-B score of 110.3 (76.6%) indicates a moderately high quality of life amongst the sample participants. The FACT-B scores are comparable to other similar sample groups, although the scores ranged from 109.1 to 125.6, (75.8% to 87.2%) they nevertheless indicate a good quality of life (Avis, Crawford, & Manuel, 2005; Beaulac, McNair, Scott, LaMorte, & Kavanah, 2002; Mak et al., 2009; Wenzel et al., 1999). Wenzel et al (1999) utilized the FACT-B measure to examine the age-related differences in quality of life. The authors compared those age 50 and under (FACT-B score of 111.7) to those over age 50 (FACT-B score of 117.6) and reported a significant

difference ($p=0.021$). In addition, there was a significant age-related difference in the emotional well-being and the breast cancer subscale ($p=0.0002$ and 0.022 respectively). While an age comparison was not undertaken in the current study analysis, it is interesting to note that the mean age of the study participants was 60.8 years and the mean FACT-B score was lower than reported in the study by Wenzel (Wenzel et al., 1999). The literature consistently reports that younger women manifest a poorer level of quality of life and a higher prevalence of symptoms than older women after breast cancer treatment (Ganz, Lee, Sim, Polinsky, & Schag, 1992; Holm et al., 2012; Kroenke et al., 2004; Mor, Malin, & Allen, 1994; Yoon et al., 2008). Quality of life after a breast cancer diagnosis is multi-factorial and is associated with age, level of psychosocial adjustment, treatment variables, severity of treatment side-effects, physical disability and dysfunction, social supports, comorbid conditions, and socio-economic status (Ashing-Giwa & Lim, 2009; Beaulac et al., 2002; Engel et al., 2003; Fleissig et al., 2006; Ganz et al., 1992; Hurny et al., 1996; Longman, Braden, & Mishel, 1999; Rodriguez, Mayo, & Gagnon, 2013; Wenzel et al., 1999; Yoon et al., 2008).

The current study did not examine the FACT-B score in relation to those reporting lymphedema; however it would be worthwhile to determine if there was a relationship, as 20.5% of the participants reported lymphedema. A study by Mak et al. (2009), examined quality of life and lymphedema in breast cancer survivors. In all but one of the FACT-B domains, including the total score, breast cancer patients with lymphedema had significantly lower quality of life than those without lymphedema (mean FACT-B score 112.2 vs. 125.6, $p<0.0001$) (Mak et al., 2009). Many studies have demonstrated that breast cancer survivors with lymphedema have significantly

lower quality of life than those without lymphedema (Ahmed et al., 2008; Beaulac et al., 2002; Coster et al., 2001; Kwan et al., 2002; P. A. Morgan, Franks, & Moffatt, 2005).

5.2.5 Disability of the Arm, Shoulder and Hand: DASH

The mean DASH score (17.1%) indicates that most participants had minimal disability of their arm, shoulder and hand. This report of minimal disability 1 to 5 years post-surgery for breast cancer is congruent with the literature (Miedema et al., 2008; Swisher et al., 2010; R. L. Thomas-Maclean et al., 2008; R. L. Thomas-Maclean et al., 2010; Velloso et al., 2011). It appears that most women in the current study and others, despite the high prevalence of physical problems, did not report high disability and were able to adapt to their limitations and participate in daily home, work, and recreational activities. The mean time since diagnosis was 21.3 months, so it is possible that if an assessment of disability had occurred at a time point closer to primary treatment, higher disability scores may have been found. While not reflected in the disability scores on the DASH, many women experienced a high number of physical problems even at close to 2 years after diagnosis. It is possible that some of the primary treatment-related physical problems, while still present, had lessened and did not result in reports of disability or were not considered severe enough in the “greater context of cancer survival issues” (Swisher et al., 2010).

Normative data has been established for DASH and a mean score of 10.1 has been reported for all age groups and genders (Hunsaker, Cioffi, Amadio, Wright, & Caughlin, 2002). A mean DASH score of 1.85 has also been reported among the young (mean age 29 years), active, and symptom free population (Clarke, Dewing, Schroder, Solomon, & Provencher, 2009). Another study examined DASH scores for men and women doing

manual and non-manual labour (Jester, Harth, & Germann, 2005). The women had higher mean values (14.3) than the men (11.6) and had most difficulty with opening a tight jar, pushing a heavy door, doing heavy housework and carrying a heavy object. In addition, the authors also examined age-related differences in the mean DASH scores. Men and women aged 18 to 29 years had a mean score of 5.4, those age 30 to 49 years had a mean score of 14.0 and those that were age 50 to 65 years had a mean score of 19.0, indicating a greater disability with increasing age. The mean scores reported in the general population are overall lower than what was reported in the current study. Although the difference in the mean scores may be statistically significant, whether it is clinically meaningful is unclear. The minimally clinically important difference (MCID) for the DASH is 10.2 points (Schmitt & Fabio, 2004). The MCID is the smallest change in the measure that a patient would identify as important, or the minimum amount of change required for the patient to feel a difference. Therefore, in the current study, the mean score of 17.1 may not indicate a clinically importance difference in the study cohort compared to the normative data. Additionally, the mean DASH scores in the current study may be a function of increasing age and not related to the breast cancer experience.

Higher disability of the arm, shoulder and hand has been demonstrated in breast cancer survivors who have lymphedema, shoulder pain, shoulder pathology, upper limb dysfunction and a decreased quality of life (Jeong et al., 2011; P. A. Morgan et al., 2005; B. Smoot et al., 2010; R. L. Thomas-Maclean et al., 2008). An examination of these variables, their co-dependencies and associations are beyond the scope of this thesis, however, future secondary analyses are warranted.

5.3 Discussion of Qualitative Findings

The questions posed for the qualitative aspect of this study included the following:

- 1) What are breast cancer survivors' understandings of the role of cancer rehabilitation?
- 2) What is the current availability of physical rehabilitation services for breast cancer survivors in Manitoba and what has been the experience in accessing these services?,
- and 3) What are the recommendations and strategies for improved future provision of physical rehabilitation services for breast cancer survivors in Manitoba?

The qualitative findings, therefore, give an insight into the experiences with cancer rehabilitation from the perspective of those diagnosed with breast cancer and provide recommendations for future provision of cancer rehabilitation. While it was proposed that the qualitative inquiry would explore the understanding of the role of cancer rehabilitation, this question was not directly asked or answered. The function of cancer rehabilitation in the cancer care system was alluded to in statements referring to a knowledgeable health professional, resource, or program that could assist them through their rehabilitation after their diagnosis. They referred to this aspect of recovery being very important to their overall recuperation. The role of cancer rehabilitation, therefore, could be extrapolated from these statements to be an integral part of the cancer journey. The role of cancer rehabilitation has been similarly explained "as a valuable step in an ongoing process towards recovery" (Korstjens et al., 2008).

It is interesting to note that the women had a difficult time sharing solely about the physical aspects of their cancer journey. They conveyed that their cancer diagnosis affected all areas of their lives and that they were all equally impacted. This finding is corroborated in a study by Stephens, Osowski, Fidale and Spagnoli (2008), who reported

the study participants identified a combination of social, physical, emotional and spiritual aspects as being equally important, and that “they all tie together” (Stephens, Osowski, Fidale, & Spagnoli, 2008). Whole-body health is a function of the interaction of physical health, emotional status, social relationships, and a meaningful spiritual life. This strong interaction was evident in the focus group discussion.

In Manitoba there are a number of services and supports for the breast cancer survivor. However, there appears to be a disconnection between the available services and the awareness, understanding and utilization of these services. Many women report being underserved despite the identification of some of these services. It is possible that since these women were diagnosed and treated over 2 years ago, there was even poorer awareness and access to these services. Additionally, these challenges were identified by a small group of women and cannot be generalized to the breast cancer population at large. Further investigation into this disconnection of service availability and utilization is warranted.

Notwithstanding the reported usage of some of the available rehabilitation services and supports, the women shared some of the challenges they faced in their recovery after breast cancer. The three themes that became apparent in the focus group findings that articulated the participants’ perspectives on their experiences with cancer rehabilitation after a breast cancer diagnosis include the following: 1) Difficulty in finding clear and consistent information; 2) The need for integration of cancer rehabilitation services; and, 3) Financial challenges related to cancer rehabilitation services.

5.3.1 Difficulty in Finding Clear and Consistent Information

5.3.1.1 Informational needs.

The physical problems experienced after breast cancer treatment result in many needs, with one such need being able to find clear and consistent information. The women expressed that the need for information was often unmet. A systematic review of the unmet supportive care needs of people with cancer (Harrison, Young, Price, Butow, & Solomon, 2009) reported that the highest unmet informational needs occur during the treatment and post-treatment phase of the cancer trajectory. The authors also reported that information provision was inadequate concerning information and management of treatment side effects. In the present study, the women were all in the post-treatment phase and were faced with physical effects of cancer treatment, such as pain, lymphedema, fatigue, and deconditioning (all reported by 71% of the focus group participants). They articulated the need for simple and clear information regarding the side effects and if they required further attention, they needed to know who to see for additional information, management advice, or treatment. In another study, the perceived needs of women diagnosed with breast cancer were examined: 43.0% reported an unmet need for information about the side effects of treatment and 30.0% reported an unmet need for information on ways to manage their side effects (Girgis, Boyes, Sanson-Fisher, & Burrows, 2000). In a review of informational needs of long-term breast cancer survivors it was revealed that women experience ongoing informational needs 5 years past diagnosis and that these needs are often not being met (Vivar & McQueen, 2005). This frequent problem of the “unmet need” of the provision of quality information regarding treatments, side effects of treatments, and follow-up care has been replicated by

others (Ashbury et al., 1998; Easley & Miedema, 2012; Ferrell et al., 1997; Ganz et al., 1996; Ganz et al., 2008; Griesser et al., 2011; Hack, Degner, Parker, & SCRN Communication Team, 2005; Harrison et al., 2009; Karki, Simonen, Malkia, & Selfe, 2004; Lee, Kilbreath, Sullivan, Refshauge, & Beith, 2010).

An interesting finding regarding informational needs was revealed in a study by Thewes, Butow, Girgis, and Pendlebury (2004). Rather than wanting specific information about interventions to deal with the side-effects of treatment, the participants were seeking information to reassure them that the symptoms were to be expected or that they were normal (Thewes, Butow, Girgis, & Pendlebury, 2004). This finding is consistent with a second study which found that women wanted information about how to interpret their physical symptoms (Gray et al., 1998). The information and reassurance needed by women is replicated in the current qualitative data as many women revealed that they often sought answers to their questions to “confirm their new normal”.

A majority of the focus group participants experienced lymphedema, and they shared that they needed additional information, education, and support. This qualitative inquiry indicates that the provision of information and guidance related to lymphedema, risk reduction strategies, and management is sometimes inadequate, and has been validated by others (Girgis, Stacey, Lee, Black, & Kilbreath, 2011; Hare, 2000; Ryan et al., 2003; R. Thomas-MacLean, Miedema, & Tatemichi, 2005). The ongoing effect of lymphedema on women’s lives can be extreme and potentially even more severe when women are poorly equipped with information and management advice. One reason for the poor provision of information about lymphedema could be the lack of awareness of lymphedema among health care professionals (P. A. Morgan et al., 2005; R. Thomas-

MacLean et al., 2005). This lack of awareness can lead to delayed diagnosis and referral for treatment and, in turn, worsening edema and a higher risk for complications such as cellulitis (P. A. Morgan, Murray, Moffatt, & Honnor, 2012).

5.3.1.2 Ongoing need for information.

While there are key time points for the giving of information for breast cancer patients, such as at diagnosis and in the treatment planning phase, the need for information has been shown to continue up to two years after diagnosis (Luker, Beaver, Leinster, & Owens, 1996). For the focus group participants, the mean time since diagnosis was 27 months, and although the women were reflective in their comments, the findings indicate that there were information needs beyond 2 years after diagnosis. These information needs well after breast cancer diagnosis could reflect the impact of the side effects and long-term effects of breast cancer treatment. Some studies revealed that information in this area is considered to be among the most important (de Bock et al., 2004; Hack et al., 2005), and this need for information continues well into survivorship (Cancer Journey Survivorship Expert Panel et al., 2011; Girgis et al., 2011; Gray et al., 1998; S. C. Hayes et al., 2012; Howell et al., 2012; Howell et al., 2013).

5.3.1.3 Consistent information.

The need for consistent information was also disclosed in this study. The report of women receiving conflicting advice regarding their affected arm after surgery and the prevention or management of lymphedema has been confirmed in the literature (Carter, 1997; Collins, Nash, Round, & Newman, 2004; Karki et al., 2004; Lee et al., 2010; Ryan et al., 2003). There seems to be confusion about how to care for your arm after surgery

and when to start exercises. One woman was told by one health professional to never sleep on her affected arm and not to move it in a certain way after surgery. She was later told by another health professional that this was incorrect advice, resulting in much frustration and confusion. The inconsistent information given by health care professionals could be indicative of the lack of knowledge and awareness of some of the physical effects of cancer treatment and how to best prevent or manage them. It is clear that women want consistent and reliable information, and health care professionals should strive to provide evidence-based, consistent and accurate advice for those going through cancer treatments (Collins et al., 2004; Gray et al., 1998).

5.3.1.4 Emotional response to unmet informational needs.

The focus group transcript was replete with frustration, confusion, and anxiety around the challenge of finding clear and consistent information, answers to questions, and knowing where to go for guidance. The participants revealed their anxiety and confusion when stating, “I don’t know where to go to ask these questions” when they had specific concerns after surgery or regarding unusual swelling. They felt that knowing where to go and who to ask for guidance would reassure them and allay much of their anxiety. This frustration and anxiety related to inadequate or conflicting information revealed in the present study is congruent with the literature (Collins et al., 2004; Gray et al., 1998; Greenslade & House, 2006; Hack et al., 2005; Lee et al., 2010). Other research also confirms that provision of information may assist in the reduction of feelings of anxiety (Beaver, Twomey, Witham, Foy, & Luker, 2006; Hack et al., 2005). A qualitative study by Rosedale and Fu (2010), described that women experienced a great deal of anxiety and distress when living with the unexpected lingering symptoms of

cancer treatment, such as pain, loss of energy, impaired limb movement and lymphedema (Rosedale & Fu, 2010). The author also described that these women were often not counseled or informed about the lasting effects of treatment and subsequently they had added anxiety about these unforeseen symptoms. If they would have received adequate information early in the treatment phase, this possibly may have allayed some of their distress. These findings indicate, as validated by the current study, that emotions of frustration and anxiety are related to inadequate, delayed, and inconsistent information.

5.3.1.5 Need for a central liaison.

The women in the present study referred to a “lifeline to tie into” - a knowledgeable resource person that could guide them throughout the cancer journey. While the term ‘navigator’ was not used, this lifeline could certainly be described as a patient navigator. The definition of a patient navigator could encompass the following: a) a skilled communicator that acts as a patient advocate; b) one who facilitates access to care and empowers patients with information and knowledge; and c) one who is knowledgeable of the cancer system and its resources (Pedersen & Hack, 2010). A central liaison and breast cancer patient navigator has been reported to be important and necessary for the provision of information and coordination of the multidisciplinary service providers (Collins et al., 2004; Easley & Miedema, 2012; Robinson-White, Conroy, Slavish, & Rosenzweig, 2010).

It is interesting to note that some women in the present study had high praise for cancer care professionals at the Breast Cancer Centre of Hope. They did not refer to anyone as a patient navigator, while indeed that is the role of these professionals. It appears that the women did not know these professionals were their “lifeline to tie into”

and could act as their guide through the cancer care system. It is also possible that some were not aware of this service and did not access this service. It may be that there is not a routine referral of newly diagnosed patients, or those already on treatment, to patient navigators. This navigation does exist in Manitoba, but there may a gap in the system that results in poor awareness and utilization of this needed navigation for breast cancer survivors.

5.3.1.6 *Finding answers on your own.*

Even though there are many services for women diagnosed with breast cancer in Manitoba, including patient navigation, it is of interest that women in the focus group revealed that they were often left to search out information for themselves. Those diagnosed with breast cancer have many more services and information sources than other disease sites. One woman validated this by saying “with breast cancer there are so many more resources than with other cancers”. Thus, despite this availability of information and resources, there appears to be some gaps in the awareness of these resources, or a lack of understanding on how to access information and services. The concept of having to search out information for oneself is not new to this population. One author reports that some women are not satisfied with the information they have received, and often have to search on their own for the needed information (Fitch, Nicoll, & Keller-Olaman, 2007). Other studies confirm that many women are required to be their own advocate when it comes to identifying and resolving their information needs (Greenslade & House, 2006; Lee et al., 2010). In Manitoba, it would be important to determine why those diagnosed with breast cancer, despite the availability of information and services, perceive the need to search for information on their own.

5.3.2 The Need for Integration of Cancer Rehabilitation Services

As already reported, a majority of the focus group participants experienced at least one physical problem after their breast cancer diagnosis, yet only 43.0% received a rehabilitation service such as physiotherapy. The women in the focus group reported that no-one within the cancer care system was “in-charge” of their rehabilitation. There was a lack of integration and coordination of cancer rehabilitation. No-one asked them about their specific physical concerns, no-one assessed their physical need for rehabilitation and no-one coordinated their rehabilitative care. The need for integration and coordination of cancer rehabilitation services and appropriate management of the physical effects of cancer treatment has been revealed by other authors (Alfano & Rowland, 2006; Ashbury et al., 1998; Campbell et al., 2012; Cheville et al., 2011; S. C. Hayes et al., 2012; Schmitz, Stout et al., 2012; van Harten et al., 1998). It is evident, therefore, that the path to cancer rehabilitation services is not always expedient or consistent for women after a breast cancer diagnosis. This is related to a poor awareness of the physical rehabilitation needs and the available rehabilitation services, both among patients and health care professionals, and the inadequate integration and coordination of rehabilitation services. These factors often leave women having to search out the services for themselves, and if they do not have the adequate skills to do this, they are often lost in the system and left un-serviced or under-serviced.

5.3.2.1 Awareness of services.

In this study, several women expressed that they were not aware of some of the rehabilitation services and even if they were aware they were not offered any rehabilitation service. This lack of awareness was reflected in statements like: “I didn’t

know anything about any of this (rehabilitation)”, or “who is offering you any kind of rehab?” This lack of awareness was echoed in other studies that examined rehabilitation care for younger breast cancer survivors. Half of their study participants reported they did not receive any information about any rehabilitation service, and 94% reported that they were unaware of the available breast cancer rehabilitation services (Easley & Miedema, 2012; Miedema & Easley, 2012). In another study, Kumar et al (2012) reported that the main patient-reported barriers to access of support services, such as physical therapy, were a lack of knowledge of the support service (22.7%), and the lack of a physician referral (23.3%) (Kumar et al., 2012). The lack of awareness of services is not just with the patient themselves, but also among health care professionals. Many do not know the treatment options, what cancer rehabilitation services are available or how and when to refer patients (Kumar et al., 2012; P. A. Morgan et al., 2012; Williams, Moffatt, & Franks, 2004). Congruent with the current study, many of these authors report that a majority of women experienced physical problems after a breast cancer diagnosis, yet less than half ever received an intervention to address these issues.

5.3.2.2 Searching for and receiving rehabilitation services.

In this study, women had to often search for information on their own. This was the same when it came to finding assistance and services for their physical problems as many women had “sought it out” for themselves. While the women identified many cancer rehabilitation services and supports that were available to them, they also shared that they usually had to “do their own homework” when it came to finding and accessing the appropriate rehabilitation service. They felt that they were not often directed by the cancer care professionals to specific rehabilitation services. One participant questioned,

“Who is going to refer us to rehab?” This finding is collaborated by several studies. In one, the authors reported that 22.0% of the participants were not offered physical therapy or physical training even after expressing a need for this service (Thorsen et al., 2011), and in a second study, 80.0% of the participants shared with a health care professional their need for rehabilitation, yet only 48.0% received the needed treatment (R. Thomas-Maclean et al., 2009). Another study examined the offering of cancer rehabilitation and revealed that 30.0% were not offered a rehabilitation service, 24.0% stated that the information on the available resources was inadequate, and finally, 16.0% reported not receiving help to manage the physical side effects (Ross et al., 2011). The focus group participants reported poor identification of rehabilitation needs, limited disclosure of resource information, and a deficient referral infrastructure for cancer rehabilitation services, congruent with other studies that report that many patients either go without these services, receive a delayed referral, or are left to search for and access these services on their own (Easley & Miedema, 2012; Lattanzi et al., 2010; Paul & Buschbacher, 2011; Towers, Carnevale, & Baker, 2008).

5.3.2.3 Self-motivation.

The women in the focus group identified themselves as being self-motivated. They sought information, asked questions and availed themselves of rehabilitation services. However, they felt that not every breast cancer patient has the same self-motivation and these women are often “lost in the system”. Those that lack self-motivation may be those that do not have English as their first language, do not have adequate social supports and are of lower socioeconomic status. In the focus group, five of the seven women had college or university education. The literature reports that those

with higher education may have improved access to health care and other support services, and also better health outcomes (Backlund, Sorlie, & Johnson, 1999; Kogevinas & Porta, 1997). Therefore, those with lower self-motivation, less education and possibly a lower capacity to understand health information, and an overall lower socio-economic status may have far greater information needs and the need for guidance through the cancer care system (Ashing-Giwa & Lim, 2009; Griesser et al., 2011).

5.3.2.4 Coordination and access to lymphedema services.

Much of the discussion in the focus group was concerning lymphedema and its management. Five of the seven women in the focus group reported having problems with lymphedema. They expressed that more information, education, support and coordination is needed related to the prevention, diagnosis, and management of lymphedema. This need for improved information and better support for those that have lymphedema has been consistently shown in other studies (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002a; Carter, 1997; Greenslade & House, 2006; Miedema & Easley, 2012; P. A. Morgan et al., 2005; Williams et al., 2004). Women experience a myriad of emotions about having lymphedema, and when it is poorly managed due to inconsistent information and inadequate coordination of services, it further adds to the frustration and anxiety. Lymphedema can be a progressive condition if not treated, and a delay in diagnosis and treatment can result in more advanced lymphedema and a host of unfortunate complications including recurrent cellulitis and functional and vocational limitations (Bar Ad et al., 2010; Beaulac et al., 2002; Casley-Smith, 1995; Karki et al., 2005; P. A. Morgan et al., 2012). This poor management of lymphedema can also result in many direct and indirect costs, including the need for intensive treatment, lost time

from work, and hospitalizations (P. A. Morgan et al., 2012; Shih et al., 2009; Stout, Pfalzer et al., 2012). It appears that improved information and better coordination and access to timely lymphedema management is needed to sufficiently meet the physical and psychological needs of those with lymphedema after breast cancer treatment.

5.3.2.5 Continuity of care and post-treatment abandonment.

Women reported they appreciated the support and attention they received during their active treatment phase, but expressed frustration and distress when transitioning to care with their family physicians. Many women shared that they were just “dropped” once this phase was completed. The feeling of abandonment has been reported in other studies (Collins et al., 2004; Easley & Miedema, 2012; Gray et al., 1998), and appears to be a common theme among breast cancer survivors. In a qualitative study by Greenslade and House (2006), the authors describe that their participants felt that the health care system was apathetic to their situation and they were dismissed once they finished their active treatment (Greenslade & House, 2006). Another qualitative study of women with breast cancer-related lymphedema also revealed that the women felt abandoned by the medical community, and had to search for information and treatment on their own (Carter, 1997). Studies examining the transition period from active treatment within the cancer care system to the family physician have recognized this period as potentially difficult and often poorly managed interval (Bergeson & Dean, 2006; Ganz et al., 2008; Gray et al., 1998; Howell et al., 2012; Howell et al., 2013; Miedema, MacDonald, & Tatemichi, 2003; Pennery & Mallet, 2000). The implementation of a survivorship care

plan³ would assist in this transition period (Cancer Journey Survivorship Expert Panel et al., 2011; Earle, 2006; Ganz & Hahn, 2008). CancerCare Manitoba is currently implementing a process for better transitional care after primary treatments are completed, including customized survivorship care plans.

5.3.2.6 Accessibility of Rehabilitation Services.

The literature supports that access to rehabilitative care after a breast cancer diagnosis can be challenging for some women. Access may be more difficult for the rural population due to a lack of specialized rehabilitation services and the time and cost required for travel (Easley & Miedema, 2012; Miedema & Easley, 2012). These authors report that the women would like equal access and standardized rehabilitation services across all geographic regions. The aspect of accessibility did not emerge in the focus group discussion in the current study. All the women in the focus group were from the urban area, and 43.0% reported receiving physiotherapy and 71.0% reported receiving lymphedema treatment. It appears that women in the urban area, despite some of the challenges they conferred, did access some of these rehabilitation services. The scope and composition of the focus group did not allow for illuminating accessibility to cancer rehabilitation services for rural breast cancer survivors.

³ A Survivorship Care Plan (SCP) is a written, individualized, and comprehensive care summary and follow-up plan that is provided to patients and their primary physicians on completion of their active cancer treatment. The SCP includes a cancer treatment history, any complications experienced, potential long-term and late-effects of treatment, recommended surveillance for long-term, late-effects, recurrence and new cancers, information on general health and wellness for cancer survivors, and a specific timeline for follow-up care. The key goals of a SCP are communication, coordination of care, and patient empowerment. (Ganz, Casillas, & Hahn, 2008)

5.3.3 Financial Challenges Related to Cancer Rehabilitation Services

The financial challenges faced by survivors of breast cancer have been revealed by the focus group participants. The expenses of rehabilitation services, whether it is physiotherapy, massage therapy or lymphedema management, can be prohibitive for many women. Services such as physiotherapy, occupational therapy, and lymphedema management are available through government funded out-patient programs. It was not revealed in the focus group discussion how many women accessed these funded services. All of the participants in the focus group had private health insurance. They revealed that there were strict limits to this coverage and that there was often inadequate reimbursement for cancer rehabilitation interventions.

The participants expressed their frustrations with the high costs of managing their lymphedema. Women with lymphedema may require intensive lymphatic drainage treatment, bandaging supplies and compression garments. This barrier of the high costs of treatments and proper management has been echoed in other studies, specifically related to the cost of compression garments (Carter, 1997; Cheville et al., 2003; P. A. Morgan et al., 2012; Ryan et al., 2003; Shih et al., 2009; Stout, Pfalzer et al., 2012; R. Thomas-MacLean et al., 2005; Towers et al., 2008). The inadequate funding of garments is not unique to the Province of Manitoba and may be related specifically to the Canadian context. The funding of compression garments varies across Canada. Several provinces have government funded health care plans that cover compression garments, while Manitoba and a few other provinces do not (Lymphovenous Canada, 2012). In addition, there is a disparity in the provision of government funded lymphedema services across Canada. Some provincial health plans offer multiple options for lymphedema services,

while other regions have very limited or no services (Lymphovenous Canada, 2012). While service is limited to the breast cancer population, Manitoba is fortunate that lymphedema services are available at the Winnipeg Regional Health Authority Breast Health Centre at no charge. The inequity of government funded lymphedema services and compression garments across Canada is unfortunate, and efforts are needed to improve the access to lymphedema services and the funding of compression garments.

All the women in the focus group subscribed to private health insurance, and therefore had some coverage for compression garments, physiotherapy and massage therapy treatments. They expressed that this funding was quickly exhausted and in order to properly manage their lymphedema they incurred many out-of-pocket expenses. These findings validate those of others who describe that many breast cancer survivors can face thousands of dollars in out-of-pocket expenses (Easley & Miedema, 2012; Miedema & Easley, 2012; Shih et al., 2009).

The financial burden of the needed physical rehabilitation as well as the management of lymphedema are generally unexpected by women after a breast cancer diagnosis (Collins et al., 2004; Hare, 2000; Ryan et al., 2003). Many don't realize that they may need private health insurance to cover some of these additional expenses, and that even with this private health insurance, there are many out-of-pocket expenses. It is unfortunate that some women decide to go without rehabilitation treatment, lymphedema treatment or garments simply because they cannot afford these costly services and supplies. One focus group participant stated "if we don't have coverage for it, we're not going to go". This financial hardship and inability to pay for treatment and garments often leads to further psychological problems (P. A. Morgan et al., 2012). The women in

the focus group discussed the direct costs of cancer rehabilitation; however, they did not talk specifically about the other significant burdens that women who have been treated for breast cancer have reported, such as changes in employability, and impairment and disability related to work tasks and other activities (Cheville et al., 2011; Johansson et al., 2003; Towers et al., 2008; Williams et al., 2005). A further examination of the full financial impact on breast cancer survivors and the cost of disablement of breast cancer in Manitoba is warranted.

5.4 Synthesis of Findings and Cancer Rehabilitation Recommendations

The findings from this study clearly indicate that most women (88%) experience ongoing physical problems for several years after breast cancer treatment. While these physical problems only led to a mild to moderate report of disability, many women reported these problems had a persistent adverse effect on their lives. These women, despite the high prevalence of physical problems, were still able to enjoy a satisfactory quality of life within a few years of their cancer diagnosis. The findings also show that even with the high prevalence of physical problems that are amenable to cancer rehabilitation, less than half of the participants received the needed intervention to address these problems.

It is interesting to note that for one of the physical problems after breast cancer treatment, specifically lymphedema, there was a large discrepancy in the prevalence between the survey and focus group participants. In the focus group, 71.4% (5 out of 7) reported lymphedema, while 20.5% of the survey participants reported lymphedema. The sample of women in the focus group could have been skewed as a result of the recruitment methods. Women with lymphedema and other post-treatment physical

problems may have been inclined to join the focus group thereby resulting in a higher prevalence of lymphedema and other physical problems in the small sample of focus group participants.

A wide variety of available services and supports were identified by the women in the focus group; however, the women also expressed several challenges that can be described as gaps or barriers in the cancer care system related to cancer rehabilitation. These gaps and barriers refer to unmet or poorly met informational needs, a lack of integration and coordination of cancer rehabilitation services, and inadequate funding for cancer rehabilitation services. These gaps and barriers revealed in the current study, while reported for the first time in Manitoba, are not unique to this population and have been described by other authors (Binkley et al., 2012; Cheville et al., 2009; Collins et al., 2004; Easley & Miedema, 2012; Lattanzi et al., 2010).

5.4.1 Physical Rehabilitation Needs

Of those reporting physical problems, 85.6% of the women expressed only mild to moderate activity limitations and participation restrictions with low to moderate physical need. A small percentage (14.4%) had severe or extreme activity limitations and participation restrictions, with higher physical needs. There appears to be a hierarchy of physical needs among this population. One author referred to these physical needs ranging from “incidental to grave”, requiring an incremental level of management (Watson, 1990). A majority of breast cancer survivors experience a few, basic, uncomplicated physical needs that may only require information, education, screening and self-management. A lesser proportion has moderate physical needs that may require targeted sub-acute cancer rehabilitation interventions and follow-up as needed. A third,

even smaller group, has high complicated physical needs that may require intensive cancer rehabilitation interventions, long-term management, and ongoing surveillance. A similar description of the cancer patient's needs and the supporting services has been given by Fitch (2008), who has researched and written extensively on supportive care⁴ needs of cancer patients. She describes that all cancer patients require assessment of their needs, with provision of information, emotional support and symptom management. She further explains that some cancer patients will need additional support, information and professional interventions, and a final few (10 – 15%) require intensive and ongoing complex interventions (Fitch, 2008).

The difficulty related to this hierarchy of needs is determining who has low, moderate and high physical needs after a breast cancer diagnosis. Women after a breast cancer diagnosis do receive information, education and some screening for supportive care needs. However, the women in the focus group reflected that there was no system in place for the identification of the physical rehabilitation needs, no determination of which rehabilitation intervention is needed, and therefore no coordination of or referral to rehabilitation services. The women concluded and were in agreement that routine assessments of their physical needs were needed. The implementation of this type of assessment would assist in determining who has low, moderate, or high physical needs, and thereby contribute to the formulation of the appropriate level of intervention. This routine identification and understanding of the physical needs after a breast cancer diagnosis, as suggested by the focus group participants, facilitates timely referral to

⁴ Supportive care is defined as “the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliative care and bereavement”. (Fitch, 2008)

rehabilitation professionals and the implementation of the appropriate therapeutic intervention (Cheville et al., 2009; Collins et al., 2004; Gray et al., 2000; Lehmann et al., 1978; J. K. Silver, Baima, & Mayer, 2013; Stout et al., 2012).

5.4.2 Prospective Surveillance Model

The women in the focus group recommended the routine and systematic assessment of their physical needs. A model of prospective surveillance has been proposed to systematically address the identification and understanding of the physical needs of breast cancer survivors (Binkley et al., 2012; Campbell et al., 2012). The goals of the Prospective Surveillance Model (PSM) are four-fold and include the following: 1) promotion of surveillance for common physical problems and functional limitations; 2) providing of education to reduce risk or prevent adverse side effects of treatment and facilitate early identification of physical problems and functional limitations; 3) provision of referral for rehabilitation and exercise interventions when physical problems and functional limitations are identified; and, 4) promotion and support of physical activity, exercise and weight management throughout treatment and survivorship (Binkley et al., 2012; Stout et al., 2012). These authors emphasize that the model aims to ensure that physical problems and functional limitations are assessed, identified, and managed proactively throughout the cancer care trajectory for the timely implementation of rehabilitation interventions. Another important component of PSM is the promotion of healthy lifestyle behaviours throughout the treatment and survivorship phases. They also underscore that the PSM is designed to be integrated into multidisciplinary survivorship care for all breast cancer survivors.

Three PSM assessment phases are proposed throughout the cancer management trajectory. The pre-operative assessment phase would serve as a baseline measurement for premorbid level of function, prior physical impairments, current exercise level and other comorbidities. Upper-limb range of motion, limb volume, and strength, as well as body weight, function, fatigue, and level of physical activity could be assessed at this time. It is also an opportunity to provide education regarding post-operative care, including exercises and activity advice, and risk reduction and prevention information for the common side effects of treatment. The second phase would be the early post-operative assessment preferably within one month of surgery. This would repeat the baseline measures, and if any physical problem or functional limitation is identified, a rehabilitation intervention may be initiated. Time could also be taken to reinforce post-operative care and advice regarding exercise and activity. The third phase of surveillance is ongoing and baseline measures are repeated at each follow-up visit. This again allows for early detection of physical problems and functional limitations with timely referral for rehabilitation interventions. There would be continued education and information regarding long-term or late effects of treatment, with repeated emphasis on health promoting behaviours (McNeely et al., 2012; Stout et al., 2012; Stout, Pfalzer et al., 2012).

The PSM would address the first two challenges to cancer rehabilitation identified by the study participants. The women did not identify this specific model; however, they were in agreement that they needed consistent and reliable information and advice. They also expressed that they needed regular assessments of their physical rehabilitation needs, and if any physical problem or limitation was identified, they could then be referred for

the appropriate rehabilitation. The PSM proposes that it allows for improved and consistent communication and information sharing with the breast cancer survivor, and regularly assesses and identifies the physical problems or functional limitations early with proactive interventional measures (Binkley et al., 2012).

While the PSM is endorsed by experts and has significant promise to reduce the gaps that exist in identifying women's physical needs and the early referral to rehabilitation services, there are many possible issues that could arise when considering its implementation. Some of these issues include the following: ability of the health care setting to implement this model, determining who is responsible for the assessments and rehabilitation coordination, determining if this model of surveillance is applicable to every breast cancer patient or just those at high risk, establishing assessment frequency, deciding on the assessment tools, consideration of an additional burden for the individual patient, and the cost of implementation of this model (Cheville et al., 2012; Gamble et al., 2011; L. H. Gerber, Stout, Schmitz, & Stricker, 2012; Schmitz, Stout et al., 2012; Stout et al., 2012; Stout, Andrews, Binkley, Schmitz, & Smith, 2012; Stout, Pfalzer et al., 2012). While there are certainly some reservations about the exact implementation of the PSM, evidence supports that a surveillance plan that is in place from the time of diagnosis with ongoing monitoring of post-treatment morbidities and early intervention to respond to impairments and functional limitations is of significant value and may improve physical outcomes for those diagnosed with breast cancer (Cheville et al., 2009; Devoogdt et al., 2011; Ganz et al., 2008; Gosselink et al., 2003; Kitamura et al., 2005).

A distinct advantage of PSM is the proposed surveillance of *all* women diagnosed with breast cancer. The women in the current study referred to some women being "lost

in the system”. There are those with little education, low income, poor literacy and inadequate social supports that would benefit from this universal and integrated surveillance and coordination of cancer rehabilitation (Dalton et al., 2011; Schmitz et al., 2012). Socioeconomically disadvantaged women after a breast cancer diagnosis may have a difficulty in understanding their diagnosis and treatment and a higher rate of non-compliance with the proposed treatment. It has been shown that the survival rate is better for those with a higher socioeconomic status than those of lower socioeconomic status (Canadian Partnership Against Cancer, 2012). It would be advantageous, then, to give all women the best possible access to information, education, instruction and rehabilitation, using a model such as PSM, in order to attain the greatest possible health outcomes.

5.4.3 Prehabilitation and Ongoing Surveillance

Many researchers have specifically examined the value of pre-operative information, education, and baseline assessments. Lattanzi et al (2010) reported that women had challenges finding information and had post-operative functional impairments, and strongly recommended the implementation of a pre-operative consultation to provide education and advice well in advance of potential impairments (Lattanzi et al., 2010). This phase of surveillance has often been referred to as prehabilitation (J. K. Silver & Baima, 2013; J. K. Silver et al., 2013). As was described in the PSM, this phase is a time when baseline tests and measures can be performed and pre-treatment impairments, function, and comorbidities can be identified. In addition, it is an opportunity to provide valuable information on risk reduction strategies, instruction is self-care, and preventative teaching to lessen or cope with the side effects of treatment. Silver and Baima (2013) propose that prehabilitation not only results in better physical

outcomes, but also improved psychological outcomes such as anxiety, coping skills, and adjustment (J. K. Silver & Baima, 2013). There is growing evidence that supports women experience better health outcomes when adverse treatment effects are identified early and a therapeutic intervention is implemented sooner (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002a; Schmitz et al., 2010; Springer et al., 2010; Stout Gergich et al., 2008; Torres Lacomba et al., 2010).

In the present study, women expressed much frustration and difficulty with the timely diagnosis of lymphedema. The women reported that they did not routinely receive pre-operative assessments or post-operative monitoring for lymphedema. Several authors conclude that preoperative assessments, especially baseline limb volume measurements, could allow for more accurate and early diagnosis of lymphedema (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002a; Schmitz et al., 2010; Stout Gergich et al., 2008; Torres Lacomba et al., 2010). In addition, ongoing surveillance is needed for early identification and referral for management of lymphedema (Stout Gergich et al., 2008). The highest frequency of the onset of lymphedema occurs within the first three years post-surgery, but can occur years later (Petrek et al., 2001), and therefore ongoing monitoring for lymphedema through a model such as the PSM would be efficacious.

5.4.5 Integration and Coordination of Cancer Rehabilitation

The integration and coordination of cancer rehabilitation including pre-treatment and ongoing prospective surveillance for all those diagnosed with breast cancer within the cancer care system could have many potentially positive benefits (Binkley et al., 2012; L. H. Gerber et al., 2012; S. C. Hayes et al., 2012; Karki et al., 2004; Lehmann et al., 1978; Paul & Buschbacher, 2011; Stout et al., 2012). Women could receive clear and

consistent information about the risk reduction strategies, post-operative instruction and the side-effects of treatment and their management, as well as an improved understanding of their new “normal”. Women’s physical rehabilitation needs could be quickly identified, avoiding delayed diagnoses and potentially worsening sequelae, with the prompt implementation of the appropriate therapeutic intervention. Women could have better and more equal access to cancer rehabilitation services, including the servicing of those of lower socioeconomic status. Women could feel confident that they are seeing therapists that are specifically trained in cancer rehabilitation and have the expertise needed for this potentially complex chronic condition. Women would have potentially less anxiety and frustration of searching for answers and services on their own. Women could have better peace of mind knowing that these services are fully covered by government funding and that they can receive the needed rehabilitation service at no great impact to their personal finances. We need to recognize that the provision of timely and effective cancer rehabilitation and lymphedema management tools are likely more economical and could have the potential to keep women in the work force, off disability and out of the hospital, and, in addition, enjoying an enhanced quality of life with minimal functional impairments than in the absence of these integrated and comprehensive rehabilitation services (Binkley et al., 2012; Stout et al., 2012; Stout, Pfalzer et al., 2012).

Despite the identification of the need for integrated and comprehensive cancer rehabilitation programs and the positive benefits of these programs, there is still much work to be done in the areas of cancer rehabilitation research and education. A recent consensus document from the Partners in Cancer Rehabilitation Research (McEwen,

Egan, Chasen, & Fitch, 2013) outlined the priorities for cancer rehabilitation in Canada. They recommend that there should be investigations on the optimal timing of cancer rehabilitation services, cancer rehabilitation in the rural and remote communities, the development of a referral process so individuals receive the appropriate service at the right time, the cost-effectiveness of cancer rehabilitation interventions, and the impact of services on participation outcomes. They also propose that further specific study is needed in multiple disease sites in the areas of cognition, fatigue, nutrition, physical function, sexual function and return to work. They further outlined two educational priorities: the development and dissemination of the description of cancer rehabilitation and its mandate, and the increased awareness among health care professionals and patients of the need for and effectiveness of cancer rehabilitation. These initiatives, it is hoped, will elicit discussion and foster new directions for cancer rehabilitation research, educational priorities and improved health outcomes for cancer survivors.

5.4.6 Meeting the Financial Challenges

The financial challenges related to breast cancer rehabilitation and lymphedema management revealed by the women in this study have an obvious solution: improved recognition and increased government funding for cancer rehabilitation and lymphedema management in Manitoba. This solution, while obvious, is not that simple. There is much work that has to occur for the realization of complete funding and the implementation of an integrated and comprehensive cancer rehabilitation program and lymphedema management in Manitoba. While there is lymphedema management services available for breast cancer survivors at one government funded centre in Manitoba, it is possible that

even more services are needed, and certainly funding for compression garments is essential. It is hoped that a study such as this will be the start of the effort that is needed to help bring forth a transformation of cancer rehabilitation in Manitoba.

Some work is proceeding in the area of lymphedema management. The Canadian Lymphedema Framework published a national strategy and agenda for lymphedema management in 2011 (Hodgson et al., 2011). They identified the lack of funding resources and limited access as being two of the major barriers to lymphedema care and that there is a definite funding and policy inequity across Canada and even within Provinces. They refer to a 3-year strategy that is striving to “raise the profile of lymphedema, develop a national coordinated patient advocacy strategy, gain consensus and adopt best practice guidelines and promote the development of research networks”. It is hoped then, that this will lead to improved funding and access to lymphedema services across Canada.

5.5 Limitations

A number of limitations associated with the findings generated from this study need to be identified. Firstly, the retrospective self-report method used in the study was subject to recall bias. The participants may not have accurately reflected on the months or years since their breast cancer diagnosis, and may have underestimated or overestimated their physical problems, receipt of rehabilitation, or their experiences with cancer rehabilitation. This recall may limit the accuracy of the study findings.

Additionally, there is possible selection bias that occurred with both the survey and focus group participants. The women in this study were invited to participate by letters of invitation or by responding to a study poster. The sample group was self-selected and these women may have been more inclined to participate because of their challenges related to the physical effects of cancer treatment or their experiences, both positive and negative, with cancer rehabilitation, than women who did not have these challenges or experiences. Additionally, the qualitative study findings could have been skewed toward those who were comfortable in talking about their experiences. The women volunteered to participate in the focus group discussions, which indicated their openness and interest in talking about their experiences with others. This sample, therefore, may not be representative of the overall population of breast cancer survivors.

A limitation specifically related to the qualitative aspect of the study was the relatively small sample of seven women. It was proposed that two focus groups of six to eight women each would be conducted. However, the recruitment for these focus groups was low and only a group of seven women participated in the focus group. It is unlikely that the data reached saturation, or that the breadth of themes was exhausted. The seven women were all from the urban area, fairly well-educated and overall homogenous. They were also a well-informed and well-motivated sample. These findings are a representation of a small number of specific breast cancer survivors who agreed to participate in this study, and do not represent those that live in the rural area, or those that are less well-educated. This limits the transferability of the qualitative findings to the breast cancer population as a whole.

A final factor of consideration in this study is the experiential and positional bias of the researcher toward the role of cancer rehabilitation. It is acknowledged that the researcher is a breast cancer survivor, a physiotherapist and a novice researcher. Strategies were implemented to minimize bias, which included reflective journaling during the focus group proceedings and analysis, and involving the expertise of the unbiased, experienced focus group facilitator and committee members during the data analysis stage.

Notwithstanding these limitations, there is much to be learned from this study. A large amount of data was generated from this study and identifies not only the physical problems and rehabilitation needs of women, but also several important challenges that are faced by breast cancer survivors. It is also a unique study to the Province of Manitoba and will potentially foster further research, raise awareness of the long-term impact of breast cancer treatment, and move us closer to creating integrated and coordinated cancer rehabilitation programs for breast cancer survivors.

5.6 Future Directions

It is hoped that the results of this study will provide some valuable insights for all breast cancer stakeholders in Manitoba. It is evident that women experience a high prevalence of physical problems after breast cancer, yet do not receive adequate cancer rehabilitation services. The rationale for this has been proposed and recommendations have been presented. Despite the cancer rehabilitation and lymphedema services that do exist in Manitoba, there continues to be several gaps in the awareness, access, availability, and reimbursement of breast cancer rehabilitation and lymphedema

management. It is hoped that the policy and decision makers would make the integration, coordination and funding of cancer rehabilitation a priority and strive to make changes that would allow for better and more equal access to cancer rehabilitation for breast cancer survivors.

The results of this study raise a variety of questions that warrant further analysis. A large amount of survey data was generated from the quantitative aspect of the study, and it would be worthwhile to conduct secondary analyses to investigate the associations and correlations among several collected variables. This would include the following: 1) the correlation of FACT-B scores with demographic and medical variables, report of physical problems, report of lymphedema, receipt of rehabilitation, and DASH scores; 2) the correlation of DASH scores with the above mentioned variables; 3) age-related correlations; 4) the correlation of demographic and medical variables with the reports of physical problems and receipt of rehabilitation; 5) the correlation of the reported number of lymph nodes removed with the report of lymphedema and treatment for lymphedema; 6) the correlation of place of residence (urban vs. rural) with receipt of rehabilitation; and, 7) the correlation of those with private health insurance and the receipt of rehabilitation. The findings of these secondary analyses would be reported in manuscripts for journal publication.

The quantitative component of this study could be replicated and collect additional variables to provide more robust data with regard to the description of the sample group and additional possible variables for correlations or predictors for statistical analyses. These additional demographic and medical variables could include ethnicity,

marital status, income level, the receipt of hormonal therapy, whether breast reconstructive surgery was performed, and the presence of comorbidities. The capturing of this data could provide a more complete demographic profile and a clearer picture of the sample group and the relationship of these variables.

In order to enhance the understanding of the lived experiences of breast cancer survivors, the qualitative aspect of this study could also be replicated utilizing a larger sample to achieve saturation of data. The conduction of one focus group of seven women did not have sufficient depth of information and redundancy of data that could be afforded by a larger study sample. A greater quantity of interview data could allow for the emergence of additional themes related to breast cancer rehabilitation and provide a better and more complete understanding of the lived experiences of women diagnosed with breast cancer. The sample could also be broadened to include a more diverse group of women, including women from rural Manitoba.

Several questions were raised from the qualitative aspect of this study that would be meaningful to follow-up in future research to further understand this phenomenon and expand the available research evidence. The current study revealed that some women received cancer rehabilitation and others did not; some were unaware of the services available to them, and some were referred and others had to self-refer to rehabilitation. A qualitative inquiry of the awareness and utilization of rehabilitation services could shed light on referral sources and patterns, gaps in the awareness of rehabilitation and the sharing of information.

A second area of needed inquiry is lymphedema management. Much of the discussion in the focus group was around this topic. Many women reported difficulty in being diagnosed and finding information and adequate support for the management of their lymphedema. An in depth qualitative inquiry could expose some of the specific experiences of women with lymphedema after breast cancer treatment, and increase the understanding and awareness of those seeking timely diagnosis and treatment. It could also illuminate why, despite the existing lymphedema management services in Manitoba, information and access was identified as a challenge.

A third area that would be of value to explore is the financial impact and cost of disablement of breast cancer in Manitoba. The women expressed much grief over the personal financial burden after their breast cancer diagnosis. In addition to the personal financial burden is the cost of disablement to society, in terms of loss of productivity, disability claims, mobility and activity of daily living aids, early retirement, hospitalization, and institutionalization (P. A. Morgan et al., 2012; Stout et al., 2012; Stout, Pfalzer et al., 2012). Future studies could focus on the extent of the cost implications to society for breast cancer survivors living with the long-term side effects of breast cancer treatment.

5.7 Knowledge Translation

The dissemination of the findings of this study are planned to further the understanding and awareness of breast cancer physical needs and the role of cancer rehabilitation and lymphedema management. The plans for knowledge translation include the preparation of two manuscripts for submission to peer reviewed journals. In

addition, abstracts of the study findings will be submitted to various conferences, such as the Canadian Physiotherapy Association Congress, the Canadian Lymphedema Conference, the Canadian Association of Psychosocial Oncology, and the International Lymphedema Framework.

Communication of the study findings outside of the academic community is equally important. Presentations of the study findings are planned to health care professionals in rehabilitation, nursing, psychosocial oncology and medical oncology, and in addition to professional associations, special interest groups, patient support groups and other patient advocacy groups.

It is anticipated that dissemination of these study findings will stimulate discussion about the physical needs of breast cancer survivors and the challenges they face regarding cancer rehabilitation. It is further projected that this dialogue will lead to the development of improved cancer rehabilitation services in Manitoba.

6.0 CONCLUSION

This mixed method study provides insight into the physical problems experienced after breast cancer treatment and the lived experiences of women related to cancer rehabilitation. Most women encounter physical needs after breast cancer treatment, yet less than half receive the rehabilitation services to meet those needs. It appears that there is a disconnect between the provision of information and rehabilitation resources and the utilizations of these services. This study provides recommendations to consider for the expansion and implementation of integrated and comprehensive cancer rehabilitation programs inclusive for all those diagnosed with breast cancer. This study has added important insights into the physical recovery and lived experiences of breast cancer survivors in Manitoba. The results of this study can be utilized to provide guidance to policy makers and program managers for the purpose of addressing the gaps and challenges that currently exist in the provision of cancer rehabilitation. This study proposed that the provision of integrated and comprehensive cancer rehabilitation services could better address the physical needs after breast cancer treatment and potentially result in the best possible health outcomes for those diagnosed with breast cancer.

Table 1 Breast Cancer Treatment Short-Term, Long-Term and Late-Effects

Breast Cancer Treatment	Short-Term Effect	Long-Term Effect	Late-Effect
Surgery Lumpectomy Mastectomy SLNB ALND	Infection Hematoma Seroma Swelling Pain Axillary Web Syndrome	Shoulder/Arm Morbidities: - Limited ROM - Weakness - Limited Function Lymphedema Myofascial Dysfunction Sensory Changes Post-Mastectomy Pain Syndrome Body Image Concerns Peripheral Neuropathies	Lymphedema
Chemotherapy	Nausea Vomiting Loss of Appetite Alopecia Peripheral Neuropathy Neutropenia Thrombocytopenia	Fatigue Peripheral Neuropathy Cognitive Problems Sexual Dysfunction Deconditioning Weight Gain Pre-mature Menopause Cardiotoxicity Pulmonary Dysfunction	Cardiotoxicity Pulmonary Dysfunction Pre-Mature Menopause Osteoporosis Associated Comorbidities Second Malignancies
Radiation Treatment	Skin Erythema Desquamation Aplastic Anemia Fatigue	Fatigue Shoulder/Arm Morbidities Lymphedema Myofascial Dysfunction Sensory changes Post-Mastectomy Pain Syndrome Deconditioning Cardiotoxicity Pulmonary Dysfunction	Lymphedema Second Malignancies Cardiotoxicity Pulmonary Dysfunction

SLNB = Sentinel Lymph Node Biopsy, ALND = Axillary Lymph Node Dissection, ROM = Range of Motion

Table 2 *Survey Data Participant Demographic and Medical Characteristics*

Characteristic	Mean (Range)	Percent (number)
Age (years)	60.8 (27 – 83)	
Time Since Diagnosis (months)	21.3 (4 – 45)	
Breast Cancer Stage		
Stage 1		33.3 (158)
Stage 2		29.5 (140)
Stage 3		14.6 (69)
Stage 4		1.9 (9)
Unknown		19.2 (91)
Missing Data		1.5 (7)
Surgery Type		
Lumpectomy		59.9 (284)
Mastectomy		38.0 (180)
Unilateral		77.8 (140)
Bilateral		22.2 (40)
Missing Data		2.1 (10)
Treatment		
Chemotherapy		55.5 (263)
Radiation Therapy		81.2 (385)
Missing Data		0.8 (4)
# of Lymph Nodes Removed	6.9 (0 – 38)	
0 to 5		55.9 (265)
6 to 10		7.8 (37)
11 to 15		4.4 (21)
16 to 20		7.0 (33)

21+		8.0 (38)
Unknown		15.6 (74)
Missing Data		1.3 (6)
Private Health Insurance		
Yes		67.7 (321)
No		30.6 (145)
Missing Data		1.7 (8)
Highest Education Level		
Some High School		16.9 (80)
High School Graduate		31.2 (148)
College/University Graduate		49.0 (232)
Missing Data		3.0 (14)
Current Employment Status		
Currently Working		32.9 (156)
On Leave/Unable to Work		12.9 (61)
Homemaker/Retired		52.7 (250)
Missing Data		1.5 (7)
Place of Residence		
Urban		63.3 (300)
Rural		35.0 (166)
Missing Data		1.7 (8)

Table 3 *Distribution of FACT-B Subscales Variables*

Scale (possible score range)	n	Mean (raw scores)	SD	Range	Rescaled Mean (%)
Physical Well-Being (0-28)	473	22.9	5.0	1-28	81.8
Social Well-Being (0-28)	473	22.8	5.6	1-28	81.4
Emotional Well-Being (0-24)	465	18.8	4.3	2-24	78.3
Functional Well-Being (0-28)	468	21.1	5.5	0-28	75.4
Breast Cancer Subscale (0-36)	467	24.8	6.1	3-36	68.9
Arm Subscale (0-20)	468	16.1	4.4	0-20	80.5
TOTAL FACT-B (0-144)	459	110.3	20.5	38-143	76.6

Table 4 *Focus Group Participant Demographic and Medical Characteristics*

Characteristic	Mean (Range)	Percent (number)
Age (years)	51.7 (41 – 60)	
Time Since Diagnosis (months)	27 (15 – 36)	
Breast Cancer		
Stage 2		86% (6)
Stage 3		14% (1)
Surgery Type		
Lumpectomy		57% (4)
Mastectomy (all bilateral)		43% (3)
Treatment		
Chemotherapy		100% (7)
Radiation Therapy		86% (6)
# of Lymph Nodes Removed	11 (2 – 20), one unknown	
Private Health Insurance		
Yes		100% (7)
Highest Education Level		
High School Graduate		29% (2)
College/University Graduate		71% (5)
Current Employment Status		
Currently Working		43% (3)

On Leave/Unable to Work		14% (1)
Homemaker/Retired		43% (3)
Place of Residence		
Urban		100% (7)
Physical Problems Since Diagnosis		
Lymphedema		71% (5)
Shoulder Weakness		57% (4)
Shoulder Stiffness		57% (4)
Fatigue		71% (5)
Scar Tightness		57% (4)
Numbness or Tingling		57% (4)
Pain in the Area of Surgery		71% (5)
General Weakness		57% (4)
Being Out of Shape		71% (5)
Receipt of Rehabilitation Services		
Physiotherapy		43% (3)
Occupational Therapy		0% (0)
Massage Therapy		71% (5)
Lymphedema Treatment		71% (5)
Physical Activity Program(CCMB)		29% (2)
Physical Activity Program(Comm)		57% (4)

CCMB = CancerCare Manitoba, Comm = Community

TABLE LEGENDS

Table 1. *Breast Cancer Treatment Short-Term, Long-Term and Late-Effects*

This first row of this table describes the possible short-term, long-term and late-effects of breast cancer surgery – lumpectomy, mastectomy, sentinel lymph node biopsy (SLNB), and axillary lymph node dissection (ALND). The second row describes the possible short-term, long-term and late-effects of chemotherapy. The third row describes the possible short-term, long-term and late-effects of radiation therapy.

Table 2. *Survey Data Participant Demographic and Medical Characteristics*

This table shows the demographic and medical characteristics of the survey participants. Means and ranges are shown for the continuous data and percentages and numbers are shown for the categorical data. The percentages and numbers for missing data are also portrayed.

Table 3. *Distribution of FACT-B Subscales Variables*

This table depicts the mean, standard deviation and range of the FACT-B subscale scores and the total FACT-B score. The column on the left shows the scale and the possible range for each item. For easier comparison and to present the subscales using the same metric, the FACT-B subscales were rescaled using a simple linear transformation to have a possible range of 0-100. The PWB, SWB and FWB subscales were multiplied by 100/28, the EWB was multiplied by 100/24, the BCS was multiplied by 100/36, the Arm Subscale was multiplied by 100/20 and the total FACT-B was multiplied by 100/144 (the Arm Subscale is not included in the calculation of the total FACT-B score). To convert

back to the raw scores, a simple reversal of the linear transformation can be applied. The last column on the right represents rescaled scores in percentage for each FACT-B subscale and the total FACT-B score.

Table 4. *Focus Group Participant Demographic and Medical Characteristics*

This table shows the demographic and medical characteristics of the focus group participants. Means and ranges are shown for the continuous data and percentages and numbers are shown for the categorical data. Physical Activity Program (CCMB) refers to physical activity programs through CancerCare Manitoba, and Physical Activity Program (Comm) refers to physical activity programs through the community.

Figure 1 *Physical Problems Reported on Demographic Form*

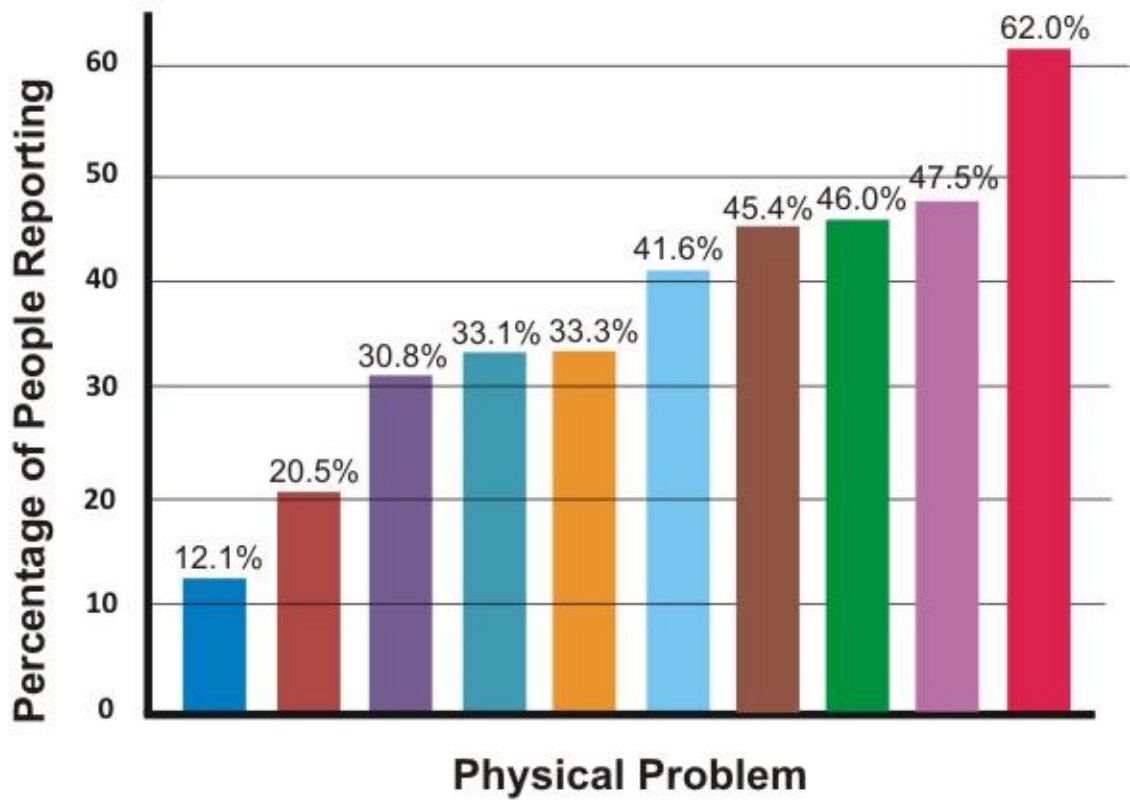
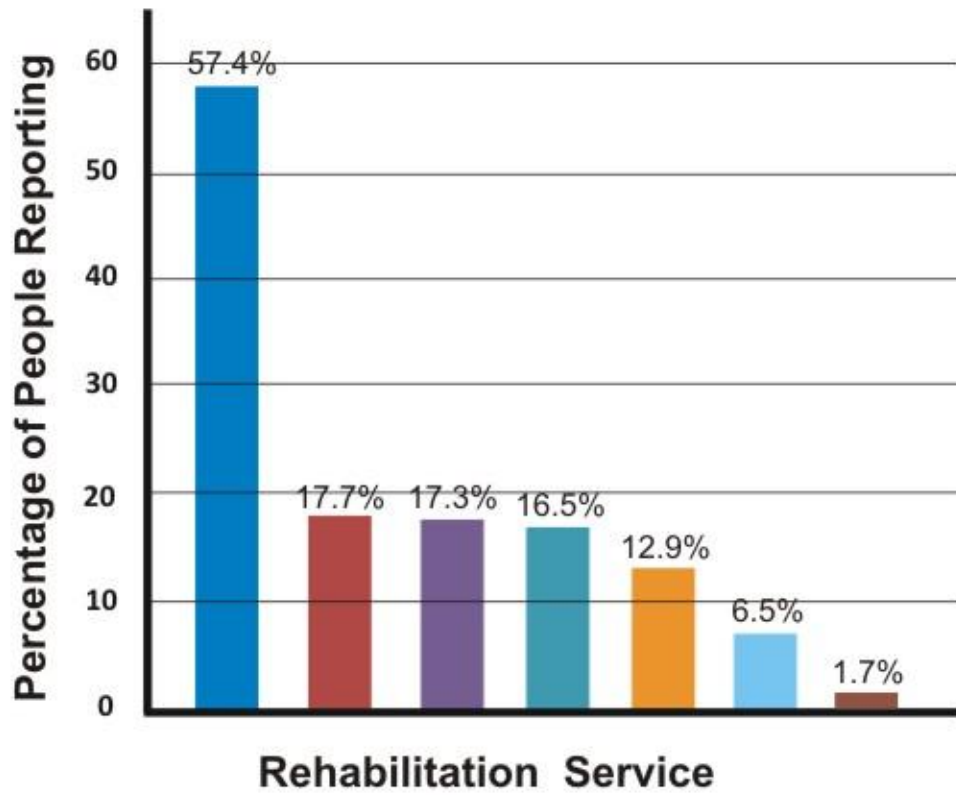
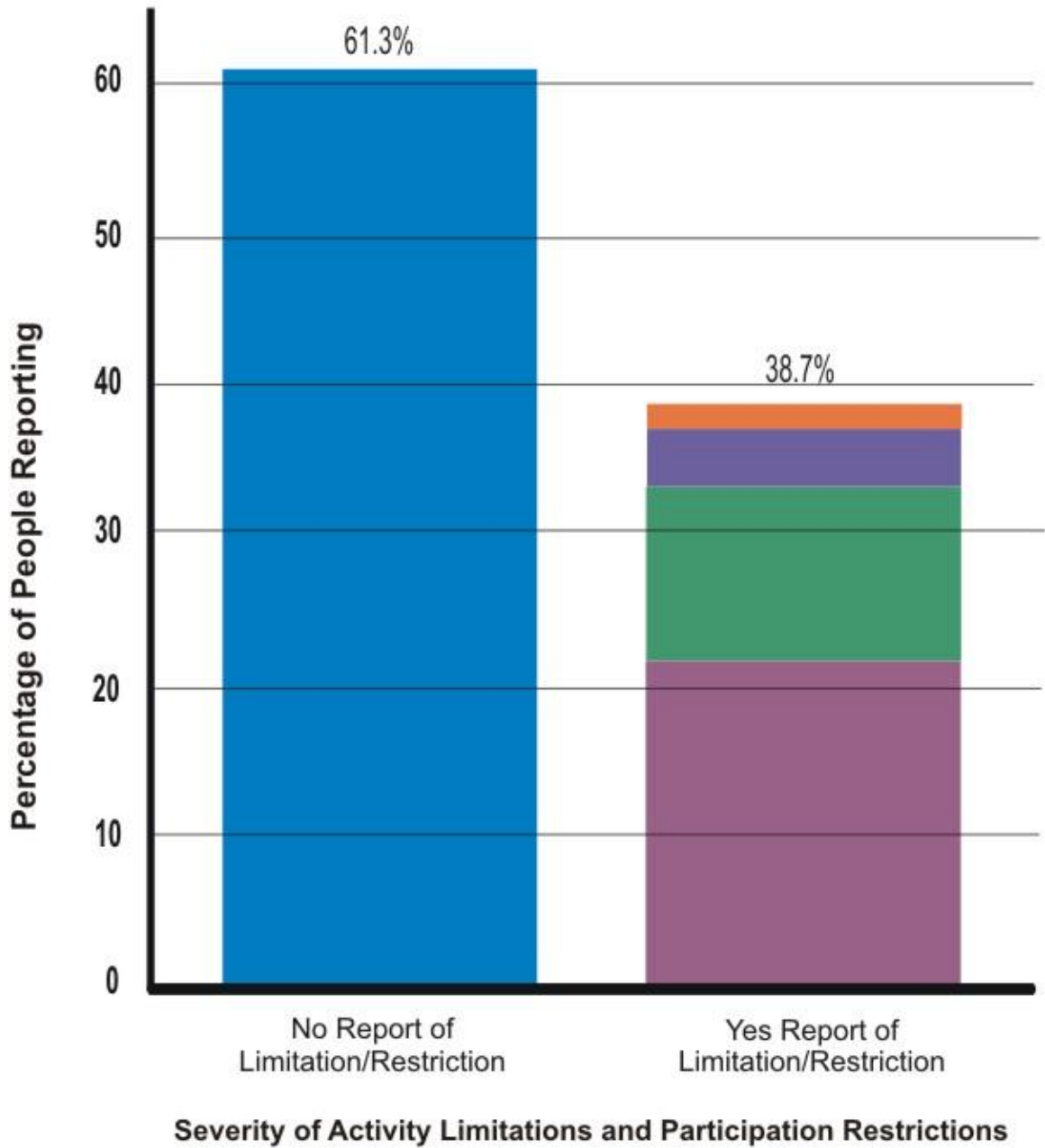


Figure 2 Receipt of Rehabilitation Service Reported on Demographic Form



- None Received
- Massage Therapy
- Physiotherapy
- Physical Activity Program (Community)
- Lymphedema Treatment
- Physical Activity Program (CCMb)
- Occupational Therapy

Figure 3 *Severity of Activity Limitation and Participation Restriction Reported on DASH*



- Mild Severity - 56.3%
- Moderate Severity - 29.3%
- Severe Severity - 10.0%
- Extreme Severity - 4.4%

Figure 4 *Severity of Arm, Shoulder, and Hand Symptoms and Impairments Reported on DASH*

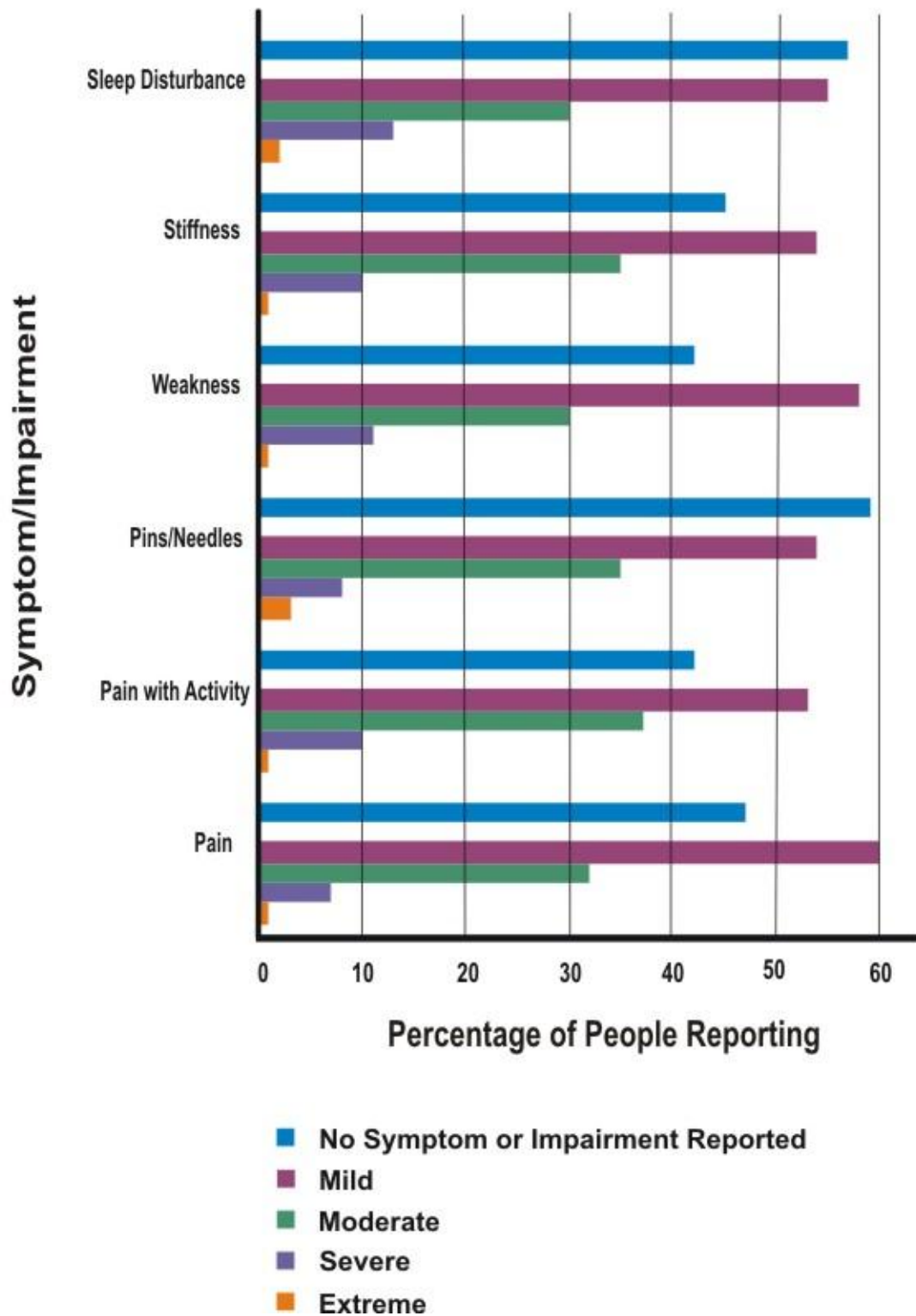


FIGURE LEGENDS

Figure 1. Physical Problems Reported on Demographic Form

This bar graph shows the physical problems reported in the survey data from the patient information form (demographic form). There were 12.1% of the participants that reported no physical problems. Of those that reported a physical problem, the most commonly reported was fatigue at 62.0%, followed by scar tightness (47.5%), pain in the area of surgery (46.0%), numbness or tingling (45.4%), being out of shape (41.6%), general weakness (33.3%), shoulder stiffness (33.1%), shoulder weakness (30.8%), and lymphedema (20.5%). The percentages do not add to 100% due to women reporting more than one physical problem.

Figure 2. Receipt of Rehabilitation Service Reported on Demographic Form

This bar graph shows the receipt of a rehabilitation service as reported on the patient information form (demographic form) from the survey data. There were 57.4% of the participants that reported they did not receive any rehabilitation service. The most commonly reported rehabilitation service was massage therapy at 17.7%, followed by physiotherapy (17.3%), a physical activity program in the community (16.5%), lymphedema treatment (12.9%), a physical activity program within CancerCare Manitoba (6.5%), and occupational therapy (1.7%). The percentages do not add to 100% due to women reporting the receipt of more than one rehabilitation service.

Figure 3. Severity of Activity Limitation and Participation Restrictions Reported on DASH

This graph depicts the severity of activity limitations and participation restrictions of the arm, shoulder and hand reported on the DASH survey (individual DASH items 1 to 23). The first bar on the left in blue represents the 61.3% that did not report any limitations or restrictions; the second bar represents the 38.7% that did report some activity limitation and participation restriction. Depicted within this bar of those reporting an activity limitation or participation restriction is the percentages of those reporting mild to extreme limitation or restriction. The majority reported a mild limitation (56.3%), 29.3% a moderate limitation, 10.0% a severe limitation and 4.4% an extreme limitation.

Figure 4. *Severity of Arm, Shoulder, and Hand Symptoms and Impairments Reported on DASH*

This graph demonstrates the severity of arm, shoulder and hand symptoms and impairments reported on the DASH survey (individual DASH items 24 to 29). The percentage of participants reporting a symptoms or impairment is shown on the x-axis. The y-axis shows the symptom or impairment. The top blue bar for each symptom or impairment represents those that reported no symptom or impairment. For sleep disturbance, 57.0% reported no sleep disturbance and for the remaining 43.0% that responded yes to a sleep disturbance, 55.0% was mild, 30.0% was moderate, 13.0% was severe and 2.0% was extreme. For upper limb stiffness, 45.2% reported no stiffness and for the remaining 54.8% that responded yes to stiffness, 54.1% was mild, 35.3% was moderate, 10.2% was severe, and 0.4% was extreme. For upper limb weakness, 41.7% reported no weakness, and for the remaining 58.3% that responded yes to weakness, 57.9% was mild, 30.3% was moderate, 11.4% was severe, and 0.4% was extreme. For pins and needles, 58.8% reported no pins and needles, and for the remaining 41.2% that

responded yes to pins and needles, 53.9% was mild, 35.6% was moderate, 7.8% was severe, and 2.6% was extreme. For upper limb pain with activity, 41.5% reported no pain with activity, and for the remaining 58.5% that responded yes to pain with activity, 52.9% was mild, 36.4% was moderate, 9.9% was severe, and 0.7% was extreme. For upper limb pain, 46.6% reported no pain, and for the remaining 53.4% that reported pain, 59.9% was mild, 32.0% was moderate, 7.3% was severe, and 0.8% was extreme. The percentages may not add up to 100% due to rounding.

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Appendix A

PARTICIPANT INFORMATION FORM

Study Title: Cancer Rehabilitation and the Physical Effects of Breast Cancer Treatment
Principal Investigator: Karen Dobbin, Physiotherapist, Graduate Student, University of Manitoba

Participant Information - Please complete this short form regarding your personal information:

Date of Birth: _____ **Date of Breast Cancer Diagnosis:** _____
(dd/mm/yyyy) (mm/yyyy)

Stage of breast cancer: Stage 1 Stage 2 Stage 3 Stage 4 Unknown

Treatment Already Completed or Currently In Progress:

Surgery: Lumpectomy: Right Left Both

Mastectomy: Right Left Both

Chemotherapy: Completed: _____ Currently on treatment
(mm/yyyy)

Radiation: Completed: _____ Currently on treatment
(mm/yyyy)

Number of Lymph Nodes removed: _____ Unknown

Do you have additional health insurance? Yes No

(such as Blue Cross, Great West Life, Manulife, Canada Life, Sun Life, Standard Life, Green Shield)

Education Level Completed: Some High School

High School Graduate

College/University Graduate

Occupational Status: Currently working outside of home

On leave/unable to work at this time

Homemaker/Retired

Since your breast cancer diagnosis, have you had any of these physical problems?

(please check all that apply)

Swelling (lymphedema) Shoulder stiffness Numbness or tingling

Shoulder weakness Scar tightness Pain in area of surgery

Fatigue General weakness Being out of shape

Since your breast cancer diagnosis, have you received any of the following rehabilitation services?

(please check all that apply)

Physiotherapy

Treatment for Lymphedema

Occupational Therapy

Physical Activity/Fitness Program (within CancerCare)

Massage Therapy

Community Fitness Program (outside of CancerCare)

Appendix B

FACT-B + 4 (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

<u>PHYSICAL WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

<u>SOCIAL/FAMILY WELL-BEING</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends.....	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness.....	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i>					
GS7	I am satisfied with my sex life	0	1	2	3	4

FACT-B + 4 (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>EMOTIONAL WELL-BEING</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
GE3	I am losing hope in the fight against my illness.....	0	1	2	3	4
GE4	I feel nervous.....	0	1	2	3	4
GE5	I worry about dying.....	0	1	2	3	4
GE6	I worry that my condition will get worse.....	0	1	2	3	4

<u>FUNCTIONAL WELL-BEING</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling.....	0	1	2	3	4
GF3	I am able to enjoy life.....	0	1	2	3	4
GF4	I have accepted my illness.....	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun.....	0	1	2	3	4
GF7	I am content with the quality of my life right now.....	0	1	2	3	4

FACT-B + 4 (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
B1	I have been short of breath	0	1	2	3	4
B2	I am self-conscious about the way I dress.....	0	1	2	3	4
B3	One or both of my arms are swollen or tender	0	1	2	3	4
B4	I feel sexually attractive	0	1	2	3	4
B5	I am bothered by hair loss	0	1	2	3	4
B6	I worry that other members of my family might someday get the same illness I have.....	0	1	2	3	4
B7	I worry about the effect of stress on my illness.....	0	1	2	3	4
B8	I am bothered by a change in weight.....	0	1	2	3	4
B9	I am able to feel like a woman	0	1	2	3	4
P2	I have certain parts of my body where I experience pain....	0	1	2	3	4
Q6	On which side was your breast operation? Left Right (please circle one)					
B10	Movement of my arm on this side is painful.....	0	1	2	3	4
B11	I have a poor range of arm movements on this side.....	0	1	2	3	4
B12	My arm on this side feels numb	0	1	2	3	4
B13	I have stiffness of my arm on this side.....	0	1	2	3	4

DISABILITIES OF THE ARM, SHOULDER AND HAND

THE **DASH**

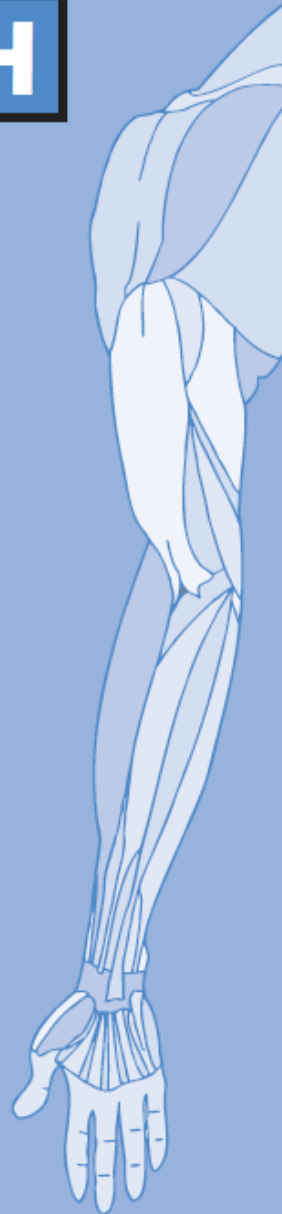
INSTRUCTIONS

This questionnaire asks about your symptoms as well as your ability to perform certain activities.

Please answer *every question*, based on your condition in the last week, by circling the appropriate number.

If you did not have the opportunity to perform an activity in the past week, please make your *best estimate* on which response would be the most accurate.

It doesn't matter which hand or arm you use to perform the activity; please answer based on your ability regardless of how you perform the task.



DISABILITIES OF THE ARM, SHOULDER AND HAND

Please rate your ability to do the following activities in the last week by circling the number below the appropriate response.

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. Open a tight or new jar.	1	2	3	4	5
2. Write.	1	2	3	4	5
3. Turn a key.	1	2	3	4	5
4. Prepare a meal.	1	2	3	4	5
5. Push open a heavy door.	1	2	3	4	5
6. Place an object on a shelf above your head.	1	2	3	4	5
7. Do heavy household chores (e.g., wash walls, wash floors).	1	2	3	4	5
8. Garden or do yard work.	1	2	3	4	5
9. Make a bed.	1	2	3	4	5
10. Carry a shopping bag or briefcase.	1	2	3	4	5
11. Carry a heavy object (over 10 lbs).	1	2	3	4	5
12. Change a lightbulb overhead.	1	2	3	4	5
13. Wash or blow dry your hair.	1	2	3	4	5
14. Wash your back.	1	2	3	4	5
15. Put on a pullover sweater.	1	2	3	4	5
16. Use a knife to cut food.	1	2	3	4	5
17. Recreational activities which require little effort (e.g., cardplaying, knitting, etc.).	1	2	3	4	5
18. Recreational activities in which you take some force or impact through your arm, shoulder or hand (e.g., golf, hammering, tennis, etc.).	1	2	3	4	5
19. Recreational activities in which you move your arm freely (e.g., playing frisbee, badminton, etc.).	1	2	3	4	5
20. Manage transportation needs (getting from one place to another).	1	2	3	4	5
21. Sexual activities.	1	2	3	4	5

DISABILITIES OF THE ARM, SHOULDER AND HAND

	NOT AT ALL	SLIGHTLY	MODERATELY	QUITE A BIT	EXTREMELY
22. During the past week, to what extent has your arm, shoulder or hand problem interfered with your normal social activities with family, friends, neighbours or groups? (circle number)	1	2	3	4	5

	NOT LIMITED AT ALL	SLIGHTLY LIMITED	MODERATELY LIMITED	VERY LIMITED	UNABLE
23. During the past week, were you limited in your work or other regular daily activities as a result of your arm, shoulder or hand problem? (circle number)	1	2	3	4	5

Please rate the severity of the following symptoms in the last week. (circle number)

	NONE	MILD	MODERATE	SEVERE	EXTREME
24. Arm, shoulder or hand pain.	1	2	3	4	5
25. Arm, shoulder or hand pain when you performed any specific activity.	1	2	3	4	5
26. Tingling (pins and needles) in your arm, shoulder or hand.	1	2	3	4	5
27. Weakness in your arm, shoulder or hand.	1	2	3	4	5
28. Stiffness in your arm, shoulder or hand.	1	2	3	4	5

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	SO MUCH DIFFICULTY THAT I CAN'T SLEEP
29. During the past week, how much difficulty have you had sleeping because of the pain in your arm, shoulder or hand? (circle number)	1	2	3	4	5

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
30. I feel less capable, less confident or less useful because of my arm, shoulder or hand problem. (circle number)	1	2	3	4	5

Scoring DASH function/symptoms: Add up circled responses (Items 1-30); subtract 30; divide by 1.20 = DASH score. If there are responses missing, see detailed instructions.

Appendix D

Focus Group Interview Guide

(version date 09/Jan/2013)

Purpose and Objective of Focus Group

- ◆ To determine the awareness and role of cancer rehabilitation services as viewed by women diagnosed with breast cancer.
- ◆ To explore the viewpoint of women diagnosed with breast cancer and their experiences with cancer rehabilitation services.
- ◆ To identify the shortcomings of existing cancer rehabilitation services and the barriers related to cancer rehabilitation faced by women diagnosed with breast cancer.
- ◆ To ascertain the recommendations for future provision of cancer rehabilitation services for women diagnosed with breast cancer.

1) Participants to complete demographic data and consent forms (6:30 -6:45)

2) Welcome, Introductions, Purpose, Context, Confidentiality (6:45-6:55)

3) Awareness and Role of Cancer Rehabilitation (6:55 - 7:25)

a) Can you tell us about what cancer rehabilitation services are available in Manitoba for women diagnosed with breast cancer? Please list and describe these services. (6:55 – 7:01)

b) What do you think each of these services can contribute to your physical recovery after breast cancer? (7:01 – 7:11)

c) Were any of these services something you had a need for either during or after your breast cancer treatment? (*in the current study exploring the physical effects during or after breast cancer treatment, 115 survey results have produced preliminary findings indicating that up to 65%*)

have had problems such as lymphedema- 23%, shoulder weakness- 33%, shoulder stiffness – 36%, general weakness – 37%, felling out of shape – 41%, numbness and tingling – 51%, scar tightness – 54%, pain in area of surgery – 55%, and fatigue – 65% during or after cancer treatment, whereas only 37% have indicated they have received any kind of treatment – PT, PT, MT, lymphedema treatment for physical problems, and only 17% have received physical exercise programs/instruction) (7:11 – 7:21)

d) What physical cancer rehabilitation services do you feel should be essential to your recovery from breast cancer treatments? (7:21 – 7:25)

4) Referral, Access and Barriers to Cancer Rehabilitation Services (7:25 – 7:55)

a) To what extent have you been offered and used cancer rehabilitation services during or after your breast cancer treatment? *(previous studies have indicated over half of the participants have not received any information regarding rehabilitation services after breast cancer treatment – Miedema, 2011) (barriers of lack of awareness by cancer care professionals, lack of identification of the need for cancer rehabilitation) (7:25 – 7:35)*

b) If you were offered cancer rehabilitation for a physical problem after breast cancer treatment, please describe your experience with cancer rehabilitation. *(barriers of inaccessibility, in affordability, lack of knowledge or availability of services, lack of timely access) (7:35 – 7:45)*

c) Please describe some of the barriers to being referred and accessing physical cancer rehabilitation after breast cancer treatment? *(barriers of inaccessibility, in affordability, lack of knowledge or availability of services, lack of timely access, lack of knowledge of cancer care professionals) (7:45 – 7:55)*

- 5) Recommendations for Cancer Rehabilitation in Manitoba (7:55 – 8:20)
- a) What do you think can be done to improve cancer rehabilitation services in Manitoba? (7:55 – 8:10)
 - b) If there were put in place regular physical assessments for breast cancer patients at various times during and after cancer treatment, for example before and after surgery, before and after chemotherapy and radiation treatment, or after completion of all breast cancer treatment, would this be helpful to you? What are your thoughts on this? (8:10 – 8:15)
 - c) Knowing what you know now about going through breast cancer treatment and some of the physical effects, what would you advise others newly diagnosed with breast cancer? (8:15 – 8:20)

6) Focus Group Summary (8:20 – 8:25)

Given what we have discussed about cancer rehabilitation, what does the term cancer rehabilitation mean to you? How would you define cancer rehabilitation? (Recognized definition: *processes intended to enable people to attain and maintain the optimal physical, functional, psychological, social, vocational and mental health within the limits imposed by the disease and its treatment, the aim of cancer rehabilitation is to help a person achieve the highest level of function, independence and quality of life possible*)(8:20 – 8:25)

- 7) Closing of Focus Group: thank you, avenue for further input and access for focus group results, explanation of how the data will be used (8:25 – 8:30)

Appendix E



CancerCare
MANITOBA
Action Cancer Manitoba

○ 675 McDermot Avenue
Winnipeg, Manitoba
Canada R3B 0V9

○ 409 Taché Avenue
Winnipeg, Manitoba
Canada R2H 2A6

www.cancercare.mb.ca

July 23, 2012

Karen Dobbins
Graduate Student – School of Medical Rehabilitation
R106-771 McDermot Avenue
Winnipeg, MB

COPY

Re: RRIC #37-2012: Identification of physical effects and the role, availability and accessibility of Breast cancer Rehabilitation

The above-named study has been approved by the CancerCare Manitoba (CCMB) Research Resource Impact Committee (RRIC) pending receipt of a copy of the REB approval letter for the most recent version of the study. Please send a copy of the REB approval letter to the RRIC coordinator (Jennifer Cabral) as soon as it is available.

The following departments or persons at CCMB have signed off on this study: Cancer Registry, Epidemiology, Patient & Family Support Services and Dr. Pitz

According to the CCMB RRIC submission form that you completed, no CCMB paper charts will be required for this study and expected study duration is 10 months.

A copy of the signed CCMB PHIA form for research is appended to this letter.

ANY SIGNIFICANT CHANGES TO THIS RESEARCH PROJECT MUST BE REPORTED TO THE RRIC BY SUBMITTING A "REQUEST FOR AMENDMENT FORM" FOR CONSIDERATION IN ADVANCE OF IMPLEMENTATION OF SUCH CHANGES. Significant changes include (but are not limited to): a change in the study design or in the data to be collected; a change in the study duration, the patient cohort to be studied, or the number of participants to be studied; the need to review CCMB paper charts (when not originally planned) or the need to review significantly more CCMB paper charts than originally planned; the addition of other trainees or co-investigators to the project; or the inclusion of additional individuals who will have access to the data or database.

Please cite the RRIC number for this study in all future correspondence with the RRIC about it. Please note that annual approval is not required if there are no changes to the project (as outlined above).

This approval is for RRIC use only. For ethics of human use and/or regulatory bodies, approval should be sought from the relevant parties as required.

Yours sincerely,


Rochelle Yanofsky, MD FRCPC
Chair, CCMB Research Resource Impact Committee

Enclosure: Signed CCMB PHIA Form for Research (to Karen Dobbins and Cheryl Clague only)

cc: Cheryl Clague – Epidemiology/Cancer Registry
Jill Taylor-Brown – Patient & Family Support Services
Dr. Marshall Pitz – Medical Oncologist
File copy

Appendix F



P126 - 770 Bannatyne Avenue
Winnipeg, Manitoba
Canada R3E 0W3
Tel: (204) 789-3255
Fax: (204) 789-3414

Principal Investigator: Ms. K. Dobbin
Supervisor: Dr. B. Shay

Ethics Reference Number: H2012:225
Date of REB Meeting: June 25, 2012
Date of Approval: July 12, 2012
Date of Expiry: June 25, 2013

Protocol Title: Identification of the physical effects and the role, availability and accessibility of Breast Cancer Rehabilitation

The following is/are approved for use:

- Protocol, Version dated July 12, 2012
- Research Participant Information and Consent Form, Version dated July 12, 2012
- Advertisement, Version dated July 12, 2012
- Letter of Invitation Focus Groups, Version dated July 12, 2012
- Focus Group Questions submitted June 11, 2012
- Letter to Potential Participants submitted June 11, 2012
- Letter of Invitation Survey, Version dated June 11, 2012
- Recruitment Cover Letter (from Manitoba Cancer Registry), Version dated June 11, 2012
- Participant Information Form, Version dated June 11, 2012
- Disabilities of the Arm, Shoulder and Hand (DASH) submitted June 11, 2012
- FACT-B + 4, Version 4 dated 16 November 2007

The above was approved by Dr. John Arnett, Ph.D., C. Psych., Chair, Health Research Ethics Board, Bannatyne Campus, University of Manitoba on behalf of the committee per your letter dated July 11, 2012. The Research Ethics Board is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement, and the applicable laws and regulations of Manitoba. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the *Food and Drug Regulations of Canada*.

This approval is valid for one year from the date of the REB meeting at which the study was reviewed. A study status report must be submitted annually and must accompany your request for re-approval. Any significant changes of the protocol and informed consent form should be reported to the Chair for consideration in advance of implementation of such changes. The REB must be notified regarding discontinuation or study closure.

This approval is for the ethics of human use only. For the logistics of performing the study, approval must be sought from the relevant institution, if required.

Sincerely yours,



John Arnett, Ph.D., C. Psych.
Chair, Health Research Ethics Board
Bannatyne Campus

Please quote the above Ethics Reference Number on all correspondence.
Inquiries should be directed to the REB Secretary Telephone: (204) 789-3255 / Fax: (204) 789-3414

Appendix G

Recruitment Cover Letter (on Manitoba Cancer Registry letterhead)

September 12, 2012

Identification of Physical Effects and the Role, Availability and Accessibility of Breast Cancer Rehabilitation

CancerCare Manitoba is pleased to mail this survey to you on behalf of the research team: Karen Dobbin and Dr. Barbara Shay from the School of Medical Rehabilitation at the University of Manitoba and Dr. Marshall Pitz and Jill Taylor-Brown from CancerCare Manitoba. The purpose of this study is to explore the physical effects of breast cancer treatment in women in Manitoba and to gather information of their experiences with cancer rehabilitation.

We are inviting you to participate in this study by the completion of two questionnaires and a participant information form, which will take approximately 30 minutes to complete. These questionnaires ask about your quality of life and well-being and also the physical problems you have experienced during or after treatment of breast cancer.

No information from the questionnaires will be shared with your health care providers and your care will not be altered in any way. In addition, no identifying information is collected with the survey and your responses are anonymous and confidential. This package has been mailed to you directly from the Manitoba Cancer Registry in order to protect the confidentiality of your information. The research team will not know who has been invited to participate in the study, nor will the Manitoba Cancer Registry know who has agreed or not agreed to participate in the study.

Your input is important; however, **participation in this study is strictly voluntary.**

This study has been approved by the Health Research Ethics Board at the University of Manitoba and the Research Resource Impact Committee at CancerCare Manitoba.

If this survey has reached you in error, please accept our apology. If you would like to have your name removed from the contact list for this and other similar studies, please contact Cheryl in the Cancer Registry toll free at 1-877-787-1272.

Sincerely Yours,

Jane Griffith, PhD
Lead Epidemiologist/Manager
Epidemiology and Cancer Registry

Gail Noonan, CTR
Manager
Manitoba Cancer Registry

Appendix H

Letter of Invitation Survey (from K. Dobbin)

September 24, 2012

Identification of Physical Effects and the Role, Availability and Accessibility of Breast Cancer Rehabilitation

My name is Karen Dobbin and I am a physiotherapist and a breast cancer survivor. This survey I am conducting is part of a research study for the requirements of my Masters of Science in Rehabilitation degree. The purpose of this study is to explore the physical effects of breast cancer treatment in women in Manitoba and to gather information of their experiences with cancer rehabilitation. This study has been approved by the Health Research Ethics Board at the University of Manitoba and the Research Resource Impact Committee at CancerCare Manitoba.

Enclosed are two questionnaires and a participant information form, which will take approximately 30 minutes to complete. These questionnaires ask about your quality of life and well-being and also the physical problems you have experienced during or after treatment of breast cancer.

Your responses are anonymous and confidential. Only I, and my research committee members, Dr. Barbara Shay of the University of Manitoba and Dr. Marshall Pitz and Jill Taylor-Brown of CancerCare Manitoba will have access to the questionnaires.

While there are no serious risks or physical dangers involved in this research study, you may feel some psychological distress related to the identification of physical problems after cancer treatment. This may be new and distressing information for you. If you experience any distress and would like some help in dealing with this, we ask that you contact Patient and Family Support Services at CancerCare Manitoba (phone number: 204-787-2109) for referral for psychosocial support. If you have a need for treatment for a physical problem that would require rehabilitation we ask that you to contact your primary physician or oncologist for a referral to an appropriate rehabilitation service.

There may or may not be direct benefit to you from participating in this study. Your participation in this study may help us to understand the physical needs of breast cancer survivors and the role of rehabilitation in an effort to improve cancer rehabilitation services for breast cancer survivors in Manitoba.

If you choose to participate, I ask that you please complete the enclosed questionnaires and return them in the postage paid envelope as soon as possible. Your willingness to complete these questionnaires and return it to me will indicate that you are consenting to participate and allowing your responses to the questionnaires to be included in this study.

Thank you for your time and help. It is hoped that your completion of these questionnaires will provide improved cancer rehabilitation services to women in Manitoba. If you are interested in speaking with me or have any questions about the study, please contact me at 204-XXX-XXXX. You may leave a message on my confidential voice mail if I am unable to answer. You may also contact me by e-mail at XXXXXXXXXXXXXXXX

Sincerely,

Karen Dobbin, BMRPT, MSc Graduate Student,
School of Medical Rehabilitation, Faculty of Medicine, University of Manitoba

Appendix I

The Physical Effects of Breast Cancer Treatment

Have you been diagnosed
with breast cancer in
the past three years?



You are invited to take part in a study exploring the physical problems after breast cancer treatment (surgery/ chemotherapy/radiation) and your experience with cancer rehabilitation.



Please contact me for further information:

Name: Karen Dobbin, physiotherapist and breast cancer survivor
Study Title: Cancer Rehabilitation and the Physical Effects of Breast Cancer Treatment
Phone: 204-XXX-XXXX
E-mail: xxxxxxxxxxxxxxxxxxxxxxxx

This study has been approved by the Health Research Ethics Board at the University of Manitoba and the Research Resource Impact Committee at CancerCare Manitoba.

Physical Effects Breast Cancer Treatment Karen Dobbin 204-xxx-xxxx xxxxxxxxxxxxxxxxxxxxxxxxxx	Physical Effects Breast Cancer Treatment Karen Dobbin 204-xxx-xxxx xxxxxxxxxxxxxxxxxxxxxxxxxx	Physical Effects Breast Cancer Treatment Karen Dobbin 204-xxx-xxxx xxxxxxxxxxxxxxxxxxxxxxxxxx	Physical Effects Breast Cancer Treatment Karen Dobbin 204-xxx-xxxx xxxxxxxxxxxxxxxxxxxxxxxxxx	Physical Effects Breast Cancer Treatment Karen Dobbin 204-xxx-xxxx xxxxxxxxxxxxxxxxxxxxxxxxxx	Physical Effects Breast Cancer Treatment Karen Dobbin 204-xxx-xxxx xxxxxxxxxxxxxxxxxxxxxxxxxx	Physical Effects Breast Cancer Treatment Karen Dobbin 204-xxx-xxxx xxxxxxxxxxxxxxxxxxxxxxxxxx	Physical Effects Breast Cancer Treatment Karen Dobbin 204-xxx-xxxx xxxxxxxxxxxxxxxxxxxxxxxxxx
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Appendix J

Letter of Invitation Focus Groups (from K. Dobbin)

September, 2012

Identification of Physical Effects and the Role, Availability and Accessibility of Breast Cancer Rehabilitation

My name is Karen Dobbin and I am a physiotherapist and a breast cancer survivor. I am conducting a study on women who have experienced a diagnosis of breast cancer who are currently receiving or have completed cancer treatment. This research study is part of the requirements of my Masters of Science in Rehabilitation degree. The purpose of this study is to explore the physical effects of breast cancer treatment in women in Manitoba and to gather information of their experiences with cancer rehabilitation.

If you decide to participate, the study will involve taking part in a focus group discussion. A focus group is a type of a group interview with 6 to 8 participants. In the focus group we will ask questions related to the physical problems you may have experienced after cancer treatment, your need for rehabilitation, your experience with rehabilitation services and your awareness of rehabilitation services. The focus group will last from 1 to 2 hours and will be audio-recorded so I can accurately review what is discussed. A date, time and place for the focus groups will be arranged with all those participating.

No information from the focus groups will be shared with your health care providers and your care will not be altered in any way. Only I, and my research committee members, Dr. Barbara Shay of the University of Manitoba and Dr. Marshall Pitz and Jill Taylor-Brown of CancerCare Manitoba will have access to the focus group recordings and transcription.

Your input is important; however, **participation in this study is strictly voluntary.**

This study has been approved by the Health Research Ethics Board at the University of Manitoba and the Research Resource Impact Committee at CancerCare Manitoba.

If you are interested in speaking with me about the possibility of participating in this study or if you have any questions about the study, please contact me at 204-XXX-XXXX. You may leave a message on my confidential voice mail if I am unable to answer. You may also contact me by email at XXXXXXXXXXXXXXXXXXXX.

Sincerely yours,

Karen Dobbin, BMRPT, MSc Graduate Student,
School of Medical Rehabilitation, Faculty of Medicine, University of Manitoba

Appendix K

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: Identification of physical effects and the role, availability and accessibility of Breast Cancer Rehabilitation.

Principal Investigator: Karen Dobbin, R106-771 McDermot Ave., Winnipeg, MB R3E 0T6
Co-Investigator: Dr. Barbara Shay, University of Manitoba, R106-771 McDermot Ave., Winnipeg, MB R3E 0T6

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research study is being conducted to explore the physical rehabilitation needs of breast cancer survivors in Manitoba, to gain new insights into their understanding and awareness of the role of cancer rehabilitation, and to determine the availability and accessibility of cancer rehabilitation services for breast cancer survivors. While the physical effects of cancer treatment are quite prevalent amongst breast cancer survivors, there is little provision for adequate and accessible rehabilitation services. The objective of this study is to identify the gaps that exist in the identification of the physical rehabilitation needs and the adequate provision of cancer rehabilitation.

Interviews will take place in the form of focus groups and 6 to 8 women are needed for each focus group.

Study procedures

The study is based on the following procedures:

You have responded to either a poster or letter of invitation to take part in this study, and have indicated your interest in being a part of a focus group. This consent form provides you with the information you need to consent to do this. If, after reviewing this consent form, you have questions about the study, you are asked to talk to the principal investigator (Karen Dobbin).

A focus group is a type of a group interview with 6 to 8 participants. In the focus group we will ask questions related to the physical problems you may have experienced after cancer treatment, your need for rehabilitation, your experience with rehabilitation services and your awareness of rehabilitation services. The focus group will be 1 to 2 hours in length and will be audio-recorded.

Identification of Physical Effects and the Role, Availability and Accessibility of Breast Cancer Rehabilitation.

Participation in the study is a one-time only event. However, you will be contacted after the initial analysis of the focus group discussions so the principal investigator can share these findings to ensure her analysis accurately reflects the experiences and perspectives of breast cancer survivors.

If, after you have participated in the focus group and you want your information withdrawn from the study, you can make this request at any time. However, if you decide to withdraw from the study, we encourage you to talk to the principal investigator first.

A copy of the summary of this research study will be made available to you upon completion of this study if you so desire.

Risks and Discomforts

While there are no serious risks or physical dangers involved in this research study, you may feel some psychological distress related to the identification of physical problems after cancer treatment. The identification of physical problems related to cancer treatment may be new and distressing information for you. You may not realize that the physical limitations, pain or other symptoms you have experienced possibly occurred as a result of your cancer treatment and that these problems could be successfully treated or managed by rehabilitation services. If you experience any distress and would like some help in dealing with this, we ask that you contact Patient and Family Support Services at CancerCare Manitoba (phone number: 204-787-2109) for referral for psychosocial support. If you have a need for treatment for a physical problem that would require rehabilitation we ask that you contact your primary physician or oncologist for a referral to an appropriate rehabilitation service.

Benefits

There may or may not be direct benefit to you from participating in this study. Your participation in this study may help us to understand the physical needs of breast cancer survivors and the role of rehabilitation in an effort to improve cancer rehabilitation services for breast cancer survivors in Manitoba.

Costs

All the procedures, which will be performed as part of this study, are provided at no cost to you; however, there may be some cost for parking while in the 2-hour focus group session.

Payment for participation

You will receive no payment or reimbursement for any expenses related to taking part in this study.

Alternatives

You do not have to participate in this study to receive treatment for your cancer rehabilitation needs. Please talk to your cancer care professional or family physician about all your treatment options.

Confidentiality

Information gathered in this research study may be published or presented in public forums; however your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

Only the researchers will have access to the audio-recording of the focus groups. All participants in the focus groups will be reminded that everything they say in the focus group is to be held in confidence and not to be repeated out of the focus group.

The audio-recording of the focus group discussion will be transcribed and the recording, consent forms and all documentation will be kept secure in a locked cabinet or in an encrypted computer file for a period of 7 years. The audio-recording will be physically destroyed, computer files will be permanently deleted and all study documents will be shredded after 7 years. Only those persons identified will have access to these records. No documents will leave the University of Manitoba.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care. If the study staff feels that it is in your best interest to withdraw you from the study, they will remove you without your consent. We will tell you about any new information that may affect your health, welfare or willingness to stay in this study.

Medical Care for Injury Related to the Study

You are not waiving any of your legal rights by signing this consent form or releasing the investigators from their legal and professional responsibilities.

Questions

You are free to ask any questions that you may have about the study and your rights as a research participant. If any questions arise during or after the study contact the principal investigator and physiotherapist: Karen Dobbin at (204) XXX-XXXX or the co-investigator, Dr. Barbara Shay at (204) XXX-XXXX.

Identification of Physical Effects and the Role, Availability and Accessibility of Breast Cancer Rehabilitation.

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Karen Dobbin or her study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I can keep a copy of this consent form. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes. By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Participant Signature _____ Date: _____
(day/month/year)

Participant Printed Name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given her consent.

Researcher Signature: _____ Date: _____
(day/month/year)

Printed Name: _____

Role in the study: _____

_____ I wish to receive a summary copy of the research results upon completion of this study. Please send this summary to me at this mailing address:

or my e-mail address: _____

Appendix L

Focus Group Summary of Findings

You participated in a research study that explored the physical effects after breast cancer treatment and experiences with cancer rehabilitation. You were one of seven women that attended a focus group on January 9, 2013. The focus group was audio-recorded and was later transcribed word for word. The following is a summary of the focus group findings with the comments of the participants organized into themes. There is no reference to specific individuals.

Throughout the focus group discussion took place around cancer rehabilitation for the physical effects of cancer treatment. It was observed that the women had a difficult time separating the physical aspect of cancer recovery from the emotional and mental components. The discussion had to be repeatedly brought back to the physical effects of cancer treatment. They shared that a cancer diagnosis affected all aspects of their lives and it was obviously difficult for them to separate just the physical side. They referred to a cancer diagnosis being “life-changing” for all areas of their lives and that these areas were all interconnected.

With this encompassing holistic point of view of cancer rehabilitation, the participants were asked to list all the cancer rehabilitation services that they were aware of or that they utilized after their breast cancer diagnosis. Multiple physical activity programs (Healthy Eating Active Living, Eat Well Get Fit Program, restorative yoga, swimming, Pilates, Running Room, Dragon boat team), psychosocial programs and supports (psychosocial counseling, brain fog sessions, mindfulness sessions, Moving Forward, Look Good Feel Better, art therapy), and information support and resources (lending library, Breast Centre of Hope, booklets/information sheets, workshops, support groups, Guardian Angel Caring Room, The Navigator newsletter, dietary support, peer support program) were shared. The only two treatment services that were revealed were lymphedema treatment and physiotherapy.

After reviewing all these services, the participants felt that there were many rehabilitation services and resources available to breast cancer survivors compared to other types of cancer. Additionally, they expressed that, overall, CancerCare was presenting a unified message when supporting those diagnosed with breast cancer. They felt that the message they received during and after cancer treatment was one that instilled confidence in their care team.

Women had a lot of praise for the breast cancer resource centre, both the professional staff and the printed resources. They conveyed they found the centre “very helpful during the different pivotal points and changes in therapies.” The professional staff was readily available to share and discuss the breast cancer support programs.

Despite the identification of the available services and support and some of the positive experiences, an overarching theme emerged from the data on the systemic barriers to cancer rehabilitation. Systemic barriers refer to characteristics related to the structure of the health care system and include information and support, and availability, accessibility, and affordability of rehabilitative services. While the women felt that they did receive information, support, and some rehabilitation services, they also felt that there were many challenges within the system that posed as barriers to them receiving adequate or timely cancer rehabilitation. The systemic barriers were separated into three categories: 1) Difficulty in finding reliable and consistent information (knowing where to find answers); 2) Lack of coordination of rehabilitation services; and 3) Financial challenges related to cancer rehabilitation services.

Difficulty in Finding Clear and Consistent Information

All of the women interviewed in the focus group reported at least one physical concern after breast cancer treatment. Lymphedema, fatigue, pain in the area of surgery and being out of shape was reported by 5 of the participants, and 4 reported shoulder weakness or stiffness, scar tightness, numbness and tingling, and general muscle weakness. These physical issues raise a lot of concerns and can create new or on-going questions about managing these problems, not only during their primary treatment, but also for several years after completion of their treatment. Many women were not sure where to go when they had questions and expressed frustration and even confusion.

They also reported receiving conflicting information about how to deal with some of these issues such as exercising post-operatively, or how to care for their surgical arm. Some women were told one thing by their surgeon and later received different advice from the nurse. They expressed that this conflicting information was not helpful in their recovery.

Additionally, the women conveyed that they had the need for reliable information from knowledgeable sources. They felt that there should be an experienced and trained person they could go to with questions that could give them reassurance and guidance regarding their physical concerns.

Although they didn't use the exact word 'navigator', some women referred to a mentor, or guide to help them through the cancer care system. One woman referred to a

“lifeline to tie into”. They felt that this would certainly be a big help to them when they had questions about treatment, side-effects of treatment, and any on-going concerns.

The Need for Integration of Cancer Rehabilitation Services

The frustration and confusion in trying to find answers to questions about the physical effects they were experiencing, led most women to conclude that there was a gap in the cancer care system concerning the coordination of rehabilitation after a breast cancer diagnosis. Most women expressed that their surgeons, medical oncologists, and radiation oncologists did excellent jobs during their treatment phase. However, even during their treatments and certainly after their treatments, they felt that there was no one in charge of directing their rehabilitation, whether it was for lymphedema care, physiotherapy or physical activity programs. They expressed that there should be knowledgeable professionals that are responsible for overseeing rehabilitation care, and that some system should be in place to coordinate rehabilitation services.

Despite the prevalence of some of the physical effects the participants experienced after cancer treatment, some did not receive any kind of cancer rehabilitation service. 100% of the participants reported at least one physical effect after cancer treatment, yet only 43% received a rehabilitation service such as physiotherapy. One woman reported being unaware of any rehabilitation services. There were others who wanted a rehabilitation service, but were not offered anything. Still others felt that they had no guidance as to how to obtain a referral for rehabilitation, or they were not given direction on how to access rehabilitation services such as physiotherapy or lymphedema treatment.

Even with the inadequate coordination of rehabilitation services, some participants did receive therapy and other support services, or attended physical exercise programs within CancerCare or in the community. Six of the seven women sought out and participated in physical activity programs after their cancer treatment. They expressed that they had to “do their own homework” if they wanted to join some of these programs, and that there wasn’t anyone really coordinating the use of these services.

Of the focus group participants, 5 of the 7 women reported having lymphedema. They stated that this has a huge impact on their lives. Because of the great impact of lymphedema, women felt that there should be more information, education, support and coordination of services for those with lymphedema. All of the women with lymphedema did receive treatment; however, they expressed frustration at the difficulty in obtaining a referral and accessing lymphedema treatment. The women with

lymphedema expressed that it affects every aspect of their lives on a daily basis and that it needs to be properly managed from very early on.

The women who participated in the focus group were self-motivated, asked questions, sought answers and usually found what they needed in terms of cancer rehabilitation. The women discussed, however, that there are many that are not self-motivated and do not seek or receive the appropriate rehabilitation in a timely manner. They further discussed that some women may be in a more disadvantaged situation, such as not being able to speak English, and don't ask questions, don't know how to find what they need, and don't know how to access rehabilitation services.

This lack of a routine and universal management for all breast cancer survivors with insufficient coordination of rehabilitative services led to agreement by all the participants that a solution may be the offering of systematic post-diagnosis physical assessments. The women described that this could include the provision of preventative measures, instruction in self-care, and the identification of any physical rehabilitation needs for all breast cancer patients. They also agreed that this assessment of needs should take place pre-operatively, post-operatively, and periodically throughout cancer treatment and in follow-up care. Rehabilitation services would then be coordinated and offered to each woman with any identified rehabilitation needs after breast cancer diagnosis. One woman explained that this kind of assessment of the physical needs and coordination of rehabilitation services would take care of the physical side after cancer treatment, which she felt has been neglected.

Women also felt that these routine assessments of physical needs should be automatically included for all breast cancer patients, with the offering of rehabilitation services being "all part of the package". They referred to cancer rehabilitation as being an integral part of cancer care for all those diagnosed with breast cancer.

If a universal system of physical needs assessment was in place, women felt that then those less self-motivated and more disadvantaged would not be "lost in the system". They also felt even with this routine assessment and offering of rehabilitation services, that individuals can still choose to receive that service at that time or at later time.

In addition to routine and universal assessment of rehabilitation needs, the participants expressed the need for a complete care package for whole body health – a coordination of all the therapies, both physical and psychosocial.

Associated with a lack of coordination of rehabilitation is the poor continuity of care that women feel exists after completion of their primary treatment. At the completion of primary treatment, women are followed in oncology for a short time period and then

they are transitioned to care with their family physicians. If they have further concerns or questions about any post-treatment issue, they feel that they are not getting the attention or answers they need. They also felt that they were being a nuisance or reactionary when they had unusual concerns, and that these concerns were not being adequately addressed.

They described poor transition to care with their family physicians and inadequate follow-up to deal with some of the new or recurring concerns they encounter. They reflected that the family physicians are not necessarily knowledgeable enough about cancer treatment, or that they do not always know the specifics of the cancer treatment that was received, the follow-up care that is necessary or the side-effects of treatment for which to screen.

Women experience the effects of cancer treatment during, immediately and long after they are finished primary treatment. These on-going effects of treatment led the participants to feel they should be able to access cancer care professionals beyond the treatment phase. One consequence of this gap in continuity of care and lack of coordination of rehabilitation services is the feeling of abandonment for many women.

Financial Challenges Related to Cancer Rehabilitation Services

Even with adequate information and answers to questions, routine assessment of physical needs and the timely coordination of rehabilitation services, a major barrier exists to accessing rehabilitation services. The women shared that there is a lack of funding for rehabilitation services such as physiotherapy and lymphedema management. Many cancer rehabilitative services are not included in the Provincial Health Plan and those that are may have long waiting lists, with a limited number of treatment sessions allowed. The Provincial Health Plan also does not cover the cost of bandaging supplies or garments for those with secondary lymphedema. The expenses related to garments for managing lymphedema can be high.

Those that do have private health insurance soon realize that the coverage is very limited for physiotherapy, lymphedema therapy, supplies and garments. Private physiotherapy and costly and intensive lymphedema management often results in many out-of-pocket expenses. Those that do not have private insurance are very frustrated. Despite the need for these essential rehabilitation services or components to manage lymphedema, some women report that they just go without physiotherapy, lymphedema treatment, or garments, simply because they can't afford it. These financial challenges pose a large barrier to accessing rehabilitation services or the needed lymphedema management supplies.

There was an overwhelming agreement among the participants that more funding is needed under the Provincial Health Plan for physical rehabilitation such as physiotherapy, lymphedema treatment, bandaging supplies and garments. They felt that there should be improved access and affordability for rehabilitation services for all women diagnosed with breast cancer in Manitoba. They sensed that many women need rehabilitation services, especially lymphedema management, which if not properly managed has many unfortunate consequences. They shared that the provision of adequate funding for rehabilitation after breast cancer would certainly alleviate many fears and concerns for breast cancer survivors.

Thank you for reviewing this summary. Please feel free to contact me if you have any comments on the summary of findings from the focus group discussion.

Sincerely,
Karen Dobbin, Physiotherapist, Graduate Student