

FRAMING WOMEN'S UNDERSTANDINGS AND EXPERIENCES OF LYMPHOEDEMA
FOLLOWING BREAST CANCER SURGERY

by

Karen Chun, B.HSc.

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Abstract

According to the National Cancer Institute (US) estimates, 1 in 8 women born today will be diagnosed with breast cancer at some time in their lives (National Cancer Institute, 2006). Of those women who undergo breast cancer surgery, almost one-third will develop upper-body lymphoedema (Vignes, Porcher, Arrault, & Dupuy, 2007). Lymphoedema is a chronic health condition characterized by the accumulation of lymphatic fluid in the subcutaneous tissues resulting in arm swelling and can significantly affect one's physical and psychological health. It can also impact a woman's body image and negatively affect quality of life (QOL). The diagnosis of breast cancer is in itself a significant stress to those who have been affected, and women who undergo breast cancer treatments continue to struggle with its effects long after the operation (Thomas-Maclean, 2005). The development of lymphoedema following breast cancer surgery further compounds the problems women are faced with in coping with breast cancer's lingering effects.

Although a significant body of research on lymphoedema developed over the past decade, most lymphoedema studies are quantitative in nature and focus primarily on scientific aspects of the disease, the effectiveness of treatments, and measurements of QOL (e.g., through mobility measurements) in lymphoedema patients. The literature reveals that there are still gaps in knowledge on framing the illness, communication, and effective practices to improve the QOL for individuals living with lymphoedema.

This research contributes to this growing field of research through a qualitative investigation of twelve women's reported understandings, experiences, and perceptions of lymphoedema using Brown's (1995) theory of framing disease and illness. Investigating issues that emerge during the lymphoedema framing process provided valuable insight into women's understandings of the illness and its management, and their experiences and perspectives on body image, support, and well-being, all of which impact QOL and health outcomes.

Semi-structured interviews were conducted with women living with breast cancer-related lymphoedema in order to determine the impact of health messaging, to explore the ways in which these women made sense of conflicting messages on exercise, and to better understand how barriers to the effective adoption and integration of good management practices can be overcome.

Keywords: lymphoedema, breast cancer, health messaging, health communication, quality of life, well-being, framing illness, exercise, social supports

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INTRODUCTION

The link between regular exercise and good health is well established. In the case of chronic illness or disease, however, the level and intensity of recommended exercise relates to the nature of the illness, the patient's health and strength, as well as the level of integrated health care they receive (Lymphoedema Framework, 2006). In the case of an understudied condition such as lymphoedema in women, the integration of exercise into a treatment program is impacted by a dearth of knowledge on the health problem, as well as conflicting messages communicated by a team of health practitioners (Towers, Carnevale, & Baker, 2008). A key question then, is, what are the dominant health messages received by women living with lymphoedema? Furthermore, how does the communication of health messages impact one's quality of life (QOL) and experience with lymphoedema? My research project sought to investigate the ways in which lymphoedema is framed, to better understand issues related to the education, communication, and knowledge of good symptom management practices to improve the QOL of women living with lymphoedema. This investigation was conducted through qualitative analyses of women's accounts of living with lymphoedema following breast cancer surgery.

The lymphatic system is a crucial component of the immune system that involves the transport of lymphatic fluid from the interstitial spaces within capillary beds, through lymph nodes towards the thoracic duct (Lamont, 2007). In simpler terms, it is a pathway that allows for the drainage of lymphatic fluid in order to cleanse the system of foreign particles. Impaired drainage of lymphatic fluid is usually due to obstruction of the system and results in the accumulation of fluid and protein in local subcutaneous tissues, as well as fibrosis and swelling (Lamont, 2007). The increased amount of protein raises the osmotic pressure in the tissues and draws more fluid to the area, resulting in swelling and the eventual thickening of the tissues of

the affected area (Lamont, 2007). These symptoms are characteristic of a condition called lymphoedema.

Upper-body lymphoedema is strongly associated with breast cancer surgery. The main types of breast cancer surgery include lumpectomy (a breast-conserving surgery) and complete or partial mastectomy, and tend to be accompanied by axillary node dissection or sentinel node dissection. For those who undergo breast cancer surgery, up to 28% develop upper-body lymphoedema (Ganz et al., 2002; Vignes, Porcher, Arrault, & Dupuy, 2007). Lymphoedema can result in physical and psychological morbidity, impact one's body image and self-esteem, and can negatively affect QOL (Karadibak, Yavuzsen, & Saydam, 2008; Vignes et al., 2007). These negative effects may include a decrease in arm mobility and obstacles to daily activities or participation in sport and leisure activities. The diagnosis of breast cancer is in itself a significant stress to those who have been affected, and women who have successfully undergone breast cancer treatments continue to struggle with its effects long after the operation (Thomas-Maclean, 2005). The development of lymphoedema following breast cancer surgery further compounds the problems women cope with after breast cancer surgery.

A wealth of research on breast cancer has been published over the past three decades, exploring a wide range of topics beyond biomedical aspects of the disease, including research on diet, exercise, stress, access to health care, amongst other issues. For instance, McNeely et al. (2006) conducted a meta-analysis of 136 studies on the effects of exercise on breast cancer patients and survivors and found exercise to be an important factor in improving QOL, cardiorespiratory fitness, physical functioning and fatigue in this population. An increased focus on lymphoedema developed within breast cancer research approximately a decade ago.

Despite the recent inclusion and focus on lymphoedema in breast cancer research, knowledge gaps remain on education, communication, and effective practices to improve the QOL for individuals living with lymphoedema (Thomas-Maclean, 2005; Towers, Carnevale, & Baker, 2008; Vallance, Courneya, Plotnikoff, Yasui, & Mackey, 2007). This thesis strives to close these identified gaps through a qualitative analysis of key issues related to health communication, women's QOL and the management of lymphoedema.

The first section of this thesis investigates the dominant health messages targeted to women living with breast cancer-related lymphoedema, and explores how these messages are received and understood. Previous research on lymphoedema has shown that there is often a disconnect in health communication due largely to conflicting health and risk discourses, as well as an over-reliance on internet diagnoses that exclude qualified observation and assessment by health care personnel (Towers et al., 2008).

The focus of this research project is based on Brown's (1995) theory of framing disease and illness that involves situating and positioning a disease within its broader social context. Difficulties in framing lymphoedema are associated with the ambiguous nature of the condition. Lymphoedema remains an under-identified and under-diagnosed condition due to a lack of consensus on its definitions, framing, and measurement techniques (Towers et al., 2008). The existing research has suggested that lymphoedema is an understudied health problem. A study by Frid, Strang, Friedrichsen, and Johansson (2006) explored palliative cancer patients' perspectives on experiences of lymphoedema, and maintained that lower limb lymphoedema is a "common but neglected problem" (p. 5). Moreover, a study by Hinrichs et al. (2004) stated that "relatively little attention is given to lymphedema in studies of [postmastectomy radiotherapy or 'PMRT']" (p. 575), and that in several research studies, lymphoedema is not always reported with relation

to PMRT secondary conditions. Further compounding the problem of identifying lymphoedema as a potential condition following breast cancer surgery is that self-diagnosis is a problem. A Canadian study of 115 participants from Toronto and London, Ontario found that 42% of people living with lymphoedema reported that their condition was self-diagnosed (Lymphovenous Association of Ontario, 2006). The same study reported a significant variance between patients with lymphoedema who were aware of treatment options and those who assumed that nothing could be done to manage their symptoms. A growing concern among people who live with lymphoedema is the reported difficulties in obtaining appropriate medical advice.

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

It is important to focus the attention on the effects of competing and conflicting recommendations from physicians, nurses, physiotherapists, and oncologists, and assess how it can impact the way the illness is framed and understood by women living with lymphoedema. My research study explored whether women living with lymphoedema experienced a disconnect in health messaging from their health care professionals and whether their perceptions impact the management of their lymphoedema symptoms.

The second area of focus in my research was to better understand the impact of lymphoedema on the management of symptoms and QOL of women dealing with the condition. Thomas-Maclean's (2005) work with breast cancer survivors emphasized the importance of understanding changes in survivors' lives following breast cancer, and the meanings that

survivors attributed to these experiences. She found that “despite indications of bodily acceptance, changes to one’s body are a constant reminder of illness, limitation and disability, so that breast cancer is always an immediate and present experience, even beyond treatment” (p. 207). Thomas-Maclean’s work highlighted that negative effects of breast cancer persist long after treatment and stressed the need for increased attention to breast cancer survivors’ experiences of limitation and disability.

The ability to exercise was a common concern highlighted in the literature on successful management techniques as well as enjoying a strong QOL. Despite the proven benefits of exercise in preventing a decline in mobility and improving function in the management of lymphoedema (Collins, Nash, Round, & Newman, 2004; Ochalek, 2008), many women do not actively participate in exercise programs as a means to better control lymphoedema symptoms. The decreased levels of exercise and physical activity found among lymphoedema populations can be partially explained by patients’ fear of the risks involved with exercise (e.g., the risk of aggravating and worsening symptoms) (Frid et al., 2006), as well as obstacles they must face (e.g., fatigue, nausea, self-esteem issues and lack of knowledge on the risks and benefits of exercise) (Courneya, Mackey, & McKenzie, 2002).

Participants for this study were recruited through Breast Cancer Action in Ottawa, an organization that initiated a successful lymphoedema program: *Lymphedema: Take Control Project 2007-2009*. The goals of this program are to raise awareness about lymphoedema, and provide support, information and education to women diagnosed with lymphoedema, as well as support for their families.

The proposed contribution of this study is to enhance understanding of how communication, reception, and comprehension of health messages related to lymphoedema can

impact women's QOL and treatment strategies. Applying a thematic analysis of the responses of 12 women living with lymphoedema, this research aims to reveal barriers to a more successful inclusion and integration of effective treatment practices to increase QOL of women living and coping with lymphoedema. This study will also highlight areas for further research in this understudied area with the goal of improving communication and support for women living with lymphoedema following breast cancer surgery.

The thesis will be divided into several sections including a literature review and chapter on theory and methodology, followed by the presentation and analysis of research findings in the form of two journal manuscripts. One manuscript focuses on framing and communicating knowledge on lymphoedema. The second manuscript explores women's experiences with lymphoedema that relate to QOL and treatment, including exercise. A concluding chapter summarizes main research findings and emphasizes areas for future research.

CHAPTER I

Literature Review

Background

In the following section, the existing literature on lymphoedema will be discussed with the aim of providing a foundation on which my research is based. This review will include analysis of the ambiguous nature of framing lymphoedema, patient-provider health communication, literature on the QOL of women living with lymphoedema, and an overview of research on exercise as a means of managing symptoms. Furthermore, this literature review will help shape a gap analysis of research within this field. While this review is focused on literature on lymphoedema and breast cancer, more specific literature relating to health and risk communication is explored in the next chapter, which describes theory and methodology.

Upper-body lymphoedema primarily affects the arms and may occur at any time following breast cancer surgery. For example, symptoms may arise immediately after surgery or as late as thirty years post-operation (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002). The large window of time following the operation in which the development of lymphoedema is possible presents a significant problem to women who have undergone breast cancer surgery. It affects not only women living with lymphoedema, but also those at-risk, because of the fear of developing the condition (Box et al., 2002). People afflicted with the condition may experience physical symptoms (e.g., pain, heaviness, tightness, numbness, fatigue, and impaired mobility) as well as psychological distress (e.g., anxiety and depression), all of which have negative impacts on QOL.

Since there is no cure, lymphoedema is usually managed through a number of conservative therapies as opposed to more invasive, surgical options. These practices, deemed

“conservative” by practitioners in the field, include limb elevation, compression stockings and sleeves, manual lymphatic drainage massage, and exercise (Lamont, 2007; Ochalek, 2008). Limb reduction surgery and medication are considered alternative treatment options, but are usually only considered in severe cases resistant to conservative treatments (Lamont; Pain & Purushotham, 2000). The existing literature on lymphoedema is predominantly quantitative in nature and can be loosely grouped into two (2) broad categories: 1) the effectiveness of treatments and 2) lymphoedema and QOL. In the first case, there is a wealth of studies on assessing the effectiveness of treatments in the management of lymphoedema through the measurement of arm volume and circumference. In particular, research has focused on the effects of treatments, from manual lymphatic drainage to compression pumps (Vignes et al., 2007; Box et al., 2002; Moseley, Carati, & Piller, 2007). While there are numerous quantitative studies on the effects of lymphoedema in patients’ physical functioning, mental health, and QOL, the amount of qualitative research in this area is somewhat limited. The literature on lymphoedema and QOL primarily demonstrates through measured tests that patients with lymphoedema experience greater levels of functional impairment, poorer mental health, as well as increased anxiety and depression than individuals without lymphoedema (Karadibak et al., 2008; Ridner, 2005).

The Ambiguous Nature of Lymphoedema

Studies on lymphoedema have revealed a lack of consensus among health care providers on appropriate treatment methods for lymphoedema (Brennan & Miller, 1998; Towers et al., 2008); however, the problem appears to be rooted in the fact that there is a lack of consensus on even the most fundamental aspects of its definition and diagnosis (Logan, 1995). Logan found

inconsistencies in the criteria used by clinicians in the diagnosis of lymphoedema. Some stated that lymphoedema exists once limb circumference at any given point is at least 2 cm larger than the same point on the unaffected side (Petryk, Pressman, & Smith, 2000), while others set the measure at 2.5-3.0 cm (Harris & Niesen-Vertommen, 2000). Furthermore, Logan discussed the range of available methods used in the diagnosis of lymphoedema (e.g., arm volume measurements, multiple circumferential measurements, as well as self-reported swelling). As such, there is little consistency in the reported incidence and prevalence rates of lymphoedema in the literature.

Patient-Provider Communication

The uncertainty and confusion related to the diagnosis of lymphoedema extends to the management of symptoms. The confusion around the management of symptoms through methods such as exercise is largely mediated by patient-provider communication. A study by Fu, Axelrod, and Haber (2008) investigated the links between lymphoedema education, knowledge and risk-reduction behaviours. Lymphoedema education is defined as a “[cancer] survivors’ status of receiving information from a variety of delivery approaches, such as distribution of pamphlets, brief verbal instructions, or discussions with physicians, nurses, or physical therapists” (Fu et al., 2008, p. 342). In their study, the sample excluded women with a diagnosis of lymphoedema and focused only on breast cancer survivors from New York City who were *at-risk* of secondary lymphoedema. Their conclusions indicated that patients received their main source of information about lymphoedema from the pamphlets in the post-surgical packages. Other sources of information reported in the study included brief discussions with nurses, breast surgeons, physiotherapists, radiologists, and oncologists. Fu et al.’s study showed that

participants who received lymphoedema information reported engaging in significantly more risk-reduction behaviours; however, their results showed that out of those who received information, only between 9% and 30% reported practicing behaviours promoting lymph drainage. Furthermore, there was no mention of the impact of individual sources of information on risk-reduction behaviours. Fu et al.'s findings demonstrate that while receiving information may increase risk-reduction behaviours, the number of people practicing risk-reduction behaviours remain relatively minimal, which suggests that further research is needed to understand the strategies of health messaging in this context.

The literature on communication between breast cancer survivors and their health care providers is very limited (Clayton, Dudley, & Musters, 2008). One previous study provided a glimpse into these processes and revealed that while 50% of cancer patients report that they would seek information from their providers, only 11% were found to actually consult their providers (Clayton et al.). Clayton et al. found that 49% of cancer patients consulted the internet, family, and friends for information. The study's findings also demonstrated the significant influence of non-physician sources of information for women living with this chronic condition.

Exercise as a Conservative Treatment

The normal flow of lymphatic fluid is influenced by a number of factors including muscular contractions in lymphatic vessels, an effective valve system, muscle pump activity, as well as respiratory movements (Ochalek, 2008). Exercise has been proven to increase lymphatic flow through the stimulation of muscle contractions, which in turn reduces swelling (Pain & Purushotham, 2000; Cheville et al., 2003). Exercise involving a combination of aerobic, flexibility, and strength training, supplemented by the use of compression garments, manual

lymphatic drainage, and compression pumps have been proven to be beneficial in women with lymphoedema (Brennan & Miller, 1998). Brennan and Miller stressed the importance of individualization in all exercise regimens, and maintained that aerobic capacity, flexibility and strength should be assessed prior to the implementation of the treatment plan.

A study by Box et al. (2002) investigated the risk of lymphoedema pre- and post-counselling and education interventions, measured through arm circumference, arm volume, and multi-frequency bioimpedance. The educational component of the interventions was supplemented by a complex physiotherapy program, which focused on exercise as a component of therapy that was used to promote the recruitment of collateral lymphatic pathways in the management of symptoms (Box et al.). The study's results demonstrated that exercise programs aid in optimizing the recovery of shoulder movement, reducing the development of lymphoedema and decreasing its progression. Another study found that aerobic exercise and strength training are important for women who have undergone breast cancer surgeries, as many are at increased risk of developing cardiovascular disease and osteoporosis as a result of chemotherapy or oophorectomies (Harris & Niesen-Vertommen, 2000).

Ridner (2004) investigated the negative impacts of low levels of exercise on the management of lymphoedema and found corresponding negative effects on lymphoedema symptoms. In both Ridner's (2004) and Karadibak et al.'s (2008) studies, women who developed lymphoedema following breast cancer surgery and who tended to decrease the use of their arms, were found to suffer from limited movement of the upper extremities and an increase in the severity of swelling. The uncomfortable swelling consequently compromised their QOL.

Conflicting Views of Exercise in the Management of Lymphoedema

Although best practice guidelines for the management of lymphoedema have been established and exercise is considered a common rehabilitative intervention (Lymphoedema Framework, 2006), conflicting understandings continue to exist in practice. A contributing factor to the confusion surrounding the role of exercise in the management of symptoms relates to problems in health messaging and the fact that different types of exercise are required depending on the treatment plan. For example, certain exercises are required to supplement the compression bandage treatment, whereas other exercises are more effective for individuals who use compression pumps (Tretbar, Morgan, Lee, Simonian, & Blondeau, 2008).

Furthermore, Ochalek (2008) revealed that while there is agreement on the importance of physical activity as a therapeutic factor in the management of lymphoedema, the type, intensity, frequency, and duration of exercise for the safe reduction of swelling is not clear. For example, Pain and Purushotham (2000) argued that while exercise is an important component of the conservative management of lymphoedema, *excessive* exercise may lead to increased blood flow to the limb, which could possibly aggravate the problem. What is meant by “excessive,” however, is not fully defined in the article, which has implications for interpretation of health messages

Conversely, Harris and Neisen-Vertommen (2000) contested health care professionals who warned women who had axillary lymph nodes removed during breast cancer surgery to avoid vigorous, repetitive, and excessive upper body exercise. In their study, Harris and Neisen-Vertommen challenged the findings on which some health care professionals base their restrictions on exercise, which were based on the belief that exercise of such a nature might induce or exacerbate lymphoedema. Harris and Neisen-Vertommen conducted a series of case

reports with 20 women who had their lymph nodes removed, and who were actively involved in competitive Dragon Boat racing, a vigorous upper body sport. Their findings showed no clinically significant difference in arm circumference as a result of participation in vigorous upper body training, and the authors argued that women who were diagnosed with breast cancer already experienced a threat to their QOL, so “to limit that woman’s participation in recreational activities that might serve to enhance her overall fitness levels and sense of emotional well-being, without valid evidence that such activities are harmful, provides a further blow” (Harris & Neisen-Vertommen, p. 98).

Lymphoedema and Quality of Life

The impact of the conflicting views on effective treatment methods for lymphoedema was illustrated in a Canadian qualitative study by Towers et al. (2008), which investigated the experiences of people living with lymphoedema. The study was conducted in Quebec, where researchers recruited women and men from various socioeconomic groups through purposive sampling of participants. Participants were recruited from a university hospital-based lymphoedema clinic, from local lymphoedema specialists, as well as from the Lymphedema Association of Quebec website. Four main themes emerged from their study: patients’ frustrations with the lack of financial support from the government and insurance companies; the perception of physicians’ lack of interest, awareness, and knowledge of lymphoedema; the burden of living with lymphoedema and its impact on QOL; and the importance of lymphoedema clinics and support groups in coping with the condition.

Towers et al.’s (2008) study demonstrated lymphoedema patients’ frustration with the fact that treatments and equipment are not covered by government health insurance and are

inadequately reimbursed by insurance companies. One participant in the study expressed disappointment “that it’s taking the government so long to recognize this as a disease that has to be considered like any other in our Medicare system” (Towers et al., p. 138). As a result of this lack of support, some participants reported that they could not afford to purchase compression garments as part of their therapy program. Another strong concern was the conflicting information received from health care providers regarding treatment options. Towers et al. reported that the difficulties encountered in obtaining appropriate medical advice is due to the lack of awareness and support from the medical profession. Their research suggests the need for a more complex understanding of the framing and the significance of lymphoedema, as well as the necessity for more effective health communication for breast cancer patients and survivors with lymphoedema.

Predictors of exercise

It is important to note that a wealth of research has investigated exercise behaviours with the aim of increasing physical activity levels in various populations. Existing research across disciplines has looked at a multitude of predictors of the initiation and maintenance of exercise in a range of populations, including predictors such as motivation, intention, and social determinants amongst other areas. According to an early study on exercise following breast cancer by Leddy (1997), the most significant barriers to exercise for women affected by breast cancer were lack of time and inertia, while the most significant incentives for exercise were expectations of benefit and a sense of responsibility. More recent studies used the frameworks such as the theory of planned behaviour to better understand determinants of intention to exercise

among breast cancer survivors, and found that attitudes, subjective norms, and perceived behavioural control influenced exercise intention (Hunt-Shaw et al., 2006).

Another recent study highlighted the value of a tailored approach to strategies for overcoming barriers to exercise, and demonstrated the effectiveness of physical activity counseling interventions within primary health settings to promote exercise (O'Sullivan et al., 2010). O'Sullivan et al.'s findings revealed the importance of autonomy support in enhancing patients' motivation and perceived competence for exercise, all of which affect exercise behaviours. A study by Blanchard et al. (2008) found that 37.1% of breast cancer survivors met the recommended guidelines for exercise. Some researchers found that women living with lymphoedema secondary to breast cancer participated in lower levels of physical activity than other cancer survivor groups (Karadibak et al., 2008; Ridner, 2005).

A number of studies referred to predictors of exercise specifically related to patients with lymphoedema. For instance, a study by Frid et al. (2006) found that some patients with lymphoedema experienced difficulties with movement, leading to irritation, fear, dependence, and handicap. As a result of these experiences, patients tended to avoid movement. The phenomenographic approach used in this study effectively produced several themes (e.g., discomfort and disgust with swollen limbs, function, and avoidance), which could be linked to lower levels of physical activity. A study by Karadibak et al. (2008), which was designed to investigate the relationship between fear of movement, QOL, and adherence to home exercise programs with women who had upper-body lymphoedema, presented another possible explanation for the decreased levels of physical activity found in lymphoedema populations. An important finding in Karadibak et al.'s (2008) study was that patients often avoided certain activities due to their belief that the swelling in their arms would worsen with movement. The

researchers found that the higher the severity of the swelling, the stronger the fear of activity, and emphasized the importance of early initiation of therapy programs for upper body lymphoedema. Similarly, Vallance et al.'s (2007) work emphasized the need to improve psychosocial and physical outcomes in patients with lymphoedema through physical activity and sought to explore effective strategies to increase physical activity and QOL among this population. While existing research points to several explanations for the lower levels of physical activity associated with women living with lymphoedema secondary to breast cancer (Karadibak et al., 2008; Ridner, 2008), the findings seem to converge on problems associated with a lack of knowledge and understanding of the role of exercise in the management of lymphoedema, which in turn affect one's QOL.

In summary, this focused literature review suggests the need to further examine health communication problems in the field of lymphoedema and the impact on women's experiences and QOL. As described by Towers et al.'s (2008) article, women living with lymphoedema received conflicting information regarding treatment options, which resulted in a feeling of being misunderstood and alone with their condition. The problem of conflicting messages is reinforced by the fact that many women turn to the internet, family, and friends for information. These findings, in conjunction with Karadibak's et al.'s (2008) conclusion that fear is a significant reason for avoiding movement and exercise, revealed a disconnect between the known benefits of exercise and the communication of this information to patients with lymphoedema.

Furthermore, the existing literature on lymphoedema reflects the need for a better understanding of the impact of the current state of health communication with patients with lymphoedema', their perceptions of available treatments and their understanding of the importance of and recommendations related to exercise. At the same time, there is a need for

qualitative research to better understand patients' perspectives and barriers to the integration of exercise as part of treatment plans, with the aim of contributing to refining health messaging and treatment strategies. These new directions in research could provide insight into patients' experiences with lymphoedema with the goal to improve communication, support and the QOL for this population. The next chapter will discuss the theoretical framework and methodology for my research study.

CHAPTER II

Theoretical Framework and Methodology

This study is situated within the broader context of illness framing and the idea that individual factors, biomedical factors, as well as societal factors impact one's behaviours and experiences of illness. Brown's (1995) theoretical model of framing disease served as a tool to gain insight into the interconnected factors that influence people's understandings of the meaning of illness, which in turn affect people's actions with regards to health, illness, and the management of disease (Brown). Framing revolves around the idea that disease is not only a biological event; it also has a cultural dimension. In framing disease, one would take into consideration how understandings of it and actions towards disease are shaped by knowledge, experience and power (Brown). It takes into account factors such as the roles of the professionals, institutions, governments, media, patients and their families, in shaping the way a medical phenomenon is identified, and the ways people deal with it (Brown).

Brown's theory is derived from the idea that through the critical examination of the identification of disease, the experience of illness, treatment, and outcome, one can flesh out how disease is framed and understood. The *identification* stage consisted of themes related to the ways in which women identified or diagnosed their condition. For example, was it their physicians or oncologists who diagnosed their lymphoedema, or did they self-diagnose through internet health forums? The *experience of illness* stage was based on the idea that people who have the same condition may have different experiences of it (Brown, 1995). The *treatment* stage included themes that addressed the issue of what women believed to be the best way to manage their condition and how their perceptions were impacted by health and risk discourses. Finally,

the *outcome* stage included themes that revealed the outcome of lymphoedema and treatment practices (e.g., doing versus not doing exercises as part of treatment plans).

As previously explained, the focus of my research was twofold and included investigating the framing and understanding of lymphoedema and exploring lymphoedema's impact on women's experiences and their QOL. The first stage of Brown's (1995) theory, the *identification of disease*, was used as a guide to the investigation of health and risk messaging in the framing of lymphoedema. Brown's concept of identifying illness was valuable as an analytical framework in the interpretation of health messaging processes that contribute to the framing of lymphoedema. The latter 3 components of Brown's theory, *experience of illness, treatment, and outcome* were more directly related to women's experiences and QOL. In his article, Brown highlighted the importance of acknowledging that while a physician may view disease as a "concrete biomedical entity" (p. 44), the patient experiences the personal and social effects of the disease on his or her life. Investigating the experiences of illness, treatment, and outcome from a participant's frame of reference would offer a novel outlook on lymphoedema research.

Methodology

The project was conducted using qualitative research methodology, which allowed me to flesh out the complex perceptions and experiences of women living with lymphoedema following breast cancer surgery. Qualitative research is best suited for gathering in-depth understanding of questions relating to the *how* rather than the *why* (Becker, 1998). With this said, however, qualitative research should not be considered as a separate and distinct entity when compared to quantitative research. In my research, the qualitative methodology was employed with the

purpose of gathering a comprehensive understanding of how women dealing with lymphoedema frame their condition.

Methods

Community Partner

Participants were recruited through purposive sampling techniques to ensure I had access to women who had lymphoedema and were breast cancer survivors. As such, the community partner for this research was Breast Cancer Action (BCA) of Ottawa. BCA is a voluntary organization established in 1992, which provides support, information, and education to women living with breast cancer. It also provides support groups to breast cancer survivors and their families, counselling programs, and workshops among many other programs and services. The organization is funded by sponsors such as the Ontario Trillium Foundation, the Canadian Breast Cancer Foundation, and the Ottawa Regional Cancer Foundation. BCA is widely considered a key player in the local breast cancer activist movement, in part due to the research affiliation with Ottawa-based research hospitals, as well as the innovative public health programs, such as the *Lymphedema: Take Control Project 2007-2009*, which aimed to raise awareness of lymphoedema and promote health, fitness, and wellness for those living with lymphoedema. In addition to this, BCA offers the *Go With the Flow* exercise program, designed for risk reduction and management of lymphoedema.

Access to the Setting

In order to gain access to potential participants, I arranged a meeting with the coordinator of BCA's *Lymphedema: Take Control Project* to learn more about the organization and to share

our knowledge and views on the current research on lymphoedema. During the meeting, I explained my research interests and we discussed ways in which my research could be designed to inform and serve the needs of the BCA community.

Prior to the initiation of the research process, it was important to gain an understanding of the culture of the group. For this reason, I attended a number of BCA exercise classes as an observer and participant. During the social time organized before and after the exercise classes, I had the opportunity to interact with some of the group members as a way of establishing rapport, gaining trust and learning about the environment. According to Rubin and Rubin (2005), participants tend to trust the researcher when they can associate the researcher to a trusted person or organization. Knowing that I had the support of the executive director of BCA helped the women feel more at ease in participating in my study.

Participant Recruitment and Selection

After receiving ethics approval from the University of Ottawa Review Ethics Board and from BCA, which was facilitated by the executive director, voluntary participation in the study was requested through BCA newsletters, their website, and e-mails to its members. Twelve women responded to my recruitment advertisements and represented a sufficiently diverse range of perspectives for this project that further recruitment was not needed.

The participants' demographic characteristics were obtained through the administration of brief questionnaires immediately prior to the beginning of each interview (see Appendix A for a copy of the questionnaire). The questionnaires were structured using a Likert-scale style of questions, which allowed for ease in its administration, completion, and analysis and requested information on participants' age range, , self-reported perceptions of ability to manage their

condition, and self-reported levels of physical activity. Participants' ages ranged from 40 to 70+ years, with the majority between 60 and 70 years of age; participants' abilities to manage their lymphoedema symptoms ranged from "fair" to "excellent," with the majority of participants revealing their ability as "very good"; and the reported levels of physical activity varied between participants, and between different types of physical activity (i.e., flexibility, strengthening, and aerobic). The women interviewed reflected a range from 2 to 20 years in the number of years since lymphoedema diagnosis, while all the women rated the severity of their lymphoedema as being mild or moderate (for a complete record of the questionnaire's results, see Appendix B).

Data Collection

An important aspect of the initial phase of the research process was the researcher's self-presentation. I introduced myself to participants as a Master's student at the University of Ottawa who wished to learn about the women's experiences and perceptions of QOL in terms of the management of symptoms through treatment methods such as exercise. Prior to the interviews, I explained my research objectives to each participant, detailing my specific plans and goals. I believe that the transparency of a researcher's intentions is a key to establishing trust and rapport with research participants. Informed consent was obtained from each participant prior to the initiation of the interviews (see Appendix C for a copy of the consent form). Each participant was aware of her right to withdraw from the study at any point in the research process, and of the researcher's respect for participant confidentiality. Participants were asked for permission to be digitally-recorded during the interviews and quoted anonymously using pseudonyms in the study.

Twelve individuals from the support group were selected to participate in one-on-one interviews. Each interview session lasted between approximately 30 and 60 minutes, and took place either at participants' homes or coffee shops at a time convenient to the participant. A participant-centred interview guide was used to capture the participants' perceptions and experiences with lymphoedema (see Appendix D for the interview guide), and was divided into two (2) main sections: (1) the framing and understanding of knowledge on lymphoedema, and (2) experiences and QOL. The interviews were semi-structured in nature, which allowed for the organization of the interview in a way to ensure that the areas of interest in my research were explored, and at the same time allowed for the interview follow the direction in which the participant led. As such, not all questions outlined in the interview guide were asked during interviews, and the order of questions was not fixed.

A number of questions in the interview guide were modified throughout the data collection process as concepts and categories developed, which served to inform and clarify the focus of further areas of questioning. For example, after conducting the first interview, the question on women's perceptions of the meaning of health was relocated to the beginning of the interview guide, as it provided a better sense of flow. The questions were open-ended, allowing for in-depth and detailed explanations and descriptions. For example, I inquired whether lymphoedema had an impact on the participant's work life, and if it had, I probed for the ways in which the participant felt her work life had been affected by lymphoedema. The open-ended questions, typical of the semi-structured interview, not only allowed participants to elaborate on their perceptions and experiences of their condition, but also enabled the participants to discuss topics and issues they deemed to be relevant. The final question in each interview invited

participants to address any issues or topics that were not covered in the interview, and that they felt were significant.

Personal interviews provide the researcher with the greatest flexibility in terms of question design, especially when dealing with complex topics (de Vaus, 1991). I was able to tailor the questions to specific areas of interest, according to Brown's (1995) theory; however, the effects of social desirability tend to increase with increased personalization (de Vaus, 1991). Participants may not want to appear fearful or lazy, and may hence be reluctant to disclose to the researcher their true beliefs and perceptions with regard to their exercise habits. Similarly, questions about perceived self-efficacy may be difficult to answer. One strategy to overcome this problem was to begin the interview with broader questions in order to first establish a sense of rapport with the participant and help her feel more comfortable. As such, I began the interviews with a general question about participants' perceptions of the meaning of health. The purpose of obtaining information on participants' perceptions of health was used not only as an introductory question to help the participant feel comfortable answering an open-ended question, but also to situate the participant in terms of her position on health before investigating more specific details pertaining to the framing of lymphoedema. It was important to try to see, as much as possible, the situation from the respondent's perspective, and to understand the respondent's relatively vulnerable position in the research relationship.

The complexity of personal interviews is aptly described by Schostak (2006) in that one-to-one interviews involve interactions between the interviewer and the respondent, where each person continuously "makes judgements, has intentions, desires, feelings and can act upon them" (p. 18). Furthermore, Schostak describes the interactions as involving "negotiations, calculations and interpretations" (p. 15). As an interviewer, I needed to be aware of the dynamic nature of the

relationship between the interviewer and respondent, and took this into consideration in both the design of the interview questions as well as its actual execution. In other words, it was important to consider the impact of social interaction and context on the participants' responses. The concept of the research relationship was crucial in terms of understanding its effects on the responses obtained during interviews. That is, the researcher-participant relationship is one that can result in misrepresentations of the messages being conveyed (Schostak). Depending on the histories and the presuppositions of the interviewer and the respondent, the questions raised by the interviewer may or may not be interpreted in the same way by the respondent, which could result in less-than-optimal data for the researcher (Bourdieu, 1999). Furthermore, it was important to be aware of individual differences between participants and to make adjustments according to unanticipated developments during the interviews (Fontana & Frey, 2005). The complexity of interviews is often overlooked; however, a key to successful interviews is to be attentive to the nuances of this social interaction in order to achieve a more open and hence more informative research relationship.

Analysis

Data analysis is an ongoing process that involves numerous revisions and adjustments (Rubin & Rubin, 2005). I applied a thematic analysis to identify patterns in participants' responses. After the transcription of the interview data, each transcript was reviewed in its entirety in order to obtain a sense of each interview as a whole. In order to verify my data, I sent the completed interview transcripts to the participants and encouraged them to provide feedback. Four participants responded with slight modifications to their interview transcripts, which were mostly to clarify certain words that were misunderstood during the interview. The preliminary

examination of each transcript enabled me to present a detailed description of the individuals. Initially, I had proposed and was trained to use NVivo8™ as a tool to code the collected data, which allowed me to rigorously establish initial codes. After importing and coding the first two interview transcripts in NVivo8™, I found that it was more effective for the purpose of this research to manually code the collected data. The 10 subsequent interviews were transcribed and coded, but not imported into NVivo8™. Throughout the process, I found it helpful to go beyond pre-determined wording in coding data. It is important to note that participants may use different words to express similar meanings; thus, manually creating themes offered flexibility and the ability to provide nuance in terms of coding data, which enabled me to perform an equally rigorous analysis.

Following the preliminary examination of transcripts, participants' responses were reviewed and grouped under different the questions addressed during the interviews. This process offered an opportunity for more in-depth review of responses and allowed for comparisons between responses to be made. Next, I reviewed the grouped data and notes to identify patterns and emerging themes relevant to the framing of lymphoedema. Simultaneously, quotations were extracted and categorized under the emergent themes. The themes were then compared against published literature to check for similarities and divergences in research findings. Using qualitative and gender-based analyses, emergent themes were discussed, interpreted and situated within the larger context of lymphoedema constructions and communications.

While Brown's (1995) framework was used for the structure and interpretation of the project as a whole, several other models served more specific purposes in the analysis of the data. Northouse & Northouse's (1998) health communication model and Covello's (2003) model

of risk communication were used to contextualize the findings discussed in chapter on illness identification, and a gender-based approach was used in the chapter on experience and QOL.

Using Models of Communication in the Framing and Identification of Lymphoedema

The findings on the identification of lymphoedema generated a theme of communication. While there is a substantial body of literature of health and risk communication, for this research, which involves a close examination of the processes of health messaging and understanding, I chose to use two models in the analysis of health and risk communication processes in the identification of lymphoedema: Northouse and Northouse's (1998) model of health communication and Covello's (2003) model of best practices in risk communication. Northouse and Northouse's model offers a systems perspective of the relational, transactional, and contextual factors in the health communication process and illustrates the various channels of communication within a health care setting. On the other hand, Covello's model focuses more practical issues and identifies seven best practice guidelines for risk communication. Covello's best practices are guided by honesty and openness, involvement of stakeholders, and development of communication plans and include the following practices: (1) accepting and involving all parties that have an interest or a stake in the concern, (2) letting all parties that have an interest or a stake be heard, (3) being honest and open about risks, (4) coordinating, collaborating, and communicating with other inter-organizational and intra-organizational sources, (5) understanding the media's role in educating the general public, (6) communicating clearly and with compassion by identifying specific actions that an individual can take for protection and prevention, and (7) engaging in thorough planning. Each of Covello's guidelines

can be applied to the framing and communication of knowledge on lymphoedema-related risks to women following breast cancer surgery. Covello's model helped to pinpoint some of the problematic areas of communication within this study.

Using a Gender-Based Approach.

I applied a gender-based approach to women's responses (including experience of illness, treatment, and outcome stages) to better understand how women are affected by the various policy, planning, and decision making processes (Status of Women Canada, 2010). Some of the assumptions behind gender-based analyses include the idea that actions, policies, and socioeconomic trends affect women and men in different ways, and that women's empowerment is a key to address gender equality issues (Statues of Women Canada). Authors in the field argue that definitions of femininity and masculinity are socially constructed, and that gendered positions are formed as a result of discourses of femininity and masculinity. For instance, Butler (1990) argued that women's identities are constructed through discourses of femininity, in that the ways women are expected to look and behave are largely shaped by such discourses. Many feminist researchers argue that institutions such as schools, the family, and medical communities reproduce and reinforce dominant discourses of femininity. It is necessary to analyze women's testimonies of their experiences in order to understand how women position and construct themselves within dominant or resistant discourses (Weedon).

In using a gender-based approach in my analysis of women's responses, and paying particular attention to the discourses of health and femininity, I aimed to understand constructions of health and well-being, and to situate these women's perceptions and experiences (Schiavo, 2007; Weedon, 1997). This approach enabled me to better understand ways in which policies, programs, and actions can affect women living with lymphoedema.

The purpose of employing a gender-based analysis was not to arrive at a single conclusion to describe or explain women's circumstances in dealing with breast cancer-related lymphoedema, but rather to demonstrate the range of perceptions and experiences of women living with the same condition. It is equally important to understand that just as women's gendered identities change over time and within social contexts (Wright, 2001), women's experiences are not stable. In conducting this research, I conversed with women for a single session during individual interviews, which provided a revealing vantage into their lives. The experiences captured through this research do not represent fixed aspects of participants' lives; rather, they demonstrate the diverse ways in which women perceive and experience lymphoedema at particular instances in their lives.

The health and risk communication models, as well as the gender-based approach used in the analysis of the collected data contributed to a deeper understanding of lymphoedema framing.

Dissemination

Following the completion of the project, the results will be presented to the BCA community through a presentation and an executive summary report with the goal to streamline health communication for women living with lymphoedema, and to provide an outlet for them to voice their experiences. Research findings will also be disseminated at scholarly conferences, and published in the form of two journal manuscripts. The following chapter, the first journal manuscript, examines framing and understanding knowledge on lymphoedema among women dealing with breast cancer-related lymphoedema.

CHAPTER III

Framing and Understanding Knowledge on Lymphoedema among Women Following Breast Cancer Surgery

Introduction

Upper-body lymphoedema is a health condition that can affect up to 28% of women who undergo breast cancer surgery and can develop within days, months, or even years after the original operation (Vignes, Porcher, Arrault, & Dupuy, 2007). People living with lymphoedema may experience both physical and psychological changes, which could adversely impact one's quality of life (QOL) (Karadibak, Yavuzsen, & Saydam, 2008; Vignes et al., 2007). The diagnosis of breast cancer is in itself a significant stress to those who have been affected, and women who have successfully undergone breast cancer treatments continue to struggle with its effects long after the operation (Thomas-Maclean, 2005). The development of lymphoedema following breast cancer surgery further compounds the problems women are faced with in coping with breast cancer's lingering effects.

Despite a wealth of research on breast cancer in recent years, including research on lymphoedema over the past decade, there are still gaps in knowledge on how the disease is framed, on implementing effective education and communication practices, and on establishing best practice guidelines for treatment to improve QOL (Thomas-Maclean, 2005; Towers, Carnevale, & Baker, 2008; Vallance, Courneya, Plotnikoff, Yasui, & Mackey, 2007). Most research on lymphoedema measures the effects of treatment in the management of lymphoedema and QOL, yet few researchers have investigated these issues from a qualitative, participant-based perspective, which could help in better understanding their needs and concerns in order to develop more effective treatment programs. The literature suggests that there are barriers to the effective adoption and integration of certain management techniques, like exercise, in the

management of lymphoedema. This research argues that improving understanding of management options (i.e., exercise) would enhance the QOL of women living with lymphoedema. There are several obstacles that impede successful integration of exercise into a treatment program, which include infrequent follow-ups from practitioners, the limited knowledge on lymphoedema among the general public, and resorting to the internet for self-diagnoses and treatment programs which are not individualized. The goal of this paper is to present some of these barriers and emphasize recommendations to improve the QOL of women living with lymphoedema. In this paper, we discuss the issue of framing and communicating knowledge on lymphoedema through a qualitative analysis of original interview data on women's perspectives on framing lymphoedema.

Background

Lymphoedema is a chronic condition characterized by an accumulation of lymphatic fluid in the subcutaneous tissues, resulting in fibrosis and swelling of the affected areas, usually occurring in the limbs (Lamont, 2007). Although there is no cure, lymphoedema can be managed through a number of therapies including limb elevation, compression stockings, manual lymphatic drainage massage, and exercise (Lamont; Ochalek, 2008). Limb reduction surgery and medication are usually only considered in severe cases resistant to conservative treatments (Lamont; Pain & Purushotham, 2000).

The majority of existing research on lymphoedema is quantitative in nature and is focused on two (2) broad categories: 1) the effectiveness of treatments, and 2) lymphoedema and QOL. The first category of literature is focused on the effectiveness of various treatments (e.g., manual lymphatic drainage) in the management of lymphoedema through the measurement of

arm volume and circumference. The literature on lymphoedema and QOL has generally demonstrated that patients with lymphoedema display lower levels of physical activity and greater levels of functional impairment, poorer mental health, as well as increased anxiety and depression than individuals without lymphoedema (Karadibak et al., 2008; Ridner, 2005). Based on findings such as these within the field of breast cancer and lymphoedema, Vallance et al. (2007) focused on the need to improve psychosocial and physical outcomes in patients with lymphoedema through physical activity and sought to explore effective strategies to increase physical activity and QOL among this population. Vallance et al. contributed to the initiation of lymphoedema research to include the investigation of how physical activity can be more effectively integrated into treatment programs for women living with breast cancer-related lymphoedema.

While the link between regular exercise and good health is well established, the role of exercise in chronic illness or disease, such as lymphoedema, is more complex. Specifically, the level and intensity of recommended exercise relates to the nature of the illness, the patient's health and strength, and can be influenced by the level of health care one receives (Lymphoedema Framework, 2006). Although "best practice" guidelines for conservative treatments were established in 2006 by an international advisory board composed of health care professionals and academics (Lymphoedema Framework, 2006), there are still differing opinions and little consensus on the types of exercise that should be integrated into treatment plans (Towers et al., 2008).

Theoretical Framework

Situated within the process of framing illness and disease, my project employs Brown's (1995) theory of framing disease and illness as an overarching framework to inform the design of the project. Brown's concept of framing refers to the situation of a disease within its broader social context. It is important to note that illness is distinguished from disease in that while disease refers to the concrete biomedical entity diagnosed by health professionals, illness refers to an individual's experience of disease (Clarke, 2008), which is most relevant for this study. Through an investigation of framing illness, we can gain insight into various factors that impact people's understandings of illness, which in turn affect their actions with regards to illness prevention and treatment (Brown). Brown's theory focuses on understanding how illness is framed through a four-part analysis: (1) the identification of disease, (2) the experience of illness, (3) treatment, and (4) outcome. This paper focuses on the findings relevant to the "identification of disease" stage in Brown's theory.

The difficulties in framing lymphoedema are associated with the ambiguous nature of the condition. Lymphoedema remains an under-identified and under-diagnosed condition due to the lack of consensus on its definitions, framing, and measurement (Towers et al.). A growing concern among people who live with lymphoedema is the reported difficulty in obtaining appropriate medical advice (Towers et al.). Towers et al. suggest it is important to focus attention on the effects of competing and conflicting recommendations from physicians, physiotherapists, oncologists, which can negatively impact how the condition is framed and understood by women living with lymphoedema, which can impact the management of symptoms and impact mobility and QOL.

Methodology

This research study will contribute to the existing body of literature by investigating the framing and understanding of knowledge on lymphoedema in a specific population. A qualitative research methodology was employed to allow me to flesh out the complex experiences of women living with lymphoedema following breast cancer surgery. As Becker (1998) stated, qualitative research is best suited for gathering in-depth information in questions dealing with the *how* rather than the *why*. As such, this research investigated the question, “how do women living with breast cancer-related lymphoedema perceive health messages on lymphoedema management, and how does this affect the actions they take towards treatment?” Using a qualitative research methodology effectively allowed these questions to be explored. I chose to employ a qualitative research approach because the methods associated with it allow for a more in-depth understanding of experiences of how women dealing with lymphoedema frame their condition through their interactions with the social world in which they live.

The aim of this paper is to contribute to an increased understanding of the processes that underlie the identification and understanding of health messages in the management of lymphoedema. I am interested in the dominant health messages targeted to women and how these messages are received and understood. A qualitative analysis of women’s perceptions and experiences contextualized against health communication models will reveal the barriers to a better integration of exercise as a component of lymphoedema treatments, as well as provide insight into the ways in which the issue could be addressed, with the goal to stimulate further research in this understudied area.

Methods

The community partner for this study was Ottawa-based Breast Cancer Action (BCA), a voluntary organization established in 1992. It is widely considered a key player in the local breast cancer activist movement, in part due to the research affiliation with Ottawa-based research hospitals. Furthermore, BCA initiated a public health program entitled *Lymphedema: Take Control Project 2007-2009* to raise awareness about lymphoedema, and provide support, information and education to women diagnosed with lymphoedema, as well as their families.

A meeting was arranged between the first author and the coordinator of BCA's lymphoedema project to learn more about the organization and to share knowledge and views on the current research on lymphoedema. The meeting provided the opportunity for the coordinator to learn about the researchers' interests, and allowed for a discussion on the ways in which the research could be designed to inform and serve the needs of the BCA community.

Ethics approval was granted from the University of Ottawa Review Ethics Board, as well as the Executive of the BCA, and 12 members of BCA were recruited to participate in qualitative semi-structured interviews. Participant recruitment was ongoing throughout the data collection and analysis processes, and came to a conclusion only after the emerging concepts were saturated. Twelve women responded to the study's advertisements and were found to have a sufficient range of views that there was no need for further recruitment. . A brief questionnaire was administered immediately prior to the beginning of the interview and included questions about participants' ages, self-reported perceptions of ability to manage their condition, and self-reported levels of physical activity. The questionnaire was structured using a Likert-scale style of questions. Participants' ages ranged from 40 to 70+ years, with the majority of participants being between 60 and 70 years of age. On a five-level scale including "poor," "fair," "good," "very

good,” and “excellent,” participants’ reported ability to manage lymphoedema ranged from “fair” to “excellent,” with the majority of participants reporting their ability to manage symptoms as “very good.” The reported levels of physical activity varied between participants as well as between differing types of exercises (e.g., flexibility, strengthening, aerobic). The time since the onset of lymphoedema ranged between 2 and 20 years. The severity of lymphoedema in participants ranged from mild to moderate. Each interview lasted between 30 and 60 minutes, and took place either at the participant’s home or at a coffee shop convenient for the participant.

The interview guideline was designed following Brown’s (1995) theory of framing of disease, and included the four areas of investigation: the identification of illness, the experience of illness, treatment, and outcome. Brown’s theory was used as a framework to ensure that key areas of information were explored and collected from each participant. This enabled me to examine the multiple ways in which lymphoedema was framed by the participants; however, as the nature of semi-structured interviews lends itself to a conversational style of interviewing, the interviews ultimately followed the direction in which the participants led. As such, not every question in the guideline was asked in every interview, and the order of questions was not fixed. Furthermore, a number of the questions in the interview guide were modified throughout the data collection process with the development of concepts and categories, which informed and clarified areas of focus and further questioning. The questions were open-ended and invited detailed explanations and descriptions (e.g., what are your perceptions of the nature of information on lymphoedema?). Participants were also encouraged to address any issues or areas of information they felt were significant that were not covered in the set of interview questions. Interviews were digitally recorded using an audio recorder and then transcribed verbatim. In order to verify the accuracy of participants’ interviews, transcripts were sent to participants for

review and feedback prior to data analysis. Four participants responded with minor suggested modifications to their interview transcripts; they were predominantly to clarify certain words that were misunderstood during the interview.

Analysis

Following the transcription of each interview, each transcript was reviewed in its entirety to obtain a sense of the interview as a whole. Notes were taken and initial codes were formed throughout the initial review of the text. The preliminary analysis of each interview allowed me to reflect on potential areas that required further inquiry in subsequent interviews. Throughout the process, participants' responses were reviewed and grouped under different the question areas addressed during the interviews. The process offered an opportunity for a more in-depth review of responses and allowed for comparisons between responses. Following this, grouped data and notes were reviewed to identify patterns and emerging themes relevant to the processes underlying the framing and understanding of lymphoedema. The themes were then compared with published findings in the field, and similarities and divergences were noted.

In analyzing the data on the ways in which women identified the development and their management of lymphoedema, communication emerged as a central theme. Hence, two models served more specific purposes in the analysis of data. Northouse & Northouse's (1998) health communication model and Covello's (2003) model of risk communication were used as guiding models against which the study's results were contextualized. Northouse and Northouse's (1998) model offers a systems perspective of the relational, transactional, and contextual factors in the health communication process and demonstrated the various channels of communication within a health care setting, while Covello's (2003) focuses more practical issues and identifies seven best

practice guidelines for risk communication. Covello's best practices are guided by honesty and openness, involvement of stakeholders, and development of communication plans. Covello's model helped to identify problematic areas of communication between health care providers and women living with lymphoedema. This discussion will address the current state of risk communication literature related to lymphoedema and its management techniques, and provide suggestions for areas of improvement in lymphoedema-related health communication.

Results

As the focus of this paper is to investigate the framing and understanding of lymphoedema, the use of Brown's (1995) concept of identifying illness becomes valuable as an overarching analytical framework in the structure and interpretation of findings, within which Northouse & Northouse's (1998) and Covello's (2003) models are used as tools to contextualize the analysis. Brown offered a typology of conditions and definitions, classified into four groups: 1) routinely defined conditions, such as infectious diseases, in which a biomedical definition is applied and the condition is generally accepted by both medical practitioners and the general public; 2) medicalized definitions, 3) contested definitions, and 4) potentially medicalized definitions. At first glance, lymphoedema may seem to fall within the first category of Brown's typology, given that it has been assigned a biomedical definition and its symptoms are easily observable; however, upon closer examination of the complexities associated with lymphoedema, particularly in terms of its identification and its management, such a categorization of lymphoedema does not seem to be representative of the condition. The following section will illustrate the complexities associated with the diagnosis of lymphoedema,

and will demonstrate why lymphoedema cannot be placed neatly within any one of Brown's category of illness and disease.

Initial Discovery (or Diagnosis) of Lymphoedema

In investigating the framing of illness and how such constructions relate to health discourses surrounding the illness, the initial discovery, or the diagnosis of the illness, plays an important role. According to Brown (1995), the initial discovery of illnesses is often introduced by lay people, who raise experience-driven health problems that may not capture medical attention. Lay perspectives may conflict with biomedical authorities' perspectives, a concept that Brown labels as "conflictual" diseases; in such cases, there is often a need for professional and institutional action for the biomedical definition of a condition.

Although lymphoedema has been labeled a biomedical condition, and is therefore considered a "nonconflictual" disease, problems in its definitions and framing of the condition continue to exist and have yet to be resolved. In examining participants' experiences with their initial diagnosis of lymphoedema, two themes emerged: A lack of awareness at the time of diagnosis, and the perceived lack of concern for lymphoedema from health care providers, both of which affect the framing as well as the physical and psychological experiences of the condition.

Lack of awareness at the time of diagnosis.

For the participants, the initial diagnosis of lymphoedema was characterized by the experiences of shock, anger, and confusion, which may seem typical of the onset on a number of diseases; however, in the case of lymphoedema, the problem is compounded by health

communication issues. These issues may partially be a result of the ways in which lymphoedema is framed. For a condition that can affect almost one-third of women who undergo breast cancer surgery (Vignes et al., 2007), it is critical to note that half of the women interviewed reported that they had no knowledge of lymphoedema prior to their development of the condition. This reveals the need for more effective health communication pertaining to lymphoedema throughout the breast cancer diagnosis, treatment and recovery processes. On the other hand, the women who were aware of lymphoedema before being diagnosed admitted to having anticipated its onset with fear; however, it had no less of an impact on their experiences of the initial diagnosis of lymphoedema. One participant stated,

I've been concerned about lymphoedema for years, long before, and that's why when I had my first surgery, I was paranoid, I was truly paranoid that this was gonna happen to me, and it was like a bad dream when it did. (Abigail)

The sense of helplessness in preventing the onset of lymphoedema, on top of the initial shock of its onset, indicated the significant stress caused by lymphoedema following breast cancer surgery.

Perceived lack of concern/validation from health care providers.

An important and contrasting aspect of the identification of illness is the understanding of the condition from a biomedical perspective. In the case of lymphoedema, it is the conflicting views of the seriousness of lymphoedema rather than of the existence of the condition that is the problem. In this context, I refer to the conflicting views of lymphoedema between patients and practitioners based on the perceived impact of lymphoedema. Many of the women interviewed revealed that they felt their health care providers overlooked the seriousness of lymphoedema, particularly as it was contrasted to breast cancer. In their study on the experiences of African

American women's experiences with the breast cancer, Lackey, Gates, and Brown (2001) labeled and described women's experiences with an initial breast cancer diagnosis as a "trajectory" because of the way the women "seemed to feel hurled from the initial appointment with her doctor to biopsy, then to surgery, and on to other types of treatments, with little time to consider what was actually happening" (p. 521). These structured and fragmented procedures in dealing with breast cancer are a significant contrast to the ways in which lymphoedema is dealt with. It is not surprising to learn that women felt somewhat abandoned when they developed lymphoedema and were left to deal with it on their own.

Charlene recalled her initial diagnosis with lymphoedema: "I knew there was something wrong, but I didn't know what it was, but it was my oncologist who looked at it and said, 'oh, that's lymphoedema, it's going to get worse.'" Francine had a similar experience with her health care providers with regards of the initial identification of lymphoedema: "And you know, no one had warned me about any of that happening, so needless to say, I went running to the doctor. 'Oh, you got lymphoedema – congratulations, we saved your life' (laughter)." In both of these testimonies, participants felt that their health care providers acknowledged the existence of the condition, but dismissed it as non-life-threatening and failed to provide these women with the support and means to manage the symptoms. Conversely, in Elizabeth's case, upon observing his patient's swollen arm, the oncologist demonstrated the way in which the arm should be massaged, but did not identify the symptoms as lymphoedema.

In referring to Brown's (1995) model of framing, it is evident that the processes underlying the "identification" and diagnosis of lymphoedema are disjointed and affected the women's experiences with initial discovery of their condition. The women expressed their views on the ways in which lymphoedema has been framed by the medical profession.

The medical profession just treats it as a bit of a nuisance or a lifestyle inconvenience, but having gone through a couple of infections, I know that it can be more than that, and it's too bad that it's not treated with a little more respect. (Isabelle)

It just didn't seem to be something on the doctors' radar in that it's not life threatening. So it's just kind of a secondary nuisance. But it's not a nuisance to the person who has it. It's really... really, really annoying, and debilitating if you get it. (Helen)

They have no time to deal with somebody that's survived breast cancer and has lymphoedema. They said, "listen, you don't need chemo, you don't need radiation, you're cancer-free, go away." (Jamie)

For the most part, women felt that they were left to deal with lymphoedema on their own.

Many of the women felt that their health care providers did not provide them with adequate information on how to deal with their condition. When asked about her initial understandings of lymphoedema and its treatment options, Gina replied,

The surgeon didn't really talk about it. He had something on the wall, and that's where – I mean, I knew nothing about lymphoedema. So, I guess I saw the note on the wall and I knew swimming was good for it. (Gina)

The conflicting views between patients and practitioners on the seriousness of lymphoedema can be explained by the inadequate level of awareness of the condition among both patients and providers, which translates to the inadequate provision of information and support in its management. The fact these women felt they could not access their health care providers as knowledgeable resources further exacerbates the problems of lymphoedema framing.

Managing Lymphoedema

In investigating the identification of lymphoedema within the context of framing illness, it becomes clear that the way in which lymphoedema is defined (especially at the time of

diagnosis) affects the actions women take towards its management. The following section will focus on the management of lymphoedema and explore its connection to health communication. Emerging themes will be discussed using a model of health communication proposed by Northouse and Northouse (1998), which focuses on a systems perspective of the relational, transactional, and contextual factors in the health communication process. Northouse and Northouse's model postulates that the four main types of relationships that exist in health care settings (professional-professional, professional-client, professional-significant others, and client-significant others), are all interrelated and influence one another. Since their initial diagnosis of lymphoedema, all of the women interviewed felt that they did not receive adequate information and care for lymphoedema, which signified a disruption in dissemination and uptake of health knowledge. To better situate the findings on health communication, it is imperative to understand the process through which these women seek health information as the following section will discuss.

Frustration with the availability and reliability of resources.

The sources of information that women with breast cancer-related lymphoedema used regarding their general health were compared to sources regarding lymphoedema specifically. It is important to note that although "general health" can never be entirely separated from "breast health" (and in this case, lymphoedema) in those who have been affected by breast cancer, the differences between these sources of information are nevertheless significant.

In terms of their general health, women tended to use a variety of resources including the internet (knowing that information may be inaccurate), television, newspaper articles, nutritional magazines, books, textbooks, talking to friends, and/or consulting physicians. Among

participants that had a health or nursing background, some also used journals and published articles.

In comparison, the primary sources used in gathering information specific to lymphoedema as reported by the women were the internet, resources provided by Breast Cancer Action (BCA), namely books and information sessions, as well as physiotherapists and massage therapists. It is important to note that all participants interviewed in this study were members of BCA and thus had access to this well-established support network, whereas women not involved in BCA would lack this extra resource.

BCA was identified as an important resource in every interview conducted. Participants made use of a diverse range of programs and services available at BCA including fitness classes, the Dragon Boat program, workshops on lymphoedema, and the BCA library. Overall, BCA constituted a major resource support and network for these women interviewed. In the women's views, BCA's importance cannot be emphasized enough, especially in circumstances where women living with lymphoedema did not receive the support and information they need from their health care providers. Of the 12 women interviewed, only three felt satisfied with the amount and availability of information pertaining to lymphoedema management. The nine other women stressed the need for more accessible information:

With lymphoedema, it's kind of like a lot of women have it, and really don't know who to turn to, to get expert advice on it. I happen to be involved in the field, so I'm linked, but the average woman out there, they're not linked. [...] They don't even have a clue what they're going to have to deal with, and the follow-up to help them through all the side effects of the disease, whether it be lymphoedema or anything, is just not handled. They're just left. A lot of people slip through the cracks, which is kind of scary. (Jamie)

As someone who was involved in the field of breast health and who was also dealing with lymphoedema, Jamie revealed on the problems associated with the lack of information and support for women with lymphoedema. Her perceptions were echoed by several respondents. The frustration in participants' responses provides a clear picture of the impact a dearth of information has on the ways these women are left to manage the condition on their own. The lack of support from health care providers has implications for the treatments used by these women. Several participants reported that they never received information on the management of lymphoedema from their general practitioners, surgeons, or oncologists. Instead, they depended on their physiotherapists and massage therapists for this type of information. One participant explained her views on the issue:

Well, I've gone to the library and I've also gone to BCA. I've also asked my physicians – they don't know a lot about it though. The general practitioners, they're kind of more interested in referring you to your surgeon, and I find the surgeons don't know a lot about it because they just kind of worry about the surgery. But the rehab afterwards is... [It's] kind of more up to the physiotherapists [...] So those are the people that have helped me the most, with lymphoedema. (Jamie)

As in Jamie's case, the women who were more physically active tended to express gratitude towards their physiotherapists for helping them control their lymphoedema, and return to or begin active lifestyles. Similarly, massage therapists were viewed as important in the management of lymphoedema.

Well, I don't know what forms of management are available. I know what I did, and that was, go to massage therapy [...] And wearing all this padding and the foam and the, doing my hundred sixty strokes of... [gestures] this kind of thing every day before I got up and every night before I went to sleep. And, just absolutely religiously for years. And that was it [...] that's the only thing anyone ever told me, and I did it and it worked, so I don't know what else there might be. (Helen)

It is important to understand that these women are not only frustrated with the amount of information on lymphoedema that is available, but more importantly, with the quality of the information. The data emphasizes that the quality of information on lymphoedema is largely shaped by the ways in which lymphoedema is framed. General practitioners, as well as the surgeons and the oncologists, constitute a patient's first line of information. As such, they have the power to construct or frame the condition, which in turn impacts the management of the condition. Responses show that the perceived lack of concern for lymphoedema by health care providers contributes to many uncertainties about the condition and exacerbates the problem. Women's responses demonstrate how lymphoedema is often considered a very secondary health problem by many of their health care providers and is usually only briefly mentioned after breast cancer surgery. Furthermore, some of the women raised their concern for the lack of close follow-up and monitoring of their symptoms.

Despite the improvements and increase in knowledge and awareness of lymphoedema over the past decade, the women interviewed for this study echoed a common complaint in that greater awareness is needed. In Freidson's (1970) book, *Profession of medicine: A study of the sociology of applied knowledge*, the people in the medical profession are described as having the ability to legitimize an illness and determine what illness is. Occasionally, the patient's view of an illness may deviate from that of the practitioner; however, it is the practitioner's view of an illness that is legitimized and may even be imposed on the patient (Freidson). Freidson's concepts are reflected in Brown's (1995) work, both of which highlight the practitioner's importance in framing illnesses. Lymphoedema is a condition that has been legitimized in scientific literature, and its treatment options have been studied; however this knowledge is not effectively transferred to the patients.

An issue that seemed to recur throughout the interviews was the need for better practitioner-patient communication and “some kind of composite of good procedural information” (Helen) that would provide women with the means to manage their symptoms. In a discussion on the available treatments for lymphoedema, Isabelle stated,

Every woman who’s gone through surgery really has to have it hammered home, as to what the results are. Like, you can’t just say that “you can get lymphoedema.” It doesn’t mean anything to them. They need to know what the consequences are. And that’s what I found we didn’t get, you know, from that end. (Isabelle)

Referring back to Northouse & Northouse’s (1998) health communication model, the ways in which professionals communicate with each other has an impact on how professionals communicate with clients. In the context of lymphoedema, there does not seem to be consistent understandings of lymphoedema among health care providers, which results in problems in the professional-client relationship. In examining the health communication process more closely, a problematic theme emerged: Conflicting messages received by patients from various sources of health information.

Conflicting messages from all directions.

A consensus among health professionals in terms of the successful management methods for lymphoedema has yet to be reached. As a result, women living with the condition continue to struggle with the different advice and opinions from their health care providers. As discussed in the literature review, studies show different understandings of the role of exercise – particularly resistance exercises – in the management of lymphoedema. Such conflicting views amongst health professionals trickles down to the people living with the condition, which leaves them

uncertain as to what they should be doing to successfully manage symptoms. In talking about conflicting information that she has received, one participant stated,

Everybody's got a point of view, so it's very difficult to trim it... What is correct and what isn't correct. And that goes beyond exercise. It does affect your daily life. When you're lifting or whatever you're doing, you have to be very careful. You have to wear... I wasn't going to do anything today, so... except cook, so I didn't feel guilty about giving myself a day off, but if I was gonna do anything at all, I would wear my sleeve. Now, I still shovel. Even though my massage therapist was not too keen on that, but I think if you do it in moderation, [it's okay] you know? (Isabelle)

As in Isabelle's testimony, many women were skeptical of the information communicated to them by their health care providers and thus sought out information on their own, through alternative health professionals and sources such as the internet. Charlene discussed her experiences in searching for information from several different health professionals:

I was mad. I was much angrier about the lymphoedema than I was about the cancer [...] It was really, really, annoying because the doctors I saw told me, you know, I just had to face the fact that I wasn't gonna be able to do the things I had done before, and yeah, that made me really angry – I don't like being told I can't do things. And... but fortunately, somebody told me about the exercise centre at the cancer centre, and I went and saw them and said, you know, "is this really true? Am I never gonna be able to do these things again? Or you know, can you help me to be able to do them?", and they said they could, and so, I felt much more positive after that, and they gave me a program, which I followed, and it worked! (Charlene)

Charlene's initial frustration seemed to stem from the idea that patients expect their health care providers to provide them with reliable information, support and guidance regarding their treatment options. In the case of lymphoedema, however, gaps in knowledge exist and hinder the communication process. Among the women who had managed to overcome such barriers to exercise, there is strong awareness that these informational barriers need to be addressed.

I think, you know, there's a lot of misinformation about what people with lymphoedema can do or should do in terms of exercise, and I'm surprised that there still seems to be a fair bit of that out there in spite of the, you know,

evidence to the contrary that's come out in the last 10 years. [...] There are still some women in [the pre-op session group for newly diagnosed women] who've been told that they can't exercise after they have their surgery because this may cause lymphoedema. And I'm kind of shocked that that's still out there, you know, because I mean we've had Dragon Boat teams for, what, 13-14 years now, and the evidence has been that exercise can be good and helpful, and the idea that women are still being told this, I find, yeah, discouraging. (Charlene)

In light of the differences in health messaging from among the patient's own team of health care providers, it was found that the doctors and surgeons were the least trusted in terms of information on lymphoedema and its management. The problem is further complicated by conflicting messages even among women who have a team of health care providers working with them. This finding is consistent with the results of a Canadian study of 115 participants from Toronto and London, Ontario, which found that 42% of people living with lymphoedema reported that their condition was self-diagnosed (Lymphovenous Association of Ontario, 2006). Because of the lack of effective practitioner-patient communication, patients felt obliged to turn to alternative sources of information. All of the women interviewed have, at some point, searched the internet for information on lymphoedema, although the information found online was for the most part viewed negatively. The main criticism was the lack of accuracy in online information and, interestingly, the "alarmist" nature of health information, which will be discussed in the following section.

Feelings of fear and worry in the management of lymphoedema

One of the greatest concerns of the women interviewed was the alarmist, exaggerated nature of some of the internet-based health information on lymphoedema. Several participants elaborated on their perceptions of the information they received:

Well, pretty much, it was these bold-faced lists of things you'd never be able to do again in your life, which is so depressing. I mean, and I would say, for me, now, it's not true either. [...] So I really found that discouraging. As a matter of fact, I would say aside from the learning that you're mortal part of being told you have cancer, it was worse than getting cancer. Because, it seemed like from the stuff I read, that it was permanent, forever, and there's nothing you could do about it. (Helen).

The analysis of women's testimonies revealed an opposing tension: on one hand, the women struggled to validate lymphoedema as an illness that warrants heightened concern and care, and on the other, they felt concerned with the ways in which online information frames lymphoedema by instilling fear in its readers. Each woman interviewed felt that lymphoedema is a condition that necessitates medical attention and should not be dismissed merely as a secondary nuisance. Yet, some women were concerned that some of the information they came across exaggerated the severity of the condition, which denotes the condition as unmanageable. The dependence on online sources was in part due to the perceived lack of ongoing care from health care providers. In addition to the problem that online information is not tailored to an individual, a resulting consequence of the use of online information is the dismissal or minimization of treatment strategies such as exercise routines. For instance, recommendations to avoid exercises can contribute to the risk factors associated with increased incidence of lymphoedema and the worsening of symptoms.

Taking control of one's health

Women are not passive in taking care of their health; in this study, the participants were active in addressing fear and confusion as well as seeking reliable health information. The emergent theme of taking control of one's health was a positive link to BCA's *Lymphedema*:

Take Control public health program, which fostered women's independence in lymphoedema management. A common perception throughout the interviews was the importance of taking control, and of "being your own advocate." Many of the women interviewed indicated that the composite of information they acquired over the years was largely a result of their own efforts to seek and to share that information. For example, Kathleen compiled a collection of articles and resources on lymphoedema, which she later donated to BCA for other women who wished to consult the most current literature on the subject. Another participant, Gina, sought advice from a wide range of health professionals to gather as much information as possible on how to manage lymphoedema. She found that much of the information she received was conflicting, and decided that she would create her own care plan based on the array of messages she received.

What I did is I kind of took everything everybody, you know, telling you what they truly believe, so they're not being malicious or anything, it's just, you have to find, at least in my opinion, what works for you, and to find a comfort level of what you're willing to try, and see if it does make a difference... and consistency. [...] So you have to learn to manage it (Gina)

Abigail's response was similar to Gina's, and she stressed the value of learning about your own body and making your own decisions:

We have to learn about ourselves, and trust. This helps me, and even if somebody says, "oh you know, it's not that important", we have to establish our own care plan, and go for it, try to make sure we get that care.

Both of these women's responses reflect the existing problem with gaps in theory and practice with regards to the management of lymphoedema. The problems are indicative of the difficulty in framing lymphoedema, beginning with the initial diagnosis and continuing through the long-term management of the condition.

Within the context of framing lymphoedema, it is evident that individual, social, and biomedical factors influence the identification of the condition, and they not only affect how it is diagnosed and understood, but also how it is managed (Brown, 1995). Using a health communication model, it can be argued that there are discontinuities in the relationships (specifically between practitioner and patient), that affect the health messaging and identification of lymphoedema. Disturbances in health messaging arise from the lack of clear definitions as well as the lack of consensus on the appropriate treatments for lymphoedema. Despite the establishment of recommended guidelines in the literature, the information is not adequately transferred into practice. More importantly, in looking at the situation from the patient's frame of reference, it is the perceived lack of provider concern, both initially and during follow-up visits, the conflicting messages, and overall lack of awareness and support for lymphoedema that drives the patient to seek alternative sources of information. The majority of women turned to internet websites to find information and advice on managing lymphoedema. This practice compounds problems due to a lack of qualified individual assessment, as well as the prevalence of misleading or false information. In this study, women's responses reflected key concerns that emerge when gaps in effective knowledge exchange and in practice continue to exist.

Discussion

This paper demonstrated the potential complexities of lymphoedema-related health communication for women following breast cancer surgery. The limitations of the study included the fact that differences in racial backgrounds and socioeconomic status were not observed, as well as the representation of women only from BCA in the Ottawa region. While recruiting participants through BCA was beneficial in creating a common source from which women could

be selected to participate, it also implied that the women interviewed had chosen to become members of BCA and had volunteered to share their experiences with me.

In this article, the viewpoints and experiences of 12 women living with lymphoedema were analyzed to explore the impact of lymphoedema framing on the course of action for illness treatment and management. Research findings focused on the diagnosis and understanding of the illness, as well as problems in health communication, both of which impacted the first stage of framing illness: “identification” of disease.

The difficulty in identifying the illness begins with the initial diagnosis of lymphoedema, which is marked by conflicting patient-practitioner views of the condition. The initial diagnosis was a shocking experience to those who were unaware of lymphoedema prior to its development, and was regarded with dread in those who were aware of it and feared its onset. The participants confirmed that the onset of lymphoedema altered several aspects of their lives, such as their engagement in certain activities involving arm movements. Further compounding the problem is the women’s perceptions that their health care providers tended to overlook the seriousness of lymphoedema, viewing it as a secondary nuisance in comparison to breast cancer. In his work, Brown (1995) argued that patients and physicians exist in different social positions, which ultimately influence how illness and disease is framed: while the patient frames illness through the personal and social effects it has on his or her life, the physician frames disease as a concrete biomedical entity. A further complicating issue was the divergent, and at times conflicting messages on the importance and severity of the condition, which led to subsequent problems for patients in making effective treatment decisions.

Women’s health care providers play an influential role in framing their condition and in suggesting treatment options. The availability of treatments can impact the framing of disease in

a number of ways: (1) it can contribute to further medicalization of the professional framing of a normal process, as in the case of menopause, in which the discovery of synthetic estrogens led physicians to medicalize menopause as a disease characterized by estrogen-deficiency (Brown, 1995; McCrea, 1983); and (2) it can contribute towards the opposite effect of “invalidating” an illness. In the case of lymphoedema, the lack of individualized attention from health providers leads to the framing of the condition as a minor concern, whereas the women living with the condition disagree.

This study strongly supports Brown’s (1995) model that uncovering lay perceptions of the identification of illness is the first step to understanding how an illness is framed and sheds light on the actions people take towards its treatment. In addition to the general lack of concern received from health care providers, the women received conflicting messages that indicated a lack of consensus on effective treatment strategies for lymphoedema. In the discussion of research results, Northouse and Northouse’s (1998) model of health communication was used as a tool to understand the structural processes of health communication. Analysis of the data revealed not only a disconnect in communication between practitioners and patients, but also a lack of consensus among practitioners, which further exacerbated the process for more effective communication, reception and understanding of key health information related to the management of lymphoedema. Without the support from their health care providers, many women resorted to dealing with their condition on their own, with both positive and negative consequences. Many women reported that they became more actively involved in maintaining their own health after becoming reliant in seeking out information on their own. A positive consequence of taking control was active engagement in exercise, which enhanced QOL. On the other hand, the absence of medical diagnosis can result in self-diagnoses and seeking out

unreliable sources of information from the internet. Although it would be impractical to try to dissuade over-reliance on the internet for sources of information on lymphoedema, having the support of their health care providers to provide them with information at the outset would empower women to make more informed decisions about their treatment. In order to achieve this goal, however, it is important to target the root of the problem.

Problems in health communication reflect the difficulties in the ways in which lymphoedema is framed by those in the medical profession and by those who are dealing with the illness. By applying Northouse and Northouse's (1998) model as a tool to investigate the construction and identification of lymphoedema, important areas of mixed understandings of lymphoedema and faulty communication between professionals and clients were identified. The lack of consistent framing of lymphoedema contributed to the ambiguity of definitions, and emphasized the importance of establishing consistent health messaging and education. In the Ottawa region, the people at BCA took initiative to address this problem by better educating women at risk for developing lymphoedema, and providing appropriate information and support to those who are living with the condition; however, increased support is needed from a wider network, including health care providers involved in the field of breast cancer.

This research also reflects some of the best practice guidelines proposed in Covello's (2003) model of risk communication. Covello identifies the importance of accepting and involving all parties that have an interest or a stake in the concern. This research emphasizes the importance of communication through a wide range of channels that extends not only to professional-client communication, but also to the collaboration among professionals to support consistent health messaging. Covello also promotes listening, feedback, participation, and dialogue, which supports that idea that risk is conceptualized in different ways and is consistent

with Brown's (1995) notion of understanding how a disease is framed. The women interviewed felt that their struggles with lymphoedema were not recognized as serious by a majority of their health care providers. Covello describes the need to be honest and open about the risks, which refers to the importance of neither minimizing nor exaggerating the level of risk of the situation and directs professionals not to provide over-reassurances. This guideline is extremely relevant to health communication with respect to lymphoedema, given that it is an under-identified condition with which many women live. Covello also refers to the importance of clear and compassionate communication by identifying specific actions that an individual can take for protection and prevention. As conveyed by the participants, there is room for improvement with regards to the quality and consistency of support and information from their health care providers.

Conclusion

The research findings of this study demonstrate several important issues that arise from problems related to the identification and understanding of knowledge on lymphoedema. Specifically, this research demonstrated that a lack of knowledge and validation of lymphoedema from health care providers and conflicting messages contributed to a situation in which the women interviewed in this study felt that they had limited support from health care providers and felt uncertain of appropriate and effective techniques to manage their lymphoedema. Although these circumstances led many women to become active in their health care, communication problems remain a significant barrier to knowledge exchange necessary for the adoption and integration of exercise amongst other strategies in the successful management of lymphoedema. Given the importance of effective health communication, several recommendations from this

research study are suggested: (1) raising awareness of lymphoedema prior to breast surgery, which should begin with the team of health care providers working with women undergoing breast surgery in order to promote adequate and consistent messages and health information, (2) increasing the collaboration between physiotherapists, massage therapists and general practitioners in dealing with patients with lymphoedema (3) establishing routine pre-operative baseline measurement of the arms to aid in the detection of arm lymphoedema, (4) providing women with post-operative sessions with a physiotherapist for assessments, (5) increasing the awareness of the seriousness of lymphoedema among general practitioners and the need to communicate effectively to their patients, (6) increasing financial support for the treatment necessary for women to manage lymphoedema and (7) ensuring that women are directed to reliable sources of information by their health care providers. These recommendations center on the importance of improving collaboration among health professionals and communication between professionals and clients. It is equally important to raise awareness and provide consistent support for people living with, or at risk of developing lymphoedema.

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CHAPTER IV

Framing Lymphoedema following Breast Cancer Surgery:

Women's Experiences and Perceptions of Body Image, QOL and Support

Introduction

An understanding of breast cancer and its effects from a woman's perspective is important to the growing field of literature (Thomas-Maclean, 2005). Breast cancer survivors form the largest group of female cancer survivors (Ganz et al., 2002). For those who undergo breast cancer surgery, up to 28% develop upper-body lymphoedema (Vignes, Porcher, Arrault, & Dupuy, 2007). Lymphoedema is characterized by the accumulation of lymphatic fluid in the subcutaneous tissues and can significantly affect one's physical and psychological health. It can also impact body image and negatively affect one's quality of life (QOL) (Vignes et al., 2007; Karadibak, Yavuzsen, & Saydam, 2008), decrease arm mobility, increase dependence on the health care system, and create obstacles to one's ability to perform daily activities or take part in sport and leisure activities.

Within the field of breast cancer research, a focus on understanding breast cancer-related lymphoedema has developed over the past decade (Towers, Carnevale, & Baker, 2008; Vallance, Courneya, Plotnikoff, Yasui, & Mackey, 2007; Thomas-Maclean, 2005). While earlier research on lymphoedema focused on measuring the effectiveness of treatments for the management of lymphoedema and QOL, recent studies have explored the psychosocial impacts of lymphoedema, while others have examined specific treatment options such as physical activity (Towers et al., 2008; Ochalek, 2008; Vallance et al., 2007). This research was conducted in order to contribute to this growing field of research by investigating key issues that emerge during the lymphoedema framing process. Using a gender-based approach (Status of Women

Canada, 2010) on 12 women's reported experiences of lymphoedema, we explored women's experiences that relate to their QOL, integrating successful treatment strategies, and issues around body image and support. A qualitative analysis of women's experiences revealed these women's perceptions and experiences of living with lymphoedema, and also provided a forum for their voices to be heard with the aim to better understand how women live and cope with this illness.

Background

According to the National Cancer Institute (US) estimates from the 2001-2003 data, 12.7% of American women born today will be diagnosed with breast cancer at some time in their lives, commonly expressed as 1 in 8 women (National Cancer Institute, 2006; Hortobagyi et al., 2005). The increase in breast cancer research has contributed to improvements in detection, diagnosis, and treatment of breast cancer and the care of breast cancer patients. This has resulted in a decline in the number of breast cancer deaths in the past two decades (Greenlee, Murray, Bolden, & Wingo, 2000; Ravdin et al., 2007). During this time, breast cancer studies examined physical activity with the aim of improving the QOL of women dealing with breast cancer and breast cancer survivors. A number of breast cancer studies have discussed lymphoedema as having negative effects on women's QOL following breast cancer surgery, yet few have investigated women's experiences with lymphoedema on a more in-depth level.

A review of the existing literature on lymphoedema revealed that although there is a significant body of research in this area, most lymphoedema studies are quantitative in nature, and focus primarily on scientific aspects of the disease, the effectiveness of treatments, and measurements of QOL (e.g., through mobility measurements) in patients with lymphoedema.

This literature has described upper-arm lymphoedema as a condition that can develop at any time following breast surgery; it can develop days, months, or even years after the original operation (Vignes et al., 2007). Although there is no cure for lymphoedema, a number of treatment practices are recommended to manage symptoms. These practices include limb elevation, compression stockings and sleeves, manual lymphatic drainage massage, and exercise (Lamont, 2007; Ochalek, 2008).

Furthermore, this literature has assessed the effectiveness of treatments through clinical trials in which arm volume and circumference were measured for changes throughout treatment methods. These research findings indicated that patients with lymphoedema experience greater levels of functional impairment, poorer mental health, as well as increased anxiety and depression compared to individuals without lymphoedema (Karadibak, Yavuzsen, & Saydam, 2008; Ridner, 2005). One aspect of increasing concern is that lower levels of physical activity are found among women with a history of breast cancer, and in particular, those who are living with lymphoedema, compared to those without a history of breast cancer (Ridner, 2005). Several researchers who studied the impact of low levels of exercise on the management of lymphoedema found that women who developed lymphoedema following breast cancer surgery and who decreased the use of their arms tended to suffer from limited upper-arm movement and an increase in the severity of swelling in the arm (Karadibak et al., 2008; Ridner;). Vallance et al. (2007) recognized the need to improve psychosocial and physical outcomes in patients with lymphoedema through physical activity, and explored effective strategies to increase levels of physical activity and QOL in this population. Their work contributed to the initiation of lymphoedema research to focus on the investigation of how physical activity can be more effectively integrated into treatment programs for women living with breast cancer-related

lymphoedema. Examining perceptions and experiences with exercise among women dealing with lymphoedema will be a beneficial contribution to this growing field of research. A qualitative analysis of women's reported experiences of lymphoedema will also provide valuable insight into their experiences and perspectives on body image, support, and well-being, all of which may greatly impact one's quality of life and health outcomes.

Theoretical Framework

Since our study is concerned with understanding how lymphoedema is framed and understood, I employed Brown's (1995) model of framing illness and disease, which involves the situating and positioning of a disease within its broader social context. It is important to note that illness can be distinguished from disease in that while disease refers to the concrete biomedical entity diagnosed by health professionals, illness refers to an individual's experience of disease (Clarke, 2008) and is the focus of this investigation. Brown's theoretical model served as a tool to gain insight into the interconnected factors that influence people's understandings of the meaning of illness, which in turn, affect an individual's actions with regards to health, illness, and the management of illness (Brown). Brown's theory is based on the premise that one can understand the social construction or framing of an illness through the critical examination of four (4) stages: 1) the identification of disease, 2) the experience of illness, 3) treatment, and 4) outcome. As this paper is focused on the ways in which women's experiences shape the framing of their illness, I will focus the attention on the latter three components of Brown's theory, all of which directly relate to women and their compromised QOL. Brown argued that physicians and patients are situated in different social positions relative to disease and illness; while the patient experiences personal and social effects of the illness on her life, the physician deals with disease

as a separate biomedical entity. Investigating the experiences of illness, treatment, and outcome, from a participant's perspective would offer new contributions to lymphoedema research.

Methodology

Qualitative research methodology was employed to examine the varied experiences of women who developed lymphoedema following breast cancer surgery. Qualitative research is best suited for gathering in-depth understandings of questions dealing with *how* rather than *why* questions (Becker, 1998). In this research, qualitative methodology was employed with the purpose of gaining a comprehensive understanding of how 12 women dealing with lymphoedema frame their illness.

Methods

The community partner for this research is Breast Cancer Action (BCA) of Ottawa. It is a voluntary organization that was established in 1992 to provide support, information, and education to women affected by breast cancer, as well as support for their families. The organization is funded by the Ontario Trillium Foundation, the Canadian Breast Cancer Foundation, and the Ottawa Regional Cancer Foundation. BCA is widely considered a key player in the local breast cancer activist movement, in part due to its research affiliation with Ottawa-based research hospitals, as well as the innovative public health programs, such as the *Lymphoedema: Take Control Project 2007-2009*, which targets lymphoedema awareness. Initiating a partnership with BCA provided the opportunity for the coordinator to learn about the researcher's interests, and allowed for a collaborative discussion on the ways in which the

research could be designed in order to be most useful to women dealing with or those at risk of developing breast cancer-related lymphoedema.

Ethics approval was obtained from the University of Ottawa Review Ethics Board and the Executive Council of BCA. BCA members were invited to participate in qualitative, semi-structured interviews by posting advertisements on the BCA website, by recruiting participants in person during exercises classes at BCA, and with the assistance of BCA staff, who sent out informational emails to all its members. The semi-structured nature of the interviews, consisting mainly of open-ended questions, allowed participants to describe their perceptions and experiences of their condition, as well as address issues they deemed to be significant. Twelve women responded to my recruitment advertisements and represented a sufficiently diverse range of perspectives for this project that further recruitment was not needed. A brief questionnaire was administered to each participant immediately prior to the beginning of each interview. The questionnaires were structured using a Likert-scale style of questions which allowed for ease in its administration, completion, and analysis. The questionnaires revealed the following characteristics of the group of women interviewed: Participants' ages ranged from 40 to 70+ years, with the majority between 60 and 70 years of age; participants' abilities to manage their lymphoedema symptoms ranged from "fair" to "excellent," with the majority of participants revealing their ability as "very good"; and finally, the reported levels of physical activity varied between participants, and between different types of physical activity (i.e., flexibility, strengthening, and aerobic). In terms of the number of years since lymphoedema diagnosis, the women interviewed reflected a range from 2 to 20 years, while all the women reported the severity of their lymphoedema as being mild or moderate. The interviews took place at either

the participant's home or at coffee shops, whichever was most convenient for the interviewee. Each interview lasted between approximately 30 and 60 minutes.

The interview guide was designed using Brown's (1995) model as a framework in order to ensure that the areas of investigation pertinent to the framing of illness were explored in every interview. As such, interview questions were divided according to the four stages of Brown's theory (identification of illness, experience of illness, treatment and outcome) in a way that allowed for a sense of flow in the interview process. For the purpose of this paper, however, we will build on the earlier discussion in the previous chapter by focusing on the latter three stages of Brown's (1995) theory. The nature of semi-structured interviews lends itself to a conversational style of interviewing in which the interview follows the direction led by the participant. As such, not all questions outlined in the interview guide were asked during interviews, and the order of questions was not fixed. In addition, a number of questions in the interview guide were modified throughout the data collection process as concepts and categories developed, informing and clarifying the focus of further areas of questioning. For example, after conducting the first interview, the question on women's perceptions of the meaning of health was placed at the beginning of the interview guide since it provided a better sense of flow. The questions were open-ended, allowing for in-depth and detailed explanations and descriptions. For example, I inquired whether lymphoedema had an impact on the participant's work life, and if it had, I probed for the ways in which the participant felt her work life had been affected by lymphoedema. The final question in each interview conducted invited participants to address any issues or topics that were not covered in the interview, and that they deemed to be significant. All interviews were recorded using a digital audio recorder and then transcribed verbatim. The transcripts were then sent to participants for review and feedback in order to verify the accuracy

of their statements, views, and experiences. Four participants responded with slight modifications to their interview transcripts, primarily to clarify certain words that were misunderstood during the interview.

Analysis

While Brown's (1995) theory of framing illness was used for the structure and interpretation of the project as a whole, a gender-based analysis was employed to situate women's responses. In the first phase of data analysis, each transcribed interview was reviewed in its entirety to obtain a sense of the interview as a whole. The first review process allowed me to familiarize myself with the data, and to record initial observations. The second phase consisted of grouping participants' responses from all the questions explored during the interview that relate to the focus of this paper. This process offered an opportunity for an in-depth review of responses and allowed for comparisons between responses. The grouped data along with the initial observations and notes were then reviewed to identify recurring themes, which were reflective of women's experiences of lymphoedema and the ways in which they framed their condition. Coding data provided flexibility in terms of dealing with interrelated themes, and allowed for ease in expanding, collapsing, and dividing themes throughout the coding and analysis process. The emergent themes were then compared against published findings in the field, and similarities and divergences in these findings were discussed.

Once data were compiled and organized, I applied a gender-based analysis to my data to provide insight on the ways that women dealt with lymphoedema, how they used the health care system, as well as their views on their overall experience with its management and outcomes. Applying a gender-based analysis to research on women in the health care setting, and particularly women living with a chronic condition, can provide a better understanding of how

current framing of lymphoedema, manifested through policies and programs for those living with the condition can affect women's experiences. In employing a gender-based approach to my analysis of women's perceptions of lymphoedema, constructions of health and well-being will be discussed and women's perceptions and experiences will be situated within understandings of how this illness is framed (Schiavo, 2007; Weedon, 1997).

The purpose of employing a gender-based analysis was not to arrive at a single conclusion to explain women's circumstances in dealing with breast cancer-related lymphoedema. Rather, I endeavoured to demonstrate the range of perceptions and experiences of women living with the same condition. In conducting this research, I conversed with women during a single session, which provided a revealing vantage into their lives at that point in time. The experiences captured through this research do not represent definitive and fixed aspects of participants' lives; rather, they demonstrate the diverse and complex ways in which women perceive and experience lymphoedema at particular times in their lives.

Results

Experiencing Lymphoedema

An individual's experience of illness differs based on the ways in which she or he manages the conditions of the illness and severity of the disease, and is further impacted by other variables such as gender, race, class, ethnicity and nationality (Brown, 1995). Brown argued that differences in perceptions of health problems (especially chronic conditions) stem in part from a broader system of social, cultural, and economic interactions. Given the health struggles that breast cancer survivors are faced with, it is important to understand their individual perceptions on the meaning of health and illness.

Defining health

. Among the breast cancer survivors interviewed, health was viewed less as the absence of disease, and more in terms of the maintenance and improvement of current well-being. One participant defined health as a “balance of the elements that make for a healthy lifestyle, like sleep, and diet and exercise; and it’s about quality of life, being able to do the things that you enjoy doing, and feel good about it” (Katherine). Participants’ definitions of health were strongly related to QOL as they explained the importance of being able to function without hindrances, whether this meant having the ability to dress themselves, walk up the stairs, or participate in sport and leisure activities.

Several of the women interviewed revealed that their perceptions of health changed after being diagnosed with breast cancer. One participant admitted to being unaware and indifferent to possible health consequences before being diagnosed with breast cancer. After diagnosis, she emphasized how maintaining her health became a priority in her life, including the necessity of paying closer attention to diet, exercise and stress management. Most of the participants’ experiences of lymphoedema stem from holistic views on health. Two principle themes emerged in the process of data coding and analysis: 1) body image and 2) changes in QOL. A discussion of these two emergent themes will reveal insight into women’s experiences in dealing with lymphoedema and in their confrontation with fear and anxieties related to their illness.

Lymphoedema’s impact on body image

The literature on breast cancer and QOL has revealed that a woman’s body image and sense of self-esteem may be affected by her body’s changes after breast cancer surgery. Pitts

(2005) examined women's struggles to hide their disease as a result of societal influences and pressures,

Women often feel a social duty to hide signs of illness, repress feelings of anger or grief, embrace an optimistic attitude and even focus on beautification techniques. Sociocultural fears and expectations about femininity, women's sexuality and illness encourage a sense of shame and discrediting about breast cancer, and work to "isolate and silence" women about its horrible realities. (p. 38)

Pitts argued that some women try to hide signs of breast-related illness, as it relates closely to prevailing norms of femininity and beauty that are rooted in patriarchal constructions of gender. These constructions of gender put emphasis on women's child bearing and rearing capacities, and the significance of the breast in constructions of beauty, sexuality and motherhood. These discourses of femininity negate alternate appearances of women's bodies such as a removed breast, surgical scars or swollen arms. When living with lymphoedema, issues of beauty and self-esteem are situated within a much broader spectrum of dealing with a host of issues related to breast cancer. Gina's response illustrated the ways in which these dominant discourses not only shape the experiences of these women, but also impact their behaviours and actions.

I tried doing a night class, but it was like water aerobics, and there were regular people in there, and I remember the teacher said, "You're not using your arms enough," and I said, "Well, I have lymphoedema." You know, it just, it was too difficult to do, and just the whole changing you know, when there's regular people. It's different when you're with the women that, you know, they have the same scars and all that stuff. (Gina)

Gina's reference to the other women in the exercise group as "regular" is an example of how she constructed, internalized, and normalized beauty and the female body. Prevailing social norms emphasize and reinforce ideologies of female beauty by encouraging women to "look 'normal', erase signs of illness and re-beautify themselves" (Pitts, p. 37).

Lymphoedema is a visible sign of breast cancer, and compression sleeves are considered as a symbol of breast cancer and of lymphoedema. One participant explained the initial difficulties she experienced in adjusting to lymphoedema and wearing a compression sleeve:

I got really tired of the sleeve, and going out and everybody would look at me like it's like, (gestures to arm), you know? And you know what, I want to take it off. I'm not gonna wear it, I don't feel comfortable when I go out. (Brenda)

Brenda's recollections revealed tensions women experience between wearing a compression sleeve on the affected arm, which visually communicates one has breast cancer, and struggling to manage appearances and body image issues. Initially, Brenda decided to not wear her compression sleeve in public, as she felt uncomfortable with the attention; However, after noticing that the swelling and pain in her arm worsened, she accepted the fact that she would need to wear the compression sleeve every day to properly manage her lymphoedema. Just as efforts are made to minimize signs of illness to the casual observer, many participants revealed a reluctance to disclose the meaning of the sleeve to others due to a desire for privacy:

People just sort of look at your glove and think, "Oh, she's got something wrong with... I don't know, tendonitis or something." They don't realize that it's for lymphoedema. They just think it's for something else because... [I'm] taking rug-hooking with my sister [...] And, the teacher just said, "oh yes, a lot of people wear a glove, support for their wrist or for their... while they're working," so I didn't say anything (laughter), or I just say, "my hand swells, so I wear it." (Elizabeth)

Participants in this study encountered challenges in finding clothing and accessories that fit due to swelling in their arms and hands. Gina explained, "I can't wear rings on this hand, because of the extra swelling and I don't wanna restrict it, which is sad because I had some nice rings." Several women also spoke of difficulties in shopping for formal clothing that would fit both arms. Francine explained, "You have to be very careful when you're buying anything that involves a sleeve. Did you have the right size? For that arm. It might be big on [the unaffected]

arm.” A recurring issue that echoed throughout the interviews was that women’s experiences with lymphoedema were closely linked to physical appearances and self esteem. Since their arms were swollen, some women felt stigmatized and it affected a wide spectrum of their appearance-related activities and experiences. The construction, internalization, and normalization of femininity, beauty, and the healthy body compounded the challenges women faced with respect to body image and the management of symptoms.

Changes in quality of life

Quality of life (QOL) is defined by the WHO (1993) as the evaluation of wellness in terms of physical health, psychological health, level of independence, social relationships, personal beliefs and environment. Within the context of lymphoedema, as with any chronic condition, QOL is an important measure in understanding the impact of an illness on an individual. Each woman interviewed reported changes to varying degrees to her QOL as a result of lymphoedema. These changes affected daily activities (e.g., dressing oneself, housework) and/or recreational activities (e.g., gardening, sports), and/or work. Such changes ranged from slight modifications and adjustments in the ways in which certain activities were performed, to the complete avoidance of other activities. The following section describes research findings that relate to women’s experiences with changes in QOL, which will reveal underlying issues such as power and authority affect the ways in which women frame their condition. Specifically, QOL will be discussed as it relates to changes in roles, as well modifications and adjustments to the ways in which activities are performed.

Changes in roles.

Not only does lymphoedema impact body image and understandings about health outcomes by altering the ways health is viewed, it also impacts day to day activities such as housework. For some women, it encouraged a reflection on traditional gender roles and expectations, and for another as a single parent, it encouraged her to seek and sustain a larger network of social support.

For two of the women interviewed, the development lymphoedema was associated with a significant change in the day-to-day roles to which these women were accustomed – roles as a mother and as an artist. For these women, lymphoedema was construed as a debilitating condition through a combination of the messages they received from their health providers and from their own experiences. Brenda is a breast cancer survivor of two years who developed lymphoedema immediately after surgery, and who struggled at first to balance the responsibilities as a mother with the changes in her life due to her lymphoedema. She recalled,

And right away they stopped me from any cooking, like I'm not allowed – I was not allowed to cook, not allowed to do any housework, and after awhile they ordered the sleeve, and till now, I'm not allowed to take off the sleeve. (Brenda)

Like many other women diagnosed with lymphoedema, Brenda's experiences with lymphoedema were influenced by the risks of aggravating symptoms associated with the treatments, and the worry of worsening her condition. She was encouraged by her health providers to avoid many activities she had performed on a regular basis. She described the difficulties she experienced with these lifestyle changes, especially with her added responsibilities as a single mother of two children.

It was really hard to know you cannot cook anymore. You know, especially when you have your kids, you cannot clean, take care of them, and I don't know why you just like, you feel like, useless, in a sort of way. But then I said, "no, I have a lot of people around me, I'm gonna ask for help." (Brenda)

Brenda felt as though her role as a caregiver was threatened once she developed lymphoedema. She worried about lymphoedema affecting her ability to provide care to her children. Brenda was not the only one to experience challenges with role adjustments. Elizabeth, an artist by profession, expressed her concern about how lymphoedema affected her work. Her work as an artist was a priority in her life, which challenged traditional views of women's roles in social/domestic work and within the home. Lymphoedema presented as a threat to her role as an artist. Elizabeth developed lymphoedema in her left arm, which allowed her to continue painting with her right hand; however, the lymphoedema affected other areas of her work, such as stone lithography, which involved the manipulation of large blocks of stone. Both Brenda's and Elizabeth's responses illustrate the significant impact lymphoedema had on their QOL and lifestyles.

Modifications and adjustments to activities.

All of the women who claimed that lymphoedema did not significantly affect their lifestyles emphasized their commitment to maintain their usual activities by making the necessary adjustments. For example, Gina, who always identified herself as a very active individual, described the lifestyle limitations lymphoedema caused, impacting her QOL.

Especially, something as – I'm gonna say, debilitating – as lymphoedema, because it changes what you can and cannot do. I mean, I can't water ski now. And even snow shoveling, that kind of stuff. I have to just do a little bit, be very careful, and I feel it when I overdo it. It hurts, it really, really hurts. (Gina)

Gina's response revealed her desire to return to the level of physical fitness she had achieved and maintained prior to developing lymphoedema; however, elements of risk limit the range of her activities. Even with the limitations caused by lymphoedema, however, Gina was determined to

remain physically active by adjusting her activities and routines. For instance, rather than running, she reported that she spends more time walking and swimming.

Jamie provided another example and explained how she modified her work schedule:

Normally I would work maybe three or four days in a row and it not bother me, but with the lymphoedema, I definitely can't work three or four days in a row. I have to kind of work a day, take a day off, yeah. So it has limited how many consecutive days I work in a row and how often I work. (Jamie)

In addition to reducing the amount of activity performed at a given time, protecting the arm during activity was a recurring issue discussed by all participants. The most frequently mentioned methods of protection included wearing a glove when gardening, applying skincare (e.g., antibiotic ointments to wounds), and wearing a compression sleeve. Laura explained the importance of planning ahead to ensure that her arm is protected during physical activity.

Like, you know you're never, ever gonna get rid of it. It's never gonna go away. So you do have to plan... like, I have to wear – I don't wear my sleeve every single day, but I would never go and do anything physical without my sleeve, so you're always having to plan, I think. (Laura)

For Laura, managing lymphoedema necessitated careful planning, while for others, methods of management were more subconsciously integrated into their everyday activities as a result of habit. Participants' responses revealed that regardless of lymphoedema's varying levels of impact on each individual's experiences, the condition nevertheless had a negative impact on every participant's QOL. A key concern that emerged from the data was that despite lymphoedema's negative effects on QOL, many women felt that QOL concerns were not adequately understood and addressed by their health care providers.

Brown (1995) argued that the experience of illness can never be fully separated from elements of clinical interaction, and that such interactions (i.e., with health providers) form a strong basis for people's understandings of illness, which in turn, influences diagnosis and treatment. The

following section describes the impact of health providers' interaction on women's understandings and experiences of the treatment stage of Browns' theory of framing a disease, and reveals problems associated with the universalization of women's experiences living with lymphoedema following breast cancer surgery.

Treatment

Regardless of whether or not the participants explicitly stated they used the recommended conservative treatments, every woman interviewed engaged in at least one method of lymphoedema treatment to improve her health and quality of life. The women's responses generally reflected agreement and compliance with the recommended conservative treatments, with the exception of exercise, an issue that will be further discussed in this section.

An individual's treatment-related decisions are linked to experiences of illness such that choices are not solely dependent on medical instructions, but also other – more social – criteria, such as responsibilities in the home, perceived stigma, and work (Brown, 1995). Dill, Brown, Ciambrone and Rakowski (1994) argued that people's decisions in dealing with self-care treatments may be made alone or in conjunction with health providers, and that such decisions structure their future illness experiences. By incorporating an analysis of the "treatment" aspect of Brown's theory, this section focuses predominantly on the use of compression garments and exercise to control the swelling from lymphoedema. The implications of these methods will be discussed with specific focus on how power and authority influence self-care and treatment decisions.

Wearing a compression garment

According to recommended guidelines, wearing an elastic compression garment on the affected arm is considered to be among one of the most effective treatments to aid in the lymphatic flow (Lymphoedema Framework, 2006). Lymphoedema compression sleeves are available in a range of forms and fabrics, which provide different levels of compression depending on individual need. Since the purpose of the compression sleeve is to provide appropriate pressure to promote decongestion in the arm, it is important that the sleeve fits properly. Women are encouraged to seek the advice of a specialist before purchasing a sleeve. The cost of lymphoedema compression sleeves varies depending of the type of sleeve required and whether or not a custom-designed sleeve is needed (most of which cost more than several hundred dollars). Most sleeves require replacement approximately every six months due to the loss of elasticity that results from day-to-day use. Lymphoedema sleeves and/or gloves were the most commonly used compression garments in the group of women interviewed. All participants reported awareness of the sleeve or the glove as a means of treatment, and only one reported that she chose not to wear compression garments. Nevertheless, many of the women interviewed recounted problems they experienced in their search for a properly-fitting sleeve.

Part of the problem about not getting [the swelling] under control was that I needed to have a glove, and it took a couple of weeks to get an appointment for the person to come look... I went to my doctor and she gave me prescriptions and I got everything lined up that I could get lined up... Finally, when I did get an appointment, it was “oh well the manufacturer doesn’t have any the size that I need” so it was another 2 weeks. And then, when those 2 weeks passed, they gave me one that was too big, and that didn’t help that much. (Elizabeth)

Elizabeth explained that the process described above took approximately three months due to miscalculations and delays. Her frustrations stemmed from her perception that women dealing with lymphoedema are not given adequate medical attention. Similar frustrations were

expressed by other participants in this study. These concerns mainly focused on the lack of support for lymphoedema from the medical system. First, there is the concern that there are no manufacturers in Ottawa or even in Canada, and thus sleeves are not easily accessible. Gina expressed her frustration that with the growing number of women in the region living with, or at risk of developing lymphoedema, there needs to be concerted efforts to address the compression sleeve shortage. There is also the financial aspect of lymphoedema care that limits some women's treatment options. Currently, the Canadian health care system does not provide coverage for compression garments, nor other conservative lymphoedema treatments and services. Although private insurance may partially cover a set number of visits with physiotherapists, massage therapists, it is often not enough to cover the cost of continued treatments. Isabelle revealed that while she made use of her husband's health coverage to help pay for the treatments, the financial assistance was "a drop in the bucket for lymphoedema patients."

A recurring concern that emerged from participants' responses was the inadequate attention women received for their struggles with lymphoedema. After the diagnosis and during the treatment phase of breast cancer, women are often generalized by health many health care providers to constitute a homogeneous group of breast cancer survivors who experience similar symptoms. It is important to understand that women with lymphoedema experience varying levels of its severity, and thus require different means and methods for managing its symptoms. For instance, Jamie, who works in the health field and works other breast cancer survivors on a regular basis, expressed her frustration with the limited support for women's individualized needs.

And I find the sleeve, a lot of the time, they just have like, small, medium, large, and... it just doesn't work, because everyone's different, like, yeah you need

custom, and then the price goes up... and so people just say, “you know what? I can’t afford it.” They don’t bother.

While women revealed the obstacles they encountered in the process of acquiring a sleeve, the problems with universalizing their experiences extended to other issues in managing lymphoedema, such as exercise, in which individualized physical assessments are necessary.

Perceptions of exercise in the management of lymphoedema

Before discussing the conflicting issues that surround exercise as a method of managing lymphoedema symptoms, it is important to understand the way in which exercise helps to promote decongestion and improve QOL. The normal flow of lymphatic fluid is conditioned by a number of factors including muscular contractions in lymphatic vessels, an effective valve system, muscle pump activity, as well as respiratory movements (Ochalek, 2008). Exercise is proven to increase lymphatic flow through the stimulation of muscle contractions, which in turn reduces swelling and decreases the progression of lymphoedema (Pain & Purushotham, 2000; Cheville et al., 2003). Individualized exercise regimens that include a combination of aerobic, flexibility, and strength training, supplemented by the use of compression garments, manual lymphatic drainage, and compression pumps have been proven to be most beneficial to women dealing with lymphoedema (Blanchard, Courneya, & Stein, 2008; Brennan & Miller, 1998).

The physical benefits of exercise are well established in the literature on cancer survivorship. They demonstrate positive effects of exercise on QOL among cancer survivors (Blanchard et al., 2008). Blanchard et al. found that 37.1% of breast cancer survivors met the recommended guidelines for exercise; however, other researchers found that women living with lymphoedema secondary to breast cancer experience lower levels of physical activity than other

cancer survivor groups (Karadibak et al., 2008; Ridner, 2005), and more attention should be focused on this group.

Exercise-related literature reveals a number of issues related to the initiation and maintenance of exercise including motivation, intention, and social determinants amongst other topics. An early study by Leddy (1997) on exercise following breast cancer found that the most significant barriers of exercise among women affected by breast cancer were lack of time and inertia, while the most significant incentives for exercise were expectations of benefit and sense of responsibility. More recent studies used various theories, such as the theory of planned behavior, to better understand determinants of intention to exercise among breast cancer survivors, and found that attitudes, subjective norms, and perceived behavioural control influenced exercise intention (Hunt-Shaw et al., 2006). While not specific to breast cancer, another recent study highlighted the value of a tailored approach to strategies for overcoming barriers to exercise, and demonstrated the effectiveness of physical activity counseling interventions within primary health settings to promote exercise (O'Sullivan et al., 2010). O'Sullivan et al.'s findings revealed the importance of autonomy support in enhancing patients' motivation and perceived competence for exercise, all of which affect exercise behaviours. *Barriers to exercise*

While the existing research on predictors for exercise behaviour are salient to understanding the barriers to exercise among participants in this study, participant's responses revealed difficulties more specific to integrating exercise into their lymphoedema treatment. In addition to the various barriers to exercise as revealed by previous studies, a sense of fear associated with certain types of exercise was revealed as a significant barrier to some of the women dealing with lymphoedema. The elements of fear and risk associated with exercise are linked to the framing of lymphoedema by health providers. Brenda's statement is revealing of

the influence health professionals can have on the women's decisions to engage in particular exercises. In a discussion about yoga classes, Brenda explained,

I tried once with BCA, but I tried another yoga [class] just close by here. It's called Dan Yoga. It's healing yoga and typically it's breathing technique for the circulation of your body. But it did not work well for me, because I'm not allowed to do repetitive movements and there is something they call brainwave that you do use your hand repetitively for 10 minutes, and another move as well, so it didn't really go well for me. So the physiotherapist said, "no, no yoga for you." So then it's like, nope, you like it, but it's not good for your health, because you can't do the repetitive movements. (Brenda)

As mentioned earlier, the reported levels of participation in physical activity as well as participation in various types of exercises varied between participants. While some participants reported engaging in over 3 hours in at least one type of exercise (flexibility, strengthening, or aerobic activity) per week, others engaged in less than 30 minutes of exercise per week. The differences between participants were partially due to health messages received from their health care providers, which influence health beliefs, as is demonstrated in the above example. Brenda's example also demonstrated the shortcomings of advice of this nature (i.e., risk avoidance), in that providers' advice often goes unquestioned by patients.

In the discussion on treatments for lymphoedema, it was evident there was no consensus on the role and level of recommended exercise in lymphoedema management. The women's responses reflected their confusion with regards to the benefits and risks of exercise which affected their participation in various activities. Isabelle revealed that she struggled with conflicting information, specifically in terms of exercise. She explained,

Everybody's got a point of view, so it's very difficult to trim it... What is correct and what isn't correct. And that goes beyond exercise. It does affect your daily life. When you're lifting or whatever you're doing, you have to be very careful. You have to wear... I wasn't going to do anything today, so... except cook, so I didn't feel guilty about giving myself a day off, but if I was gonna do anything at all, I would wear my sleeve. Now, I still shovel. Even though my massage

therapist was not too keen on that, but I think if you do it in moderation, [it's okay] you know? (Isabelle)

Isabelle's statement revealed her skepticism with regards to the advice provided to her by her health providers, which is likely a result competing opinions received from different health care providers. She dealt with conflicting messages by negotiating the risks associated with certain activities and treatments. The role of exercise in the management of lymphoedema remains unclear to the women, despite its proven benefits in the literature. The uncertainties about the benefits and risks of exercises results in a fear of aggravating lymphoedema symptoms. Hence, a number of the women were hesitant to adopt certain exercises.

I'm not confident enough to use exercise machines, because there's always a lot of resistance. Sometimes... you know, it depends on the machine. It seemed to be that I was better with my stretching and... stretching and strength. So yes, I am a little nervous about certain things. (Isabelle)

Isabelle's statement links to Pitt's (2004) work on breast cancer and personal responsibility. In her work on women's experiences with breast cancer, Pitts discussed the issue of personal responsibility and explained that the discourses of early detection and prevention in breast cancer insinuate the treatability or prevention of the disease, which leads women to feel guilt or blame if they develop the disease. Such discourses of prevention are translated to lymphoedema and the perceptions of risks related to exercise.

Some [women with lymphoedema] are very frightened, that if they do something it will aggravate it and make it worse, or that by doing some exercise, that it will, if they don't have lymphoedema, it could develop. That's one of the things. I met some of the women for the exercise classes with Breast Cancer Action, and some of them were really frightened, and I just think that's too bad... It's just too bad. (Abigail)

Abigail spoke of her experiences in working as a volunteer with women living with lymphoedema, which was revealing of her own opinions as a woman dealing with the condition. Having been very involved with BCA for a number of years, Abigail was conscious of the need

for more support from health providers in helping women establish exercise plans with their primary care providers and encouraging them to initiate or maintain active lifestyles. Her reflection revealed the extent to which conflicting messages may influence exercise participation. This problem is compounded by the fact that few women received ongoing monitoring of the secondary symptoms that resulted from breast cancer surgery. For example, Gina made a comparison between breast and knee surgery. She pointed out that a person who undergoes knee surgery will be scheduled to have an assessment with a physiotherapist following surgery. She questioned, “why would you not [have the same treatment] when they cut into your axilla?” Gina’s point addresses the issue that women dealing with, or at-risk of developing, lymphoedema following breast surgeries require individual assessments, medical attention, and legitimization. It is important for health care providers to recognize that lymphoedema is a fluid condition, and that regular assessments are necessary to observe the changes that occur, and to provide appropriate advice with regards to exercise.

Motivators to exercise

It is also important to highlight motivators to exercise as expressed by several of the women interviewed. Many of the participants felt that positive feedback from physiotherapists and support were motivators, which reflects findings in O’Sullivan et al.’s (2010) article that autonomy support, fostered by quality care and educational support, were helpful motivators to exercise. For instance, Charlene felt that positive and informed feedback from her physiotherapists enabled her to continue to engage in exercise following her diagnosis with lymphoedema. Charlene’s comment reinforced the importance of strong communicative relationships between women and their health care providers.

A second motivator for women was finding activities that “fit” with their adjusted lifestyles and routines. Four of the 12 women interviewed were members of the Dragon Boat team associated with BCA. These women found their experiences to be very positive both physically and socially. They spoke positively of their commitment to the team and to practices, as well as the strong support that being part of the team offered. Other women found alternative ways to include exercise into their lifestyles. Gina described the importance of exercise in her life: “I just can’t imagine life without exercise. To me, it’s part of me. So, it’s just like I said earlier, it just changes... You adjust it to meet your new physical being.” She described that since developing lymphoedema, she has actively sought out information and has created an exercise plan through compiling pieces of advice from various sources.

A third motivator, supported by Leddy’s study (1997), was the expectation of benefit. Just as the women reported that their perceptions of health changed after being diagnosed with breast cancer and lymphoedema, their perceptions of exercise changed as well. After having overcome breast cancer, most women reported changes in their exercise habits following diagnosis. For some women, these changes were a result of the increased awareness of the benefits of exercise:

I wasn't a person that did very much physical activity, except walking and biking were my two things, so it's opened up a whole new world for me of more options that I've got for staying fit, so it's been positive. (Kathleen)

The women’s responses demonstrated the range of barriers and motivators to exercise among women with lymphoedema, and revealed the importance of focusing on motivators to increase their level of exercise.

Outcome

All of the women interviewed reported their abilities to manage their lymphoedema as between “fair” and “excellent,” on a scale that includes “poor,” “fair,” “good,” “very good,” and “excellent,” and with the majority of reports being “very good.” With this said, many of the women attributed their ability to manage symptoms to a combination of treatment methods used. In discussing the outcome of the treatments used, the strongest reaction was the recognition of the benefits of exercise in those who were active. For instance, one participant explained:

I'm happy. Everything is going good. And, because of the knowledge, the thing I learned would be exercise and stretching, it's helping me, like... big time. Big time. Like, imagine, if 1 or 2 days I do not exercise my hand, you would see the swelling right away, and it will go tight on me, so I cannot *not* exercise. I *have* to exercise every day. (Brenda)

Brenda explained that she had attempted to adopt a more active lifestyle for years, but had never been fully committed until approximately two years after her diagnosis of lymphoedema. After starting regular sessions with her physiotherapist, she spoke of the improvements she felt and the overall impact of exercise on her QOL. Other participants reported that upon receiving their diagnosis of lymphoedema, they became more actively involved in managing their health, and more aware of the range of appropriate physical activities. Thus, although self-reports show that most of the women perceived their lymphoedema management as "very good," it is worthy to note that their ability to manage symptoms was largely a result of their own determination, support networks and advice from physiotherapists.

The importance of support groups for lymphoedema

A dominant theme related to perceived outcomes of lymphoedema was the importance of support networks. For the participants in this study, networks allowed them a physical and virtual

place in which to feel comfortable to freely share their thoughts, views, and experiences. It is widely accepted that having strong social support is a social determinant of health, and has especially positive outcomes for women (World Health Organization [WHO], 2010; Heitzmann & Kaplan, 1984). Women who participated in this study reiterated the importance of having such networks. In particular, many women emphasized the ways in which their support networks fostered a sense of shared experiences and enabled the sharing of information and resources.

In Ottawa, there are several support networks for breast cancer. An example is BCA 's Busting Out Dragon Boat program, which is a team sport offered to women affected by breast cancer. It not only provides an opportunity for adapted exercise, but also the social benefits of regular meetings for training and competition. Although almost half of the women interviewed were involved with the Dragon Boat program at BCA and felt the positive benefits of the network, there were other women who did not wish to participate in the activity. Of these women (who were not involved with the Dragon Boat team), some forged their own support groups through networking in breast cancer survivor activities. For instance, Laura, who has met with her group every week for 12 years, described her experiences and the importance of having a support network on which to rely:

[They're an] amazing group of women. I mean, I think the thing that happens, it's the same with the Dragon Boat group. You know, we've become such good friends. And you just come from backgrounds where we never would've met each other – it doesn't matter what your socioeconomic background is, what you did as a career. None of that matters. And we've become good friends in spite of all that. So it is nice. And it becomes very supportive to... and not just to if you've got a reoccurrence or anything, but anything that happens their lives, it's... a big, big support. (Laura)

Several of the women interviewed shared similar experiences, and like Laura, emphasized the importance of support groups for friendships and the common bonds they share while dealing with breast cancer and lymphoedema. On the other hand, some women felt that support systems

specifically for women with lymphoedema were lacking. The participants' responses demonstrated that although there are many advantages to support networks that are linked to health promotion programs, such networks present a number of problems; they may terminate due to a lack of funding, and may be composed of women with similar interests and passions, which exclude others.

This discussion reflects what is in the literature on social support, and demonstrates that support groups become a site where women with different histories and backgrounds can meet, discuss their problems – lymphoedema or otherwise, and enjoy the company of other women who share similar experiences. Participants' responses revealed that support networks offer valuable resources to learn more about treatment options, names of effective health care practitioners, among other lymphoedema information, and reinforced the importance of social support to one's well being. Future directions could include the establishment of more independent support networks on lymphoedema that are not exclusively under the administration, and dependent on continued funding, from other associations.

Discussion

This paper explores the ways in which women living with lymphoedema frame their condition by examining the “experience of illness,” “treatment,” and “outcome” stages of Brown's (1995) theory of framing disease. Using Brown's theory as a guide to investigate women's experiences and perceptions, I was able to flesh out themes from women's responses that revealed how their illness affected them, how they chose to treat their symptoms, and how it impacted their QOL.

Examining women's experiences of lymphoedema revealed two primary themes: the impact of lymphoedema on body image and the changes in QOL as a result of lymphoedema. Body image was found to be a significant issue in the everyday lives of many of the women interviewed, adding an additional level of stress to the physical impacts of symptoms. A number of the women felt vulnerable in public, particularly when participating in activities like swimming in which their surgery scars or swollen limbs were exposed. Every woman interviewed reported to have experienced changes in their QOL as a result of lymphoedema. For some women, these changes were significant enough to affect the roles with which women identified themselves, while for others, the changes were viewed more as slight modifications to the ways in which activities were carried out. Regardless of the level of impact, however, every woman interviewed experienced the negative effects of lymphoedema on their health and QOL.

The treatments discussed by participants primarily concerned the use of compression garments and exercise. Every women interviewed reported having tried lymphoedema compression sleeves, with the majority finding them useful. One issue raised was that the accessibility of such garments was problematic, both in terms of financial constraints, availability of the sleeves, and support from providers in the process of obtaining an appropriate sleeve. Women's perceptions of exercise, on the other hand, were found to be more complex. Despite the proven benefits of exercise, women dealing with lymphoedema following breast cancer surgery were found to experience lower levels of exercise compared to other cancer survivor groups (Karadibak et al., 2008; Ridner, 2005). Participants in this study engaged in a range of self-reported activity levels including stretching, strengthening, aerobic exercises. A wealth of research in the field of exercise science has revealed that variances in the level of activity between individuals are influenced by a multitude of factors such as time, access,

attitude, subjective norms, perceived behavioural control, autonomy support, motivation, perceived competence (Leddy, 1997; Hunt-Shanks et al., 2006; O'Sullivan et al., 2010). In addition to barriers to exercise outlined in the literature, however, a major barrier specific to women dealing with lymphoedema was a fear of health risks associated with exercise (i.e., risk of aggravating lymphoedema symptoms). The issue of fear was largely a result of the discourses on exercise for women living with lymphoedema as constructed by women's health providers and the lack of consistent patient monitoring. Discourses on exercise show that there are differences in the spectrum on what women should and should not be doing. Some of the women internalized discourses that reinforce the need to exercise but were unsure of the type of exercise they should be doing. Others were told at one time to avoid certain exercises, and have since been disconnected from the health system. On the other hand, positive feedback from health care providers, finding customized programs that fit with adjusted lifestyles, and expectations of benefit were found to be strong motivators for exercise. These findings show the importance of working to enhance the motivators to exercise.

Each woman experienced different outcomes with lymphoedema, which was likely a result of both biological and social factors. While biological factors may affect the outcome of lymphoedema (e.g., its severity), the importance of the social interactions at play throughout their experiences should not be underestimated. That is, health discourses targeted at women, through experiences with the health care practitioners and through their own support networks, had a significant impact on the ways in which they identified, experienced, and treated lymphoedema, which ultimately affected their perceived outcomes. In-depth discussions with these women revealed that although most of the women reported their ability to manage lymphoedema as "very good," these outcomes may be more of a reflection of their personal

determination, their access to a tailored lymphoedema program at BCA, their personal support networks and physiotherapists than of the advice provided by their other health care practitioners. Many women interviewed revealed the importance of support groups for women living with breast cancer-related lymphoedema. Breast cancer support groups were perceived to be beneficial as they provided sites at which women could build long-term friendships, exchange health information and advice as well as share stories with other women who shared similar experiences. As there are currently no support groups in Ottawa designed specifically for women with lymphoedema, future directions could include endeavours to establish more inclusive support networks for these women.

Conclusion

The results of this study showed that lymphoedema was framed as a condition that, while causing stress in women's everyday lives (affecting body image as well as daily activities and QOL), did not appear to warrant sufficient medical support and attention. These concerns raised in the responses were analyzed through a gender-based lens by being attentive to constructions of power and gender roles. The women's responses revealed some of these struggles in their experiences and efforts in managing symptoms of the condition. In recent years, feminists and women's health activists have launched campaigns to re-conceptualize notions of beauty for breast cancer survivors on their own terms. They contest traditional constructions of the female body which could negatively impact women dealing with breast cancer and/or lymphoedema, and particularly those with surgical scars and swollen limbs as a result of breast cancer treatments. Furthermore, some of the women interviewed struggled with discourses of

femininity and female gender roles as a result of lifestyle changes due to their development of lymphoedema.

The limitations of the study include the fact that differences in racial backgrounds, sexual orientation, and socioeconomic status were not identified, and that participants were all members of BCA in the Ottawa region. While recruiting participants through BCA was beneficial in creating a common source from which women could be selected to participate, it also implied that the women interviewed had chosen to become members of BCA and had volunteered to share their experiences with me, and that the findings may not be a representation of the experiences women not already in a breast cancer support group. Furthermore, the most of the women interviewed self-identified as being active, so the findings in this paper may not be reflective of women who do not participate in exercise programs. Future studies could explore the understanding of 'active' by seeking information on their amount and intensity of exercise, and could also include women who are less active.

Based on analysis of the data collected, the following recommendations are suggested. There is a need for increased awareness in women at risk of developing lymphoedema, as well as women who are living with the condition. Organizations such as BCA in Ottawa have taken initiative to raise awareness of this under-identified condition and have provided temporary support networks through a pilot-funded study on exercise. BCA's role is very important since health diagnoses through the internet are increasing. The establishment of general support groups for lymphoedema should be considered as a future step in the goal of enhancing the QOL of women dealing with lymphoedema.

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CHAPTER V

Conclusion

The overall purpose of this thesis was to explore the framing of lymphoedema from the perspective of 12 women living with the condition following their breast cancer surgery. The aim of this research was to better understand the barriers to the effective integration of methods and practices in managing symptoms. The methodological design informing this project followed Brown's (1995) model of framing disease and illness, which includes four stages: the identification of illness, the experience of illness, treatment, and outcome. The focus of the investigation was divided into two parts. First, the framing processes underlying the reception and understanding of health messages on lymphoedema were examined. This related to the "identification of illness" stage of Brown's theory. Secondly, women's experiences with the illness were examined and reflected the latter three stages of Brown's theory. The twelve women who were recruited to participate in this study were all willing to share their views and experiences with me during in-depth interviews and their involvement was invaluable in obtaining rich data.

Summary of Findings

Framing and understanding knowledge on lymphoedema

In the first section of this thesis, women's perceptions and understandings relating to the initial diagnosis of lymphoedema and management of the illness were explored. Applying Brown's (1995) theory to the lymphoedema context demonstrated that the way in which lymphoedema is defined at the time of diagnosis affects an individual's decisions in terms of treatment. In examining the participants' responses of their initial discovery of lymphoedema, 2 main themes emerged: (1) a lack of awareness of the health problem, and (2) a perceived lack

of validation for lymphoedema from health care providers. Half of the women interviewed reported that they were unaware of lymphoedema prior to developing its symptoms, which is a significant problem considering that almost one-third of women who undergo breast cancer surgeries develop upper-body lymphoedema (Vignes et al., 2007). The lack of awareness can be explained by health communication problems, which are likely a result of the way lymphoedema was framed. An aspect that compounded this problem was the perception that many health care providers dismissed lymphoedema as a minor concern, as it is a non-life-threatening illness. The conflicting views between patients and their health providers on the seriousness of lymphoedema can be explained by the inadequate level of awareness of the condition, and translate to the inadequate provision of information and support in the management of symptoms.

The participants' responses regarding the management of lymphoedema generated 2 themes that related to health communication problems: (1) women's frustration with the availability and reliability of resources on lymphoedema, and (2) conflicting messages received by women with lymphoedema. The sources of information on lymphoedema participants used were found to be limited to the internet, resources provided by BCA, physiotherapists and massage therapists. Only three of the 12 women interviewed reported that they were satisfied with the availability and reliability of lymphoedema information, while the nine others stressed the need for more accessible information. These findings demonstrate that despite improvements in knowledge and awareness of lymphoedema in the past decade, the information needed to successfully manage symptoms is not always being communicated to the women living with the condition. Furthermore, these findings point to a disconnect in the communication of information on lymphoedema. Lymphoedema is a condition that is legitimized in scientific literature, where treatment options have been studied; however, this knowledge is not effectively transferred to

those in need of it. Finally, many participants revealed that they struggled with the conflicting advice and opinions from their health care providers, which left them uncertain as to how to manage the condition. As such, women were obliged to seek out information on their own (e.g., using internet sources) and through alternative health professionals.

Northouse and Northouse's (1998) model of health communication and Covello's (2003) model on risk communication were used as frameworks against which this study's results were contextualized. Northouse and Northouse's model postulates that four main channels of communication that exist in health care settings, all of which are interrelated and influence one another. My findings illustrated a lack of effective health communication between practitioners and patients. Communication problems contributed to difficulties in framing lymphoedema, which affected the women's understanding of the illness and their management of symptoms.

Covello's (2003) model identified seven best practices for risk communication guided by honesty and openness, involvement of stakeholders, and development of communication plans. Using Covello's model as a framework to map out the results of this study, the findings reveal practitioner-patient communication problems, as well as problems in the translation of health messages. These remain significant barriers to the transfer of knowledge necessary for the adoption of exercise amongst other strategies in the successful management of lymphoedema. The research findings in this section highlighted several important issues that arise from problems related to the identification and communication of knowledge on lymphoedema. Women interviewed in this study felt that they had limited support from health care providers and felt uncertain of appropriate techniques to manage lymphoedema. Specifically, a lack of knowledge and validation of lymphoedema from health care providers, a disconnect in

communication, and conflicting messages all had negative impacts on women living with lymphoedema.

Women's experiences with lymphoedema.

The second section of the thesis focused on the women's experience of the illness, and included their negotiations with treatment, and their perceptions of the outcome of lymphoedema. An individual's experience of illness is not only based on the severity of the disease and the ways in which conditions of the illness are handled, but also stem in part from a broader system of social and cultural gender constructions and interactions (Brown, 1995). In examining participants' reported experiences of lymphoedema, two significant themes emerged: body image issues and changes in QOL. For women who live with lymphoedema, beauty and self-esteem were situated within a much broader spectrum of issues related to breast cancer. Existing research has shown how the changes to a woman's body after breast cancer surgery can affect her body image and self-esteem. Lymphoedema adds an extra dimension to this problem, as it is a visible sign of breast cancer that is more difficult to hide than surgical scars.

Each woman interviewed reported changes in her QOL as a result of lymphoedema, including impacts on daily activities (e.g., dressing oneself), recreational activities (e.g., gardening, sports), and work. While these changes varied among women, ranging from slight modifications to the ways certain activities were performed to the complete avoidance of other activities, all responses evoked the negative impacts of lymphoedema on every participant's life.

In looking at women's negotiations of treatment for the management of symptoms, the use of compression garments were found to be the most frequently used method of managing the swelling from lymphoedema, while exercise was viewed with mixed understandings and

uncertainties. Every participant reported to have tried compression garments, and all but one participant continued to use lymphoedema sleeves and/or gloves. Many of these women recounted the problems they experienced in their search for a properly-fitting garment, including wait times for assessments, miscalculations, and delays in the process. In discussions on exercise as a treatment for lymphoedema, many women revealed their uncertainty of the risks and benefits of certain exercises, which affected their participation in various activities. Despite the proven benefits of exercise, a number of the women interviewed were hesitant to adopt certain types of exercises. There is a significant body of research that explains barriers to exercise among a variety of populations including healthy and diseased populations, cancer survivors, and even among breast cancer survivors. While research in this field provides critical insights into the barriers of exercise among the women in this study, one recurring barrier voiced by the women in this study was a fear of aggravating their symptoms. This finding links to communication problems in the health care setting as discussed in the first paper presented in this thesis, and points to the need for more support from health care providers to provide long-term monitoring, and also in helping women with lymphoedema to establish an exercise plan and to encourage them to initiate or maintain active lifestyles. On the other hand, participants who maintained active lifestyles reported a number of motivators to exercise including positive and informed feedback from physiotherapists, finding activities that “fit” with adjusted lifestyles, and expectations of the benefits of exercise.

Finally, the perceived outcomes of the illness varied between participants in this study, and were associated with the individual’s ability to manage symptoms. The strongest reactions came from participants who managed to maintain an active lifestyle and who were able to see the positive effects of exercise on QOL. Interestingly, a number of these women revealed that

following their diagnoses with lymphoedema, they became more interested and involved in managing their health, and became aware of the range of specialized exercise programs available in Ottawa. This finding is noteworthy because it demonstrates that these women's abilities to manage symptoms is largely a result of their own determination, their support networks, and advice received from their physiotherapists rather than support received from their health care providers. Participants' responses revealed the importance of support groups, which offered a place in which to comfortably share their thoughts, views and experiences with others who shared similar experiences. Although many of the women interviewed were involved with the Dragon Boat program at BCA and reported the positive benefits of the network, there were other women who did not wish to participate in the activity. Some of the women who were not involved with the Dragon Boat team forged their own support groups through networking in other breast cancer survivor activities, while others expressed the need for more inclusive support groups specifically for women living with lymphoedema. The findings in this section reinforced the importance of support networks to well-being, and demonstrated how such support help to buffer some of the stressors related to living with breast cancer and lymphoedema.

In this thesis, women's responses were analyzed through a gender-based lens to better understand the impact of discourses on health and femininity amongst other areas. I investigated how discursive constructions of the body and gender roles, and universalizations of women's experiences were reproduced and contested through these women's responses, with the aim of identifying areas for improvement. Traditional constructions of the female body remain a significant issue in contemporary societies, and have a particularly negative impact on women

dealing with breast cancer and/or lymphoedema, as some women have their breast(s) removed, or have surgical scars and swollen limbs as a result of breast cancer surgery.

Women's responses in this study revealed how women living with lymphoedema struggled with medical understandings of lymphoedema, and the different ways lymphoedema was framed by health care practitioners and support groups, all of whom were in contact with these women. The main findings of this chapter related to the exchange of medical knowledge on lymphoedema and how mixed messages regarding the best practices for the management of symptoms (especially regarding exercise) result in confusion and uncertainty. Some of the women interviewed struggled with discourses on femininity and female gender roles as a result of lifestyle changes following the onset of lymphoedema. The women interviewed shared similar viewpoints on the inadequate level of concern and care provided by their health care practitioners. Several women also pointed out universalizations of women's experiences by many health care providers, who tend to generalize lymphoedema-related health problems when in fact women experience varying degrees of its severity and its effects on QOL, and require different methods of treatment. The universalization of lymphoedema and its impacts on women is problematic, especially if women do not regularly visit their health care providers and their condition changes. While the limited support from health providers may lead women to rely on internet self-help guidelines, it is important to note that such information is not tailored to an individual, and may not reflect most current research in the field. Most of the women interviewed in this study, however, were particularly active in managing their health and lymphoedema. They sought alternative ways to educate themselves, through their physiotherapists and their support groups, amongst other sources, and were active in managing their health care.

Limitations

There were several limitations of the study. First, differences in racial backgrounds and socioeconomic status were not observed. The participants in this study were recruited from BCA in the Ottawa region. While recruiting participants through BCA was beneficial in creating a common source from which women could be selected to participate, it also implied that the women interviewed had chosen to become members of BCA and had volunteered to share their experiences with me, which may have significant influences on the types of responses collected. For instance, participants' self-reported levels of exercise were relatively high, and the women interviewed were resourceful in their efforts to manage lymphoedema symptoms. The implications include the possibility that my findings may not be a representation of the experiences of women not affiliated or active with BCA, as well as women from vulnerable and marginalized populations. Another limitation was the fact that specific measurements for levels of physical activity were not used. Although the use of measurement tools was outside the scope of this study, measuring levels of physical activity would be a possible avenue for future studies.

The data collected in this research was obtained from conversations with women during a single interview session, which provided a revealing vantage into their lives at that point in time. As such, the findings relate to participants' perceptions of their health and their understandings of the managing lymphoedema at a particular time. Given that this is a study on a chronic illness, it is important to emphasize that symptoms of their illness can be expected to change over time. Thus, the experiences and perceptions captured through this research demonstrate the diverse and complex ways in which women perceive and experience lymphoedema at particular instances in their lives.

Research Contributions and Recommendations

A main contribution of this study was its qualitative nature, which allowed for participant-based in-depth interviews to be possible through the use of purposive sampling techniques. The establishment of a community partnership with BCA ensured a research design that would not only contribute to the growing literature on lymphoedema, but would also serve community needs and specify specific concerns that could be addressed in future funding applications. Just as the focus of this research was twofold, the findings addressed two (2) main areas: (1) the existence of communication problems in the framing of lymphoedema, which drives the need more effective communication, reception and understanding of key health information related to the management of lymphoedema, and (2) the ways in which women's experiences of lymphoedema, its treatments, and outcomes are affected by traditional constructions of the female body, gender roles and expectations, which compound the negative effects of physical symptoms. The results of this study provided insights into the communication of knowledge on lymphoedema, as well as QOL issues from a participant's perspective, with a shared link to participants' perceptions and understanding of exercise as a means of treatment. The results demonstrated the importance of recognizing the impact of lymphoedema framing on the lives of the women affected.

A critical examination of the identification, experience of illness, treatment, and outcomes of lymphoedema from a qualitative, participant-centered perspective allowed for the identification of key areas for improvement in the health system for lymphoedema. The recommendations centre on improving awareness and understandings of lymphoedema through a number of strategies. These strategies include the identification of specific actions that an

individual should take in the management of symptoms, more effective communication practices to support consistent health messaging, and the forging of partnerships between various health groups such as first line breast cancer providers, lymphoedema specialists, physiotherapists, massage therapists and support groups. These strategies have potentially positive implications for the effective integration of exercise into treatment plans. For instance, consistent messaging on the risks and benefits of specific physical activities will help to minimize the uncertainties and fear associated with exercise. Raising awareness of the risks and impacts of lymphoedema is the first step to increasing medical attention and support, with the goal of enhancing these women's QOL. The findings revealed the need for improvements in the continued monitoring of a woman's health and lymphoedema, as personal visits to one's health care providers, as opposed to internet guidelines, are crucial to the establishment of consistent treatment plans. Furthermore, the women's experiences revealed the need for health care providers to abandon the view of lymphoedema as universalized, in order to provide adequate care for individuals dealing with the illness.

Examining the framing process from women's perspectives both reinforced and reflected findings found in other studies and helped shed light on new finding. The findings of this study demonstrate the need for more research on lymphoedema and QOL following breast cancer, despite the developments in the field in recent years. Possible future directions of study in this field could include a better integration of qualitative aspects into the predominantly quantitative research on lymphoedema, which would enhance the understanding of the problems that breast cancer survivors deal with in their struggles with lymphoedema. More specifically, qualitative studies in this field contribute to in-depth understanding of the needs of women living with lymphoedema in terms of the accessibility of information on lymphoedema, experiences with

health care providers, participant-based perceptions of treatments and their outcomes, amongst other issues. Future research should continue to go beyond measuring physical effects of treatments and continue to include psychosocial aspects. Possible areas of research could explore differences in perceptions and experiences of women from racialized communities to better understand social and cultural contexts in which these women live. Furthermore, an examination of the perceptions and experiences of active women as well as those who are in marginalized and vulnerable populations would be particularly advantageous. In addition, processes specific to the acquisition of sleeves and instruction of exercise techniques should be more closely examined to ensure that women living with lymphoedema receive consistent and reliable support. Finally, future steps could involve creating strong social networks for women living with lymphoedema with the aim of including those who are marginalized and vulnerable.

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APPENDIX A

Questionnaire



Université d'Ottawa • University of Ottawa

Faculté de santé, Université d'Ottawa
Faculty of Health, University of Ottawa

QUESTIONNAIRE

Framing Critical Health Messages on Exercise for Women Living with Lymphoedema

Name: _____ Today's date: _____

Mailing address: _____

1. What is your age?

- | | |
|--|--|
| <input type="checkbox"/> < 40 years | <input type="checkbox"/> 55 – 59 years |
| <input type="checkbox"/> 40 – 44 years | <input type="checkbox"/> 60 – 64 years |
| <input type="checkbox"/> 45 – 49 years | <input type="checkbox"/> 65 – 70 years |
| <input type="checkbox"/> 50 – 54 years | <input type="checkbox"/> > 70 years |

2. In general, how would you rate your overall health?

- Poor Fair Good Very good Excellent

3. How would you rate your ability to manage your lymphoedema-related symptoms?

- Poor Fair Good Very good Excellent

4. During the past week, how much total time did you spend on each of the following?

| <u>Activity</u> | none | < 30 min/wk | 30-60 min/wk | 1-3 hrs/wk | > 3 hrs/week |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Stretching exercises (Range of motion exercises, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Strengthening and resistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |



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exercices (Using weights, etc.)

Aerobic exercises (Walking for
exercise, swimming, bicycling,
etc.)

For the current study, our aim is to recruit 12 participants. Should you be selected to participate in an interview, you will be contacted by the following week. Please indicate the method by which you would prefer to be contacted (please check one of the following):

by e-mail

E-mail address: _____

by telephone

Telephone number: _____

through BCA

Please note that there is a possibility that you may not be selected for interviews, due to the study design that seeks to capture a broad range of experiences. However, even if you are not initially invited for an interview, there is a possibility that you may be contacted in the future should the need arise due to participant attrition.

Thank you for your precious time and collaboration. It is greatly appreciated!

APPENDIX B
Questionnaire Results

Participant Characteristics

| Pseudonym | Age range | Self-reported health | Self-reported ability to manage lymph. | Flexibility exercises (per week) | Resistance exercises (per week) | Aerobic exercises (per week) | Years since lymph. diagnosis |
|-----------|-----------|----------------------|--|----------------------------------|---------------------------------|------------------------------|------------------------------|
| Abigail | 65-70 | VG | G | 1-3 hrs | 30-60 mins | 3< hrs | 6 |
| Brenda | 40-44 | G | F | <30 mins | 0 | 0 | 2 |
| Charlene | 60-64 | VG | G | 1-3 hrs | 1-3 hrs | 3< hrs | 11 |
| Darcy | 60-64 | G | VG | 3< hrs | 1-3 hrs | 1-3 hrs | 10 |
| Elizabeth | 60-64 | G | F | <30 mins | <30 mins | 1-3 hrs | 10 |
| Francine | 70+ | F | VG | 30-60 mins | 30-60 mins | 30-60 mins | 20 |
| Gina | 45-49 | VG | VG | 3< hrs | 30-60 mins | 3< hrs | 5 |
| Helen | 55-59 | VG | E | <30 mins | <30 mins | 3< hrs | 8 |
| Isabelle | 60-64 | G | G | <30 mins | <30 mins | <30 mins | 7 |
| Jamie | 55-59 | G | F | 1-3 hrs | 0 | <30 mins | 7 |
| Kathleen | 65-70 | G | VG | 1-3 hrs | 30-60 mins | 3< hrs | 12 |
| Laura | 65-70 | E | VG | 1-3 hrs | 1-3 hrs | 3< hrs | 19 |

Legend

E= Excellent
 VG = Very Good
 G= Good
 F = Fair
 P = Poor (No participants reported poor health/ability to manage lymphoedema)

APPENDIX C

Consent Form



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Faculté des sciences de la santé / Faculty of Health Sciences
Faculté des sciences / Faculty of Science / Département de pharmacologie / Department of Pharmacology / Département de pharmacologie / Department of Pharmacology

answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Name of Participant (please print)

Signature of Participant

Date

Signature of Witness (*needed in the case where a participant is illiterate, visually impaired, etc.*):

Name of Witness (please print)

Signature of Witness

Date

Signature of Researcher:

Name of Researcher (please print)

Signature of Researcher

Date

Signature of Supervisor:

Name of Supervisor (please print)

Signature of Supervisor

Date

UOttawa, 100 Jean Jacques, Ottawa, Ontario, Canada K1N 6N5
Téléphone: (451) 815-1212 • Télécopieur: (451) 815-1213 • Site Web: www.uottawa.ca

UOttawa, 100 Jean Jacques, Ottawa, Ontario, Canada K1N 6N5

APPENDIX D
Interview Guide

Framing Critical Health Messages on Exercise for Women Living with Lymphoedema

Interview Guide

Below are examples of questions that may be asked during the interviews. The guide is intended to ensure that the same general areas of information are collected from each participant; however, as the nature of semi-structured interviews lends itself to a conversational style of interviewing, the interview will likely follow the direction in which the participant leads. Hence, there is a possibility that not every question will be asked, and that questions may not be asked in the order presented in this guide.

Part I: Identification

1. Initial Diagnosis
 - a. What does health mean to you?
 - b. Do you look for information on your health generally? Where?
 - c. How long have you been dealing with lymphoedema?
 - d. Do you remember how you initially found out that you had lymphoedema?

2. Sources of information on lymphoedema and treatment options
 - a. Do you look for information on lymphoedema?
 - b. Where do you tend to turn to for information on lymphoedema and the management of the symptoms? Why?
 - c. What prompts you to seek information?
 - d. What are your perceptions of the nature of information on lymphoedema?
 - e. With all the information that is out there, which sources of information do you trust the most? Why?
 - f. Which sources do you trust the least? Why?
 - g. Do you use the internet as a source of information? How do you feel about the information available online?
 - h. Have you come across conflicting information? From what sources?
 - i. How do you make sense of conflicting information?
 - j. How do you use the information in your visits with health care professionals?

Part II: Experience

3. Experience of lymphoedema
 - a. Has lymphoedema affected your work life?
 - b. Has lymphoedema affected your personal life? (e.g., family life, hobbies, interests etc.)
 - c. Has lymphoedema affected any other aspects of your daily routine, or your life, to be more general?
 - d. Could you describe some of the support systems that have impacted your life?

4. Treatment

- a. Are you aware of the different forms of treatment available for the management of lymphoedema?
- b. What do you believe to be the best way to manage the symptoms of lymphoedema?
- c. What do are you currently doing to manage your lymphoedema?
- d. What types of exercise do you believe to be effective? Why?
- e. What types do you believe to be harmful? Why?
- f. How often do you exercise? *Refer to questionnaire
- g. Compared to before the breast cancer, did you find that your exercise habits changed? Have they changed since you have been diagnosed with lymphoedema?
- h. Have you experienced any challenges in terms of exercise?
 - i. If not, what do you think are some of the challenges in terms of exercise among women with lymphoedema?

For those who are physically active

- i. How did you manage to overcome these challenges?
- j. Could you describe a typical workout or exercise routine?
- k. How did you create this exercise plan?

5. Outcome

- a. Do you feel that exercise has had (or could have) an impact on your quality of life? In what way?
- b. What recommendations would you have for other women living with lymphoedema?
- c. Is there anything that I haven't asked that you feel would be important to add?