LYMPHEDEMA RISK AND MANAGEMENT: CHALLENGES TO NURSES EDUCATING WOMEN TREATED FOR BREAST CANCER

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Lymphedema Risk and Management: Challenges to Nurses Educating Women Treated for Breast Cancer

by

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Abstract

Twenty-five registered nurses from four different settings participated in audio-taped focus group discussions on lymphedema education for women with breast cancer. Findings were derived from themes developed through grounded theory methodology. Nurses provided samples of educational materials, which were assessed using validated readability tools, and recommendations from the literature.

Findings from this study suggest that in the absence of policy guidelines on lymphedema, educational efforts are uneven. Nurses appear to spend little time on lymphedema education. According to their assessment of patient readiness to absorb information, nurses control what information they provide. Nurses are aware of the need for preventive education, but hesitate to inform patients whom they assess as anxious about the risk of lymphedema. Nurses provide patients with a superior information kit but there is no process for patient feedback. Nurses reported that their knowledge of and attitudes to lymphedema are changing, and they require more education themselves.

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List of abbreviations

AHEC	Area Health Education Centre
ALND	Axillary Lymph Node Dissection
CDT/CDP	Complex Decongestive Therapy/Combined Decongestive Physiotherapy
MLD	Manual Lymph Drainage
NLN	National Lymphedema Network
NCI	National Cancer Institute
PDF	Portable Document Format
RAIN	Readability Assessment Instrument
RCT	Randomised Controlled Trial
RSEI	Radiation Side Effect Information
SAM	Suitability of Assessment of Materials
SMOG	Simple Measure of Gobblhedegook
SNB	Sentinel Node Biopsy

Chapter One Introduction

1.1 Purpose and overview

The purpose of this study is twofold: first, to examine the education nurses give women being treated for breast cancer on the topic of lymphedema risk and management; and second, to analyze patient education materials about lymphedema used by nurses. I take a qualitative approach and use grounded theory to analyse data collected from focus groups held at different sites within the health care system in St. John's. Focus groups have been effectively used in the fields of health promotion and health education to identify obstacles to adoption of healthy behaviours, as well as to assess needs and attitudes (Wilkinson, 1998). As I explored the broad role of nurses engaging in practices, activities and interactions within the health care system, I also found the insights of institutional ethnography to be useful (Bresalier et al., 2002; DeVault & McCoy, 2002; Dixon-Woods, 2001; Gregor, 2001; Smith, 1990). In analyzing the patient education materials I use validated assessment tools to assess readability (McGraw, 1992; Doak, Doak & Root, 1996), and recommendations from the literature to assess content.

This thesis is organized into six chapters, including this introduction. Four chapters form the body of the work, and the final chapter provides recommendations and conclusions. In this chapter I introduce the topic, outline its relevance and importance, specify the research question, and give an overview of the rationale and background to the project.

In chapter 2, I review the literature as it relates to lymphedema risk and management for women treated for breast cancer, to patient education in the nursing sphere, and the use and evaluation of educational materials. Chapter 3 describes the methodological approach and ethical concerns. In chapter 4, I present and discuss findings related to attitudes to and opportunities for lymphedema education. In chapter 5, I outline and discuss barriers to providing lymphedema education, and assessment of educational materials. Chapter 6 concludes with a summary of findings, strengths and limitations of the study, and recommendations for future work in the area of lymphedema education in St. John's and the province.

1.2 Rationale and relevance of the study problem

Lymphedema is the most feared consequence of breast cancer treatment. Lymphededma is a chronic disease of specific body tissues that occurs on average in one out of four breast cancer patients (Erickson, Pearson, Ganz, Adams, & Kahn, 2001; Gantz, 1999). In 2003, the National Cancer Institute of Canada stated that breast cancer would continue to be the most frequently diagnosed cancer for women (Health Canada, 2003). According to Statistics Canada, 31% of all cancers in women in Atlantic Canada are cancers of the breast (Health Canada, 2003). While incidence of breast cancer thus continues to be high, as a consequence of improved treatment and earlier diagnosis, women are surviving longer (Erickson et al., 2001; Petrek & Heelan, 1998). Because lymphedema can develop at any time after treatment, greater numbers of women are therefore at risk. Women treated for breast cancer face a life-long risk of lymphedema. This is a concern for women as even mild lymphedema has detrimental impacts on quality of life (Passik, Newman, Brennan, & Holland, 1993; Petrek, Pressman, & Smith, 2000; Tobin, Lacey, Meyer, & Mortimer, 1993). For these reasons, women need to know the risk factors for developing lymphedema and how it can be managed if it does develop. Women have reported receiving information about lymphedema from various sources, but not necessarily nurses (Bosompra, Ashikaga, Brien, Nelson, Skelly, & Beatty 2002).

Until recently, there has not been much awareness of the need for education about lymphedema. Little research has been devoted to care of patients with lymphedema (Loudon & Petrek, 2000) or to systematic education of breast cancer patients by physicians or nurses about lymphedema risk and management (Erickson et al., 2001). In the past, scant attention was paid to the quality of life of women with lymphedema and to the distressing and disabling symptoms that can occur. Many health care professionals have underestimated the importance of prevention and the challenges of living with lymphedema (Price & Purtell, 1997). Thus, a study investigating issues in patient education about lymphedema is both timely and necessary.

While patient education is part of nursing care, nursing practice patterns on this topic are not known. In St. John`s, as elsewhere, patient stay in hospital is now curtailed and consequently nurses in hospital have less opportunity for educational interaction with patients (Rankin & Stallings, 2001; Redman, 2001; Rees & Bath, 2000). Is lymphedema a topic that nurses discuss with patients? Patients undergoing cancer treatment interact with different nurses at various stages along the journey. Do nurses at only one stage discuss lymphedema with patients, or at every stage? What information is given? It is well established that patients do not always hear information presented during vulnerable moments such as at diagnosis of breast cancer (Dow & Kalinowski, 2000; Rankin & Stallings, 2001). Do women themselves ask nurses for information about lymphedema? The purpose of this study is to seek answers to these questions.

Because this study looks at the practice patterns of nurses in several different locations, the data gathered will provide baseline information regarding current practices. What are the challenges facing nurses educating patients about lymphedema? Are nurses sufficiently knowledgeable on this topic and confident about about educating patients? What educational materials exist for nurses? The findings of the study could be useful in the development of materials for post-mastectomy lymphedema education and of protocols in risk management, and should thus be of benefit to both nurses and patients alike.

This research study is timely. Lymphedema treatment, assessment and educational needs are now appearing more frequently on the research agenda. In May 2003, McGill University hosted the First Montreal International Lymphedema Congress in collaboration with the Quebec Lymphedema Association (Lymphovenous Canada, 2003b). In the past five years there has been an increase in the publication of studies on risk factors for developing lymphedema (Erickson et al., 2001; Petrek, et al., 2000;

Temple et al., 2002). Dr. Towers, Director of Palliative Care, Royal Victoria Hospital, Montreal is recruiting clinicians and students to research available treatments, trials underway in Quebec, and to develop pilot projects investigating treatment efficacy (Lymphovenous Canada, 2003b). A recent qualitative study of women with breast cancer-related lymphedema in New Brunswick found that the women had received little information from their treating oncologists, surgeons and family physicians (Thomas-MacLean, Miedema, Tatemichi, 2005).

In the past year or two, research projects to investigate the treatment and incidence of post-mastectomy lymphedema in Canada have started. In Ontario a large, multi-centre randomized controlled trial is taking place through McMaster University and the Hamilton Regional Cancer centre to investigate complex decongestive therapy versus standard care in the treatment of breast cancer patients diagnosed with lymphedema (Lymphovenous Canada, 2003a). A smaller study looking at family members educated in massage techniques to reduce postoperative pain and stressors, and improve family support took place in London, Ontario (Forchuk, et al., 2004). R. Thomas-MacLean is principal investigator of a CBCRA/CHIR-funded project entitled *Charting the Course of Arm Morbidity in Breast Cancer: A Prospective, Longitudinal Follow-up.* This is a national, four-site, prospective study of breast cancer survivors to determine the incidence of breast cancer-related lymphedema, possible triggers and access to treatment. (personal communication, March 30, 2005).

1.3 Background

This study is restricted to the St. John's area. Women treated for breast cancer in the St. John's region are seen at one of two hospitals: St. Clare's Mercy Hospital and the Health Sciences Centre. Women may enter the system through a family physician referral, possibly due to suspicious palpable lump, or because of an abnormal mammogram. In regions outside St. John's, a nurse practitioner may make a referral. Nurses at every site give information to the women concerning their care, and education about lymphedema can take place at any of the sites.

In 2001, a Quality Initiatives Committee for Patients and Families with Breast Cancer was set up as a pilot project to ensure standardized teaching and care across all sites in the Health Care Corporation of St. John's. This is an interdisciplinary and collaborative venture among the Surgery Program (Health Care Corporation, St. John's), the Newfoundland Cancer and Treatment Research Foundation, and Health and Community Services, St. John's Region. The aim of the committee has been to provide a comprehensive care plan for patients with breast cancer that ensures continuity of care throughout the entire process from time of diagnosis to home care in the community. As a result of this initiative, a Breast Surgery Services Checklist was created. A checklist is completed for each patient. Nurses are responsible for ensuring that each item on the checklist has been covered. To ensure that patients are made aware of volunteer services available, the checklist includes information about Cansurmount visitor contact and information packages from the Canadian Cancer Society (Committee, 2001).

In the spring of 2004, concurrent to my conducting focus groups, Greenslade and House (2004) presented unpublished data on the emotional impact on women from the Avalon region living with lymphedema to the Quality Improvement Committee. This local qualitative study highlighted the psychosocial impact of lymphedema among women treated for breast cancer and raised awareness of the need for more information about lymphedema for this patient population. A working group or sub-committee has since been formed within the hospital settings to investigate standards for lymphedema as it relates to patients with breast cancer.

1.4 Research question and objectives

It appears from the literature that little is known about how nurses, physiotherapists or physicians inform women about lymphedema. This investigation is limited to the role of nurses in St. John's in educating women treated for breast cancer about lymphedema risk and management. Nurses were chosen because as a group they are relatively homogeneous, are accessible, and because they have the widest contact with breast cancer patients, from the time of first diagnosis and entering the hospital to follow-up in the community and in the Newfoundland and Labrador Cancer Treatment and Research Foundation.

The need to educate patients with breast cancer about the potential risk of post-mastectomy lymphedema and its management may vary according to the patient care plan, and is only one among many other medical matters about which nurses must educate patients (Dow & Kalinowski, 2000). The purpose of this project is to answer the question of how and to what extent nurses in St. John's educate women treated for breast cancer about lymphedema risk and management. Specifically, the study will investigate the practice patterns of nurses in the two hospitals in St. John's, in the Dr. H. Bliss Murphy Cancer Center (Newfoundland Cancer and Treatment Research Foundation), and in the community with regard to informing women about lymphedema risk and management.

Using focus groups, a short demographic questionnaire, and through the collection and analysis of educational material, this study will:

1) Describe the practice patterns and experience of nurses in educating women treated for breast cancer about lymphedema risk and management

2) Identify and describe whether and how nurses obtain and disseminate information about lymphedema risk and management

3) Identify barriers to obtaining and disseminating information about lymphedema risk and management

4) Analyze a selected set of patient education print materials on lymphedema risk and management for readability, presentation and organization, and relevance of information.

Chapter Two Literature Review

2.1 Introduction

This chapter reviews the state of knowledge about lymphedema risk and management as it relates to nurses educating women treated for breast cancer on the topic. The majority of English language studies published on this topic were conducted in the United States. Where possible I refer to Canadian studies. Section 2.2 gives a brief overview of the condition, its description, incidence and impact. The main risk factors are outlined and problems of definition are discussed in section 2.3. In section 2.4, I review the literature on axillary node dissection and sentinel node biopsy and the process of informed consent. I describe the current knowledge of how to avoid (section 2.5), and how best to manage lymphedema (section 2.6), and the complexities associated with both. Section 2.7 discusses the use of evidence-based medicine in formulating guidelines for lymphedema. I review the Canadian Medical Association clinical practice guidelines for lymphedema and the recent, though scant, literature on exercise and lymphedema. Section 2.8 refers to the literature on the educative role of nurses while section 2.9 considers the information needs of patients with breast cancer. Section 2.10 provides a brief summary and link to the next chapter.

2.2 Lymphedema – an overview

Lymphedema is classified as primary (due to rare developmental defects and manifests at birth, adolescence or mid-life), or as secondary. Secondary lymphedema is more common and results from trauma to the lymphatic transport system because of surgery, radiation therapy, infections, or parasites (Loudon & Petrek, 2000).

Among possible consequences of breast cancer treatment, lymphedema provokes the most fear (Gantz, 1999; Petrek, et al., 2000). Lymphedema is a chronic disease that develops with the accumulation of protein-rich fluid in the interstitial spaces due to the decreased capacity of the lymphatic system to carry its normal load. Excess proteins, fluid, inflammation and fibrosis result (Smith & Miller, 1998). All edemas cause poor oxygenation and reduced healing of tissues. The permanent overload of stagnant proteins causes chronic inflammation, leading to further fibrosis and episodes of infections (Humble, 1995). Lymphedema can begin any time after breast cancer treatment, often insidiously, and, depending on the individual, can progress at varying rates from slight to severe (Petrek et al., 2000). Clinical signs and symptoms of lymphedema following breast cancer treatment include feelings of heaviness, swelling, tension, pain, stiffness, weakness, paresthesias, and reduced limb mobility (Brennan, DePompolo, & Garden, 1996; Humble, 1995).

Diagnosis, assessment and management of lymphedema are complicated by lack of research and guidelines for nurses educating patients. Lymphedema is rarely screened for, and can develop at any period after axillary dissection. In an obese patient it can be difficult to detect (Beaulac et al., 2002). Lymphedema is commonly determined by measuring the arm with a tape measure at 10 cm above and below the lateral epicondyle (Loudon & Petrek, 2000). While no standard measurement defines lymphedema, a 2 cm.

difference between arm circumferences has been commonly accepted as indicating mild lymphedema. Cheville, McGarvey, Petrek, Russo, Thiadens, and Taylor (2003) have published an innovative set of objective quantifying criteria to assess lymphedema in oncology clinical trials. These more comprehensive criteria are based on volumetric increase, dermal changes and subcutaneous fibrosis, but are not yet in regular use. Diagnosis is also problematic because baseline measurements of women`s arms are not routinely taken before surgery or radiation treatment.

While some women appear to function well with lymphedema, for a considerable portion of patients, lymphedema can be emotionally disabling (Beaulac, McNair, Scott, LaMorte, & Kavanah, 2002; Velanovitch & Szymanski, 1999). Even mild lymphedema can be distressing; two studies indicate that there is no relationship between the extent of the edema and levels of distress (Passik, Newman, Brennan, & Holland, 1993; Tobin, Lacey, Meyer, & Mortimer, 1993). Daily activities and household responsibilities can be difficult for women living with lymphedema (Carter, 1997). The psychological and physical impact can affect not only the women themselves, but also their sexual partners (Maunsell, Brisson, & Deschenes, 1993; Passik et al., 1993), and the functioning of the whole family (Radina & Armer, 2001).

Psychological distress (anxiety and depression), pain and decreased psychosocial activity are more pronounced in women with lymphedema than the North American average (Carter, 1997; Maunsell et al., 1993). Pre-menopausal women with lymphedema tend to record lower emotional and social well-being scores than do post-menopausal women with lymphedema (Beaulac et al., 2002). Physicians who focus on cancer recurrence and consider lymphedema a trivial outcome of treatment may unintentionally cause psychosocial distress (Petrek et al., 2000).

2.3 Incidence, problems of measurement and risk factors

Nurses and other health professionals educating women about lymphedema must rely on a research literature beset by a number of complexities and problems. The reported incidence of lymphedema as a result of breast cancer treatment, for example, varies from 0% in a study of women who had partial or total mastectomy and sentinel node biopsy, to 56% in a study of women who had modified radical mastectomy or breast conserving surgery and axillary node dissection (Erickson, et al., 2001).

Reported incidence varies for a number of reasons. Reliable figures are difficult to obtain because there is no standard definition of what degree of enlargement constitutes lymphedema. Studies use comparative measurements of 1, 2, or 2.5 cm. difference between arms, or volume difference of 100 or 150 ml (Cheville, McGarvey, Petrek, Russo, Taylor and Thiadens, 2003; Erickson et al., 2001). Some studies follow women only for a short period (less than a year). Women do not always report swelling, and physicians may not recognise swelling as lymphedema (Petrek & Lerner, 2000). As a result, women who indeed have lymphedema may not be included in a research study (Lymphovenous Canada, 2003a). Studies reporting incidence have all been retrospective, with relatively small numbers of patients undergoing various treatments and with data collected over time, often from a single department (Petrek & Heelan, 1998). The total number of women at risk of developing lymphedema in these studies is not known. Petrek and Heelan's (1998) review of seven studies published since 1990, found the incidence of lymphedema was about 20% with a range from 6% to 30%. Erickson et al. (2001) performed a similar review a few years later and included ten international studies published since 1990. They found that across treatments and over time, the overall incidence of post-mastectomy lymphedema was 26%.

Although etiologic factors for lymphedema have not been well studied due to low research priority, the literature does correlate lymphedema with extent of axillary dissection and axillary radiation (Petrek & Lerner, 2000). The primary risk factors are listed below (Erickson et al., 2001). Age, hypertension and air travel have also been implicated in a few studies (Loudon & Petrek, 2000) .

Risk factors for the development of lymphedema:

- Extent of axillary lymph node dissection (levels 1, 11, and 111)
- Radiation therapy to site of lymph node removal, and surrounding area
- Combination of axillary dissection and radiation
- Infections immediately post-op or later resulting in cellulitis
- Obesity before surgery, or weight gain after

2.4 Prevention: sentinel node biopsy versus axillary node dissection

Axillary lymph node dissection (ALND) has been the gold standard to detect metastasis in the 29% – 35% of patients with clinically negative axillary nodes (Porter, McMulkin, & Lovrics, 2003). The histologic status of the nodes has been the best predictor for survival and is used for purposes of staging the breast cancer (Blanchard, Donohue, Reynolds, & Grant, 2003; Zack, 2001). Axillary node dissection is, however, associated with considerable morbidity: seroma formation, sensory changes, lymphedema and chronic pain (Porter et al., 2003). A less invasive surgical procedure, combined with lymphatic mapping (lymphoscintigraphy), has now been in use for some years. Sentinel node biopsy (SNB) removes the first lymph node, which receives drainage from the tumour, and is an accurate predictor of metastatic disease in the axillary lymph nodes. If SNB detects metastasis, axillary node dissection is performed (Zack, 2001).

One would expect to find decreased morbidity following SNB. In a prospective study of 70 breast carcinoma patients, Schrenk, Rieger, Shamiyeh, and Wayand (2000) found that SNB was associated with negligible morbidity compared to axillary dissection. Sener et al. (2001) found similar results: 3% of 303 patients who underwent SNB alone developed lymphedema, compared to 17% of 117 patients who underwent SNB and axillary dissection. Temple et al. (2002) in a prospective study over 12 months found no significant difference in arm circumference between patients after SNB and those after ALND. They did find, however that the SNB group had half the sensory morbidity of the ALND group, and recommended long term follow-up to assess lymphedema. Blanchard, Donohue, Reynolds & Grant, (2003) found one axillary occurrence in 685 SNB node-negative women, who completed a survey 9 months to 2.4 years following treatment. In Canada, ALND is the standard care for less invasive stage I and II breast cancer, and for a number of reasons, SNB is used less in this country, compared to the United States where it is often performed as part of a clinical trial. It has been suggested that patient demand may be a major factor in the United States, and cost and training may be issues in Canada (Porter et al., 2003). Sentinel node biopsy is performed by some surgeons in St. John's.

Whether SNB is routinely offered to those patients who are candidates is another question. Studies in the United States have shown that some physicians avoid discussing lymphedema risk. Carter (1997, p. 879) reported that women with lymphedema received conflicting information from their physicians, who were not very knowledgeable about lymphedema, and were "reluctant to educate women regarding the possibility of developing lymphedema as an iatrogenic complication after breast cancer treatment". Despite the seven years that have passed since Carter's study was published, some physicians' knowledge of and attitude toward post mastectomy lymphedema does not appear to have changed substantially. Freedman (2003) reported that patients with breast cancer were concerned by some physicians' decisions not to inform them of treatment options, which might be of benefit in limiting long term side effects. While not all patients with breast cancer are candidates for SNB (Zack, 2001). Freedman found that surgeons who did not perform SNB did not offer it as an option to patients, and did not refer patients to other surgeons who did.

2.5 Avoiding lymphedema – precaution or prevention?

The question of prevention is controversial for health professionals educating women about lymphedema and is complicated by misuse of the word prevention where precaution is intended. Prevention would require avoiding the treatments which cause lymphedema, ALND and radiation. Guidelines for prevention published in the nursing and medical literature are really precautionary measures based on intuitive reasoning and the pathophysiological processes of lymphedema (Loudon & Petrek, 2000; Ridner, 2002). Individual women have different lymphatic and vascular anatomy, and for some women all the precautionary measures may be unnecessary and result in overprotection and problems of disuse (Petrek et al., 2000). Individual patient factors need further research, as our understanding at present is very poor. Studies of women with bilateral axillary dissections report no higher risk of lymphedema than women with unilateral axillary dissections (Loudon & Petrek, 2000; Petrek & Heelan, 1998), but the extent of the dissection is not always clarified. Clinical experience promotes the desirability of discussing precautions with patients and educating them about the lymphatic system so they are aware of the possible effects of different activities (Cheville, McGarvey, Petrek, Russo, Taylor & Thiadens. 2003). An individual approach must be taken because what is problematic for one patient may not be for another (Cohen, 2001; Struble, 2001). In the future, increasing use of lymphoscintigraphy, which provides information on the state of the lymphatics, may help determine which precautionary measures are necessary for which individual women.

The four categories of precautionary measures (in reality a mixture of precautionary and preventive measures) repeated throughout the breast cancer literature are: 1) avoidance of trauma/injury; 2) prevention of infection; 3) avoidance of constriction of the arm; and 4) use and exercise of the limb (Erickson et al, 2001). All women at risk are encouraged to wear protective gloves when gardening, and for household work; use the other arm for venipuncture and blood pressure measurement; identify and treat the first sign of infection; avoid constrictive clothing, heat, sun exposure, insect bites or trauma to the arm; and avoid repetitive motion with the arm. These guidelines may be unnecessary for some women at low risk and insufficient for those at high risk (Loudon & Petrek, 2000), and women themselves may be reluctant to follow these strategies (Coward, 1999).

2.6 Management of lymphedema – the debate continues

In 1995, the International Society of Lymphology published its Consensus Document supporting the conservative physical treatment of lymphedema which involves manual lymphatic drainage, compression, exercises and skin care (Executive Committee, 1995). In 1998 the American Cancer Society sponsored the first Lymphedema workshop in New York City. Many review articles and descriptions of the various schools of physical treatment were published in the December 1998 Cancer Supplement (Brennan & Miller, 1998; Casley-Smith, Boris, Weindorf, & Lasinski, 1998; Foldi, 1998; Petrek & Heelan, 1998). Despite this interest, some authors continue to report that too often, women receive no treatment and are told they "should be thankful to be alive" (Petrek & Lerner, 2000). The earlier treatment is started, the less is required and the better the outcome (Ramos, O'Donnell, & Knight, 1999). Treatment at different stages may consist of elevation, use of a sequential pump, of compression garments, lymphatic manual therapy, and complex decongestive therapy (CDT) (Cheville, McGarvey, Petrek, Russo, Taylor and Thiadens, 2003; Petrek et al., 2000; Struble, 2001).

Cohort studies (Boris, Weindorf, & Lasinski, 1997; Mirolo et al., 1995; Szuba, Cooke, Yousuf, & Rockson, 2000), review studies (Brennan et al., 1996; Erickson et al., 2001; Petrek & Heelan, 1998), and a number of recent parallel group and randomised treatment trials (Badger, Peacock, & Mortimer, 2000; Weiss & Spray, 2002; Williams, Vadgama, Franks, & Mortimer, 2002) have shown the efficacy of conservative treatment. Physical treatment can, however, be cumbersome, time-consuming, expensive, interfere with activities of daily living, and be unavailable in many locations so that not all women with lymphedema are willing or able to undertake it (Carter, 1997; Radina et al 2004). As with other chronic conditions, treatment is successful only when patients comply with the home care maintenance program (Casley-Smith, 1992).

Surgical techniques such as debulking and liposuction have been tried, but various complications have been reported (Brennan et al., 1996; Cohen, 2001). No follow-up studies have been published from recent interventions such as microsurgical techniques, which offer promise (Cheville, McGarvey, Petrek, Russo, Taylor and Thiadens, 2003). Properly fitted compression garments must be worn after all measures whether surgical or CDT. Diuretics, which are used to treat a number of edematous conditions, are not recommended for long-term use in treating lymphedema. (Cohen, 2001; Cheville, McGarvey, Petrek, Russo, Taylor and Thiadens, 2003).

Problems of definition, type of study, and comparison across studies plague this subject, making it difficult for medical and nursing practitioners alike to determine, or follow best practices. Erickson et al. (2001) reviewed medical guidelines for care of patients with breast cancer and found that most concentrated on cancer treatment aspects rather than long-term care. Only two of 17 studies published before 1999 for breast cancer care addressed care of patients with treatment-related lymphedema.

2.7 Determining guidelines to follow: Evidence-based medicine and the Canadian medical clinical practice guidelines

The Canadian Medical Association's Steering Committee is part of Health Canada's Canadian Breast Cancer Initiative and in 2001 published its *Clinical practice guidelines for the care and treatment of breast cancer* (Harris, Hugi, & Levine, 2001). In "Section 11: lymphedema" conservative treatment (CDT) is not recommended because of lack of evidence-based outcome studies at the highest level of randomized controlled trials (RCTs). The guidelines do bring lymphedema to the attention of the medical and nursing communities and include the following recommendations: pre- and post-operative measurement of both arms to aid in diagnosis; elicitation of symptoms of heaviness, tightness and swelling in the affected arm; encouragement of long term and consistent use of compression garments by women who have lymphedema; encouragement of patients in maintaining good skin care, exercise and body weight; and development of further research in use of compression pumps and complex physical therapy as treatment options. These guidelines reflect standard recommendations from the literature and one important innovation: routine pre-operative measurement of both arms. Instituting such a procedure would necessarily involve discussion of its rationale, and the risk of lymphedema developing after treatment.

The principles of evidence-based medicine (EBM) (Sackett, Richardson, Rosenburg, & Haynes, 1997) have in recent years spread beyond medicine to include other health care disciplines, including nursing (Craig & Smyth, 2002). Evidence-based medicine as defined by Sackett means:

> "integrating individual clinical expertise with the best available clinical evidence from systematic research", and "by best available external clinical evidence we mean clinically relevant research, often from the basic sciences of medicine, but especially from patient-centred clinical research into … the efficacy and safety of therapeutic, rehabilitative and preventive regimes" (Sackett et al., 1997, p.2).

In EBM, the research evidence is ranked with results from experimental (randomized controlled) trials (RCTs) at the top, and expert opinion at the bottom, with findings from cohort, case control, survey and descriptive studies in between (Lobchuk, 2003; Sehon & Stanley, 2003). This ranking is based on the belief that clinical experience and observational studies have a greater risk of bias than RCTs, and that this is particularly the case when investigating treatment efficacy (Sackett et al., 1997).

Evidence-based medicine has been criticized for relying exclusively on randomized controlled trials (Lobchuk, 2003; Sehon & Stanley, 2003). Nurses may value evidence from RCTs in terms of diagnosis, prognosis and treatment, but may appreciate other forms of evidence in deciding on appropriate care for a particular patient according to her beliefs, values and preferences (Lobchuk, 2003). Nurses may have little time to consider the evidence on lymphedema management that is presented in retrospective studies. There are no clinical practice guidelines for Canadian nurses.

In the lymphology literature, there have been few RCTs assessing treatment efficacy published in English and there has been some debate about the need for RCTs (Schuch, 2001). Over 10,000 cases of treatment efficacy for lymphedema have been documented (Cheville, McGarvey, Petrek, Russo, Taylor and Thiadens, 2003). Two literature reviews, both acknowledging the limitations of the available evidence, resulted in different recommendations. In contrast to Harris et al. (2001), Brennan and Miller (1998) recommended that a comprehensive therapeutic approach, including CDT, should be used in the treatment of lymphedema. In considering what women should be told about lymphedema risk and management I combine the recommendations of reviewers (Brennen & Miller, 1998, Erickson et al. 2001) and clinicians (Casley-Smith, et al., 1998; Cheville, McGarvey, Petrek, Russo, Taylor and Thiadens, 2003; Foldi, 1998) with the Canadian medical clinical practice guidelines and the latest available evidence.

Exercise is another problematic area in lymphedema risk and management, and has been cited as both a cause and a cure (Radina, Armer, Culbertson, & Dusold, 2004). Part of the difficulty lies in the definition of exercise: is it for flexibility, strength training, aerobic conditioning or remedial benefit? In the three years since the Canadian medical clinical practice guidelines on lymphedema were published, there have been a number of small experimental or quasi-experimental studies investigating both treatment methods and exercise. Box, Reul-Hirche, Bullock-Saxton, and Furnival (2002) reported promising results from use of a physiotherapy program. Williams, Vadgama, Franks and Mortimer, (2002) found manual lymphatic drainage (MLD) more effective than simple self-lymphatic drainage.

Earlier precautions to avoid strenuous exercise are now being refuted in the physiotherapy literature (McKenzie & Kaldo, 2003; Harris & Niesen-Vertommen, 2000). These are small sample size case reports, from which it is difficult to generalize, and no follow-up studies have been published. The results are encouraging, however, and point the way to further investigation.

Exercise is too broad a term. What may be too strenuous exercise for one person may not be too much for another. The frequently repeated advice not to lift more than ten pounds (Thiadens, 1997) is an example of a preventive/precautionary strategy that is beginning to be called into question. More studies are needed in order to develop guidelines on lifting. In the meantime, it is still necessary to discuss with women at risk the possibility that if they are not used to lifting heavy loads, they should take care to build up their strength gradually. An individualized approach to risk management education may be most appropriate.

2.8 The educative role of nurses

Patient education is central to nursing practice and is provided as part of direct patient care, as well as in separate programs (Redman, 2001). Texts throughout the nursing literature emphasize the duty of nurses to educate their patients (Babcock & Miller, 1994;

Rankin & Stallings, 2001). The process of patient education has been compared to the nursing process: both include assessment, diagnosis, goal-setting, intervention and evaluation phases (Redman, 2001). Both are directed by a number of theories and concepts which are situated within the contexts of health, environment and person (McCormack, 2003). Babcock and Miller (1994) outline some of theoretical approaches (general systems theory, the behavioural model, and the humanist model among others) which nurses employ as frameworks for understanding how learning takes place. In general systems theory, the learning person is thought to function as a whole system, cognitively, affectively, and in the psychomotor domain, as she interacts with the environment. Based on a client's individual need and readiness to learn, a nurse engages in a learning opportunity to affect change in behaviour. Babcock and Miller (1994) encourage nurses to promote thinking in clients, in the belief that thinking is an important subsystem of learning.

Nurses also use the health belief model (Doak et al, 1996) to achieve behavioural change. The health belief model requires that a patient understand that he or she is at risk, that the risk is serious and that benefits will accrue from a behavioural change. The self-efficacy theory builds on the need for behavioural change and promotes patient perception that the task is "doable" (Doak et al, 1996). Depending on the circumstances of what is being taught, a nurse's training and beliefs, institutional requirements and the needs of the patient, nurses may employ a variety of theoretical models. Dow and Kalinowski (2000) stress that decision-making is a process, and takes place over time. Nurses should be aware of the difficulties in making decisions, and recognize that patients are vulnerable.

While nursing literature has emphasized patient teaching as an orderly process, Gregor's (2001) institutional ethnography research highlights the actual nursing practice of more informal teaching, giving instructions and information, setting expectations and demonstrating correct methods of care. Encouraging patients to ask questions is emphasized in both informal (Gergor, 2001) and formal (Dow & Kalinowski, 2001) teaching.

The need for nurses to be more involved in educating women about lymphedema risk and management is widely stated (Bosompra et al, 2002; Coward, 1999; Davis, 2001; Dow & Kalinowski, 2000; Ridner, 2002). According to Davis (2001), little research supports current nursing practices, and studies are needed on basic lymphology, information needs of people at risk of developing lymphedema, and the outcomes of patient prevention and management education. Davis also suggests nurses should make pre-treatment assessments of arm circumferences and risk factors, and should educate patients in an individualized fashion before, during and after treatment.

Nursing texts and articles emphasize educating women on the importance of understanding how the lymph system works, knowing sources of infection and reporting signs of infection, maintaining excellent skin hygiene, and maintaining good range of motion and strength in the affected arm (Dow & Kalinowski, 2000; Ridner, 2002), and in seeking early intervention at the first signs of lymphedema (Gerber & Augustine, 2000). Reports in the journals vary between support for educating women to follow all the precautions outlined by the National Lymphedema Network[1], (Ridner, 2002; Thiadens, 1997) and a more selective, cautious approach (Bosompra et al., 2002; Coward, 1999).

Both Bosompra et al. (2002) and Coward (1999) have suggested that women are not always well advised of the risks of developing lymphedema, and are not always willing to follow precautions even when they have been advised of them. Women learn about lymphedema from oncologists, radiation oncologists, physiotherapists, other women, the Internet, and nurses. These two studies have investigated women's point of view concerning education about avoidance and management of lymphedema but no studies were found that specifically investigate nurses' educational practices on this topic. Only one report describes nursing guidelines for treatment decision-making regarding lymphedema management (Smith & Miller, 1998). As outlined above, Davis (2001) and Radina et al. (2001) both support a comprehensive approach to lymphedema care including review of risk factors, and on-going post-treatment assessment and education.

2.9 Information needs of patients with breast cancer

As health care moves toward a more patient-centred approach, and informed consent is required, the information needs of patients are becoming more important (Katz, 1998). There is a growing body of literature investigating and documenting the information needs of cancer patients and patient satisfaction with information provided (Bilodeau & Degner. 1996; Chapman & Rush, 2003; Leydon et al., 2000; Paul, Hendry, & Cabrelli,

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[1] The National Lymphedema Network (NLN) is a patient advocacy group in the United States dedicated to promoting research, securing adequate insurance coverage for treatment and creating awareness of lymphedema through education.

2004; Rees & Bath, 2000, 2001; Saino & Eriksson, 2003; Thewes, Girgis, & Pendlebury, 2003; Treacy & Mayer, 2000). Researchers are discovering that cancer patients want information about diagnosis, treatment and side effects of treatment, but that their needs vary as they progress along the disease and treatment continuum. (Luker, et al., 1995; Rees & Bath, 2001). At the time of diagnosis, women prefer verbal information from their health care providers (Rees & Bath, 2000). At this time, nurses may have to play a supportive role in assisting women who experience decisional conflict (Stacey et al, 1999). Some patients, particularly older patients, may prefer less information, and such patients may select out only what interests them from the whole that is provided to them (Jahraus et al, 2002). Leydon and colleagues (2000) found that patients who had faith in their doctors were less inclined to seek information and that female patients often relied on information from other patients rather than medical information in making decisions. Hinds and colleagues (1995) found that women wanted to be active participants in their treatment process, and Stacey and colleagues (1999) found women preferred to play an active or collaborative role in decision making.

Communication between health care professionals and cancer patients can be problematic (Coulter, 1998), and is related to institutional factors as well as to personal and social beliefs, experience and understandings of both parties. Several authors independently cite the medical tendency to maintain a paternalistic view of patients as ignorant children who must be protected from bad news and medical uncertainties (Coulter, 1998; Dixon-Woods, 2001). In order to reduce anxiety, doctors may unintentionally confuse patients by using ambiguous terms that hint at a condition (Chapman Abraham, Jenkins, &

Fallowfield, 2003). The findings of Chapman et al. (2003) suggest that patients are unlikely to understand a cancer diagnosis if another term is substituted for the word "cancer". Freedman (2003) found that communication and the beliefs and assumptions that underlie health care professionals' and patients' view would all influence their dialogue. Issues of language have not been studied with lymphedema education, but may be a factor in patient understanding of risk and management.

Patients want information for a variety of reasons. In order to make informed decisions, patients need and want information about the disease itself, the treatment and side-effects (Rees & Bath, 2000). Patients want information to help them cope, and to feel more in control (Hinds, Streater, & Mood, 1995; Saino & Eriksson, 2003). Some researchers have involved patients in the design and evaluation of educational programs with positive results (Jahraus, Sokolosky, Thurston, & Guo, 2002; Paul et al., 2004; Wengstrom, Haggmark, Strander, & Forsberg, 1999).

2.10 Educational materials

Much of the literature on evaluation of educational materials is concerned with the need to produce information that is patient friendly, i.e., that is of an appropriate reading level so that it can be understood, and attractively laid out so that the information can be easily absorbed. Content is also important, but difficult to measure and so is often neglected in assessing educational materials. The specific tools used to evaluate the educational materials are discussed in the next chapter, Methodology, as are the qualitative methods I used.

Chapter Three Methodology

3.1 Introduction

This qualitative, descriptive study is an investigation of the practice patterns of nurses using in-depth, semi-structured focus group discussions and data analysis following grounded theory practices. Because the topic of lymphedema risk and management education is complex, and because of the lack of definitions and established nursing practice guidelines, I thought the semi-structured nature of focus group discussion and the coding of data using emerging themes would provide the best methods of discovering how and why nurses do what they do. After conducting the first focus group, I also found the insights of institutional ethnography to be useful in investigating nursing practice and in helping analyze data.

In this chapter, section 3.2 outlines ethical concerns and approvals, section 3.3 discusses recruitment of nurses, section 3.4 deals with data collection and 3.5 the process of analysis. Section 3.6 highlights an example of nurses involved in co-constructing meaning as they discuss common and difficult aspects of their work. Section 3.7 is a reflection on the complexities involved in being both a researcher and a practitioner. Section 3.8 outlines the process I used to evaluate the written materials, and describes the assessment tools. Section 3.9 summarizes and concludes this chapter and introduces the next chapter.

3.2 Ethics Approval

The proposal for this project was approved by Memorial University of Newfoundland Human Investigations Committee (Appendix A), by the Research Proposals Approvals Committee of the Health Care Corporation of St. John's, by the chief executive officer of the Newfoundland Cancer Treatment and Research Foundation, and by the senior management team of Health and Community Services, St. John's Region. In the first two cases, I submitted the completed forms for review and received notice of approval in writing. In the third and fourth case, I submitted a copy of the Human Investigations Committee forms and letter of approval, as well as a summary letter. I subsequently received approval from Health and Community Services, St. John's Region, and from the chief executive officer of the Newfoundland Cancer Treatment and Research Foundation.

At the beginning of each focus group, participants were assured of the confidentiality of the process. Participants were asked to sign an undertaking of confidentiality (Appendix B) and consent form (Appendix C). They were also assured that demographic data from the questionnaire would not be used to identify any individuals. Verbal consent to audiotape and to transcribe the discussion was obtained before starting each session. No identifying names or initials are used when quoting passages from the discussion groups. The first initial of every name has been changed where it appears in this thesis.

A letter thanking the supervisors and participants for their contribution was sent after each focus group (sample letter in Appendix D). A summary of the discussion and conclusions will be sent or presented to each of the groups of nurses. Participants were offered the opportunity to comment, but declined to review the transcriptions, or any particular chapters. Participants will be able to access the completed thesis once it is published.

All data will be stored in a secure cabinet in Dr. Natalie Beausoleil's office. Only the investigator will have access to the data. Data will be kept for ten years as required.

3.3 Recruitment of study participants

Due to funding and geographical constraints, this study was limited to nurses working in St. John's. In all, I conducted four focus groups with nurses who work in the following locations: 1) Ambulatory Care at St. Clare's Hospital, 2) Pre-Admission Clinics at St. Clare's and the Health Sciences Centre hospitals, 3) in the Dr. H. Bliss Murphy Cancer Center, and 4) in Health and Community Services, St. John's Region. The inclusion criteria were broad. Any nurse working in direct patient care with breast cancer patients at one of the sites, and who had graduated from a recognized nursing program was eligible for the study. Level of training of the nurses was not considered material; licensed practical nurses were not involved as they are not employed in these settings.

My initial contact within the hospitals was with the nursing supervisor of Ambulatory Care; at the Dr. H. Bliss Murphy Cancer centre it was with the Director of Nursing; and for Health and Community Services, St. John's Region, it was with the Education Manager. First contact was by telephone. I asked about the institutional approval process at each site. It was suggested that once approval had been obtained, I should contact a nurse manager or designate for help in organizing the focus groups. Over a number of months, I completed the ethics approval process and followed up the telephone calls with a formal letter of request and included copies of the information sheet (Appendix E), letter of introduction (Appendix F), and letter of approval from the Human Investigation Committee, Memorial University.

Two nurse managers and one team leader assisted in setting up focus groups. They booked the rooms and invited or notified other nurses of the date. The first focus group was held with the nurses in Ambulatory Care and at the end of the discussion they suggested I should also contact nurses in Surgical Day Care and the Pre-Admission Clinic. When I telephoned the nurse manager, she was interested, pending granting of approval. Accordingly, I applied to the Human Investigations Committee for an amendment to my initial approval in order to conduct a focus group at a fourth location, the Pre-Admission Clinic of St. Clare's Hospital. Approval was duly granted. the nurse manager also invited nurses from the Health Sciences Centre Pre-Admission Clinic and the St. Clare's Surgical Day Care unit to attend.

The focus groups took place over the period March 2 to May 25, 2004. Five nurses attended from the Ambulatory Care Clinic at St. Clare's, five from Health and Community Services, St. John's Region, six from the Dr. H. Bliss Murphy Cancer Center (including one via teleconference from Corner Brook), and nine from the Pre-Admission Clinics. Nurses from Surgical Day Care (St. Clare's) had also been invited but declined to participate when they realized that the session would be audio-taped. No nurses from wards taking patients for overnight and longer stays participated.

Nurses who participated in the focus group discussions were a homogeneous group. All twenty-five participants were women. Fifteen were over age fifty and only two were younger than forty. Six had a bachelor of nursing degree and one a masters of nursing degree. Eighteen of the twenty-five nurses had over 20 years nursing experience, six had 11- 20 years experience and one had five or less. Eleven of the nurses had been in their current setting for five or less years, eight for six to ten years, four for 11-20 years and two for over 20 years. One nurse revealed that she had lymphedema following breast cancer surgery. She was both knowledgeable and vocal on the topic of educating women about lymphedema risk and management. No other nurse reported that she had had treatment for breast cancer.

3.4 Data collection

Duration of the focus groups varied. The shortest was about forty-five minutes, one lasted just under an hour, and two were about an hour and a half in length. At the start of each focus group, I asked the nurses to sign the consent and confidentiality agreements, and to complete the demographic questionnaire (Appendix G). I introduced myself as a graduate student and as a practitioner treating women with lymphedema, and then asked each nurse to introduce herself. Before getting to the prepared questions which had been pre-tested with my committee and another nurse, I requested a general description of how the nurses work in that area, what variety of patients they see, how they fit into the overall scheme of treatment for patients with breast cancer. The prepared questions (Appendix H) began with a general question about breast cancer concerns that nurses discuss with patients. The rest of the questions were specific to lymphedema risk and management. The same general format was followed for each group, and I invited questions, comments and the introduction of any concerns throughout and again at the end.

At each site I collected educational materials (Appendix I) that nurses use with patients. Nurses in each group distributed or referred to the Purple Lupin kit. I obtained a kit from Dr. Jon Church, co-ordinator of the Newfoundland and Labrador Breast Cancer Teleconference Network, and distributor of the kits for the province. From the sites, I also collected a Breast Surgery Services Checklist (Pre-Admission Clinic St. Clare's site), a Lymphedema after breast surgery pamphlet (Ambulatory Care, St. Clare's site), a list of dos and don'ts (Community Health and Social Services, and Dr. H. Bliss Murphy Cancer Centre), and four other photocopied articles, and information downloaded via the Internet (Dr. H. Bliss Murphy Cancer Centre).

3.5 Data analysis

All discussions were audio-taped and transcribed within five days of the taping. Following each taping session, I wrote up a summary description of the process, what I thought were the highlights, how I felt it had gone, and how I might improve my interventions with the next group.

I transcribed and then hand-coded the audio-taped discussions for emerging themes according to a modified grounded theory approach. According to Charmaz, (2002, p. 677), grounded theory involves: "(a) simultaneous data collection and analysis, (b) pursuit of emergent themes through early data analysis, (c) discovery of basic social processes within the data, (d) inductive construction of abstract categories that explain and synthesize these processes, (e) sampling to refine categories … , and (f) integration of categories into a theoretical framework". In the main, I followed this framework of thought and activity from the beginning to the end of the research process with one exception. I consciously did not undertake sampling to refine categories. As I proceeded through the analytic process I found that the same themes continued to emerge. Perhaps not every group discussed every aspect of every theme, but the same categories of discussion arose in the groups. The fourth focus group was the briefest of all, about forty-five minutes, yet the same themes were developed and some new organizational information was disclosed.

Although sophisticated programs are available for coding qualitative data, I chose to hand code because I had a relatively small amount of data. While transcribing the data I paid attention to the subjects being raised, interaction between participants, and tones of voice. After transcribing, I read over the printed versions several times, noting in the margins a descriptive key phrase to highlight the point of discussion. With the first focus group, I repeated this step several times and then began to group the key phrases together as common themes began to emerge. The grouping of key phrases was performed several times with paper and pencil. When I was satisfied that I had identified the salient categories, and included all the data, I prepared a summary sheet of analysis that collected all the key phrases and their relevant page numbers under the common themes. After the second group, I repeated the same process and found that I was grouping the key phrases under the same or very similar themes to the first group. With the last two groups, I repeated the same procedures, again noting the themes. In general, I found that the four focus groups provided data that was varied and rich, yet with the same themes appearing, with some variations, but overall consistency among the groups.

It is important in qualitative research that the identified themes be validated independently. In this case I submitted all transcripts of the focus group discussions, summary analysis, summary description and reflection on the process of each focus group to my supervisor. Her separate analysis and review of the data, process and conclusions that I reached can be considered as independent validation of the themes that I identified and the conclusions I reached.

From the first focus group, I realized that how nurses educate women about lymphedema was a complex question. As I traced the use of the Breast Surgery Services Checklist, mentioned in every group, I found the insights of institutional ethnography to be valuable. Institutional ethnography, as developed by sociologist Dorothy Smith, is based on the social organization of knowledge, and combines theory and method to investigate ruling social organizations from the viewpoint of ordinary persons (DeVault & McCoy, 2002; Smith, 1990). Institutional ethnography can be used to reveal the dynamic interactions and connections among policy at the local and institutional levels, professional practice, and everyday life experience. As I researched nurses' references to the Breast Surgery Services Checklist, my investigations examined not only what nurses do, but also how their work is organized and contained by, as well as maintaining the institutional process.

3.6 Co-constructing meaning

In this study, I have employed the constructivist approach in both a social constructionist (making sense of the world) and participative (enlisting participants as co-researchers, co-constructing meaning) fashion (Charmatz, 2002). I made the questions as open-ended as possible and tried to let the nurses explore the issue as fully as possible without intervening. It frequently happened that a nurse would answer a question I posed, and several others would chorus their agreement with her reply.

Often the nurses interacted so spontaneously with each other that I did not need to interject with prepared questions. The flow of conversation was such that nurses would discuss among each other varying points of view and then arrive jointly at a conclusion or set of conclusions that encompassed all the viewpoints, and, in addition, revealed the heart of the discussion. I quote an example below. The conversation starts with a comment on how patients handle a situation when they "don't know what they got". It is interesting to note the comfort level the nurses have with one another as they interrupt each other, contradicting and supporting each other. One after another, the nurses disclose the meaning of their work and touch on how both they and patients handle the very difficult emotional aspect of the situation in which they encounter each other.

(Because of the length of this quotation, and the number of people speaking, I have assigned letters to indicate the speech of different individuals.)

> O: they can't be dealing with stuff they don't know they got.
> H A lot of them do know what they've got before they …
> O But they don't know mets, they don't know mets.
> H But a lady yesterday she knew it was in her nodes.
> S Sure some people do know they're going to have some treatment after …
> H And they often have received that purple lupin kit before they arrive too. More often than not because they get it in the outpatient department when they see the surgeon. And so they tell them which section to read for their particular cancer. And I tell them not to look at anything else (that's right) except for that part. It's too overwhelming for them.
> S It is (yes yes).
> C We tend to give them out more, don't we? I don't think many of our patients get them.
> D Recent. Lately they're two or three have already got them.
> C They got them from their family doctors I think lately (yes yes).
> O Well some of them do have needle biopsies so they know they have cancer there and some of them don't even know if there's cancer into them where they're lumpectomies (yea yea).
> K If they know they tend to want to talk about it.
> C that's right.
> K And you just let them talk. (others: that's right, yes) let them get it out and then try and put as much positive spin on it as O says, (that's right) as much as you can (yes).
> H A lot of them are very emotional when they come through I mean. More often than not they're emotional (that's right, very emotional), and I find that really hard to deal with myself. What do you say to comfort somebody with breast cancer?
> K I mean I do too. I find it difficult sometimes. It depends on how it gets brought around (?) time (oh absolutely).
> H If they know exactly what to expect when they're coming in then they are more comfortable when they leave.
> O Most of them also know the grey area with breast cancer. We've all been there and touched by it they really don't know their prognosis until even down the road, even a year's time. So that's always in their minds too is an anxiety, oh my gosh, my next chest X-ray is it going to be OK? And often patients ask that to me and I just say: you take one day at a time. You deal with it. You try to be positive. Where there's life there's hope and that's what you do. Because a lot of patient with breast cancers are, a lot of them are dying (that's right) and that's something that they're looking at. And you can't really say that you're not going to, you don't know.

This was a very poignant discussion that obviously ended at this point. It was as though the matter of whether women know exactly what “they’ve got” had been settled, or set aside by the much bigger question of facing the possibility of dying. The essence of what “they’ve got” is an emotionally difficult situation that is hard for both patient and nurse to handle. After coming to this point, the discussion did not end, but kept going as the nurses themselves took another direction. I did not ask another question right away. It was only when I realized they had introduced a subject about which I was ignorant and which was not going to be explained fully, that I asked a question to elicit more information:

> X Do you know much about the Cansurmount visitors that we, that go to see patients?
> Y Cancer Centre?
> X They work voluntarily don’t they (voluntary) yes but they’re breast cancer survivors.
> Y They’re breast cancer survivors.
> K And they talk to them.
> X I think that’s a really good thing for them.
> PH How does that work?

This excerpt is an example of a smoothly flowing co-construction of meaning among the nurses themselves, which occurred in the largest group. While the same dynamic was also apparent, perhaps to a lesser extent, in the smaller groups, my presence was perhaps more evident, and possibly more constraining. In the larger group, a momentum existed outside of my questions. This larger group, which was composed of nurses from three different areas, had spent an hour together in an educational session just prior to my arrival. Perhaps this also contributed to the dynamics of their interaction; it is impossible to know for certain.

3.7 Evaluating the process: Reflections on a dual role

My curiosity about this topic arose from my background as a therapist providing complex decongestive therapy to women (and men) diagnosed with lymphedema. As a health care provider trained and experienced in this area, I have a certain depth of knowledge. From interacting with women to help them manage this chronic condition, I have developed some understanding of how frustrating they find the whole process. Some patients felt they had not been well informed about lymphedema as they went through their breast cancer treatment. Others (those more recently referred) commented that they had been informed, and had received good advice. As a researcher, I wanted to discover for myself what other healthcare professionals, in this case, nurses, were communicating to their patients. As I reflected on the design of the research process, I decided I would try to keep my views and knowledge in the background during the focus group discussion. My primary aim was to allow the nurses the opportunity to say, first of all from their perspective, what was their understanding, level of knowledge and practice regarding lymphedema education. I intended that, as much as possible, I would let other nurses in the group answer questions as they arose.

This strategy was somewhat difficult to adhere to during the data collection stage. My name is known in the community and I discovered the nurses in two of the groups had the expectation that I would provide them with information, rather than the reverse. This expectation was compounded by the fact that two of the focus groups took place at a time that had been allocated to educational in-service training. I did not know this and it was not made clear to me until we were part way through the discussion. Although I clearly stated the focus of my research in all correspondence and communications, perhaps this information had not been fully communicated to all the nurses.

In several groups, nurses were eager to ask questions, and I did try to provide information if I could at the end of the focus group discussion. When nurses in one group asked me specific questions, I suggested a question and answer session at the end of the focus group. They agreed and we later spent half an hour reviewing lymphedema risk and management. During the taped sessions, I let other nurses in the groups answer questions; some nurses in each group were better informed on the topic than others. Occasionally I corroborated information. In addition, at the end, I provided copies of educational material that I thought might be helpful to the nurses.

In the one group where my role as health care provider was already well known and nurses refer patients to me, the nurses explicitly mentioned this. But they also stated that they refer to other massage therapists who are not trained in complex decongestive therapy and to physiotherapists. This group was the shortest and these nurses did not ask me questions about my practitioner role until the end of the session when a nurse who had herself just completed training in complex decongestive therapy wanted to talk about it and ask technical questions.

3.8 The process of analysing educational materials

The educational materials which I assessed included the pertinent parts of the Purple Lupin kit and five examples of handouts which nurses provided to me. From the Purple

Lupin kit, I evaluated Chapter 35 *Physical therapy and management of lymphedema* (Harris and Hugi, 2001) contained in the book, *Intelligent Patient Guide to Breast Cancer* (Olivotto et al, 2001). From the kit I also assessed *Guideline 11: The management of lymphedema related to breast cancer* (Steering committee on clinical practice guidelines, 2001) from the booklet *Questions and answers on breast cancer, a guide for women and their physicians.* I also evaluated the Lymphedema pamphlet, produced locally (West, 2004). The handouts assessed included: *The prevention of lymphoedema; general dos and don'ts* (Casley-Smith & Casley-Smith, 1995); *18 Steps to prevention for upper extremities* (Thiadens, 1997); *Living with lymphedema: prevention, treatment and working towards a cure* (Lymphedema Association of Quebec, no date); a list of Do's & Don'ts (no author or date); and a three page untitled document.

In determining how best to evaluate the materials I consulted a portion of the vast literature on client/patient education, methodology, needs of patients, methods of developing and assessing written materials, and readability levels. I reviewed recent and topical articles in the literature on the development, use and evaluation of written materials for patient education (Chapman & Rush, 2003; Dixon-Woods, 2001; Jahraus et al., 2002; Mumford, 1997; Nicklin, 2002; Saino & Eriksson, 2003; Singh, 2003; Treacy & Mayer, 2000; Wilson, Mood, Risk, & Kershaw, 2003). Some authors commented on the use of information so frequently photocopied that was it was difficult to read (Mills and Davidson, 2002). I also consulted established textbooks (Babcock & Miller, 1994; Doak, Doak, & Root, 1996; Rankin & Stallings, 2001; Redman, 2001) as sources for assessment tools.

Assessment tools exist to measure both reading skills and comprehension capabilities. Ideally, by first assessing patients` abilities to read and comprehend written health care materials, health care professionals can tailor patient education materials to ensure comprehension. In practice, however, this is not always either practical or possible. I am unaware of any research that has investigated the reading and comprehension levels of patients with breast cancer in St. John's. This study restricts its investigation to evaluation of the texts only. To assess readability I used standard, validated tools: the Simple Measurement of Gobbledegook (SMOG) readability formula (McGraw, 1992), the Suitability of Assessment of Materials (SAM) assessment tool and the Area Health Education Centre (AHEC) Assessment Checklist (Doak et al., 1996). Readability formulas are shown to have high reliability (r=.75 to r= -.99) (Wilson, Mood, Risk, & Kershaw, 2003). The SMOG formula has been validated and used in many studies evaluating health education materials since its development in 1969 (Treacy & Mayer, 2000; Wilson et al., 2003). . In the sections following I outline the three assessment tools in greater detail, and discuss their limitations.

The content of educational materials is vitally important, yet is difficult to measure and often is considered last when assessing patient educational materials (Coulter, 1998; Mumford, 1997). In this study, I assessed the reliability and relevance of educational materials that nurses provided me with based on a combination (as discussed in section 2.7) of the recommendations of the Canadian medical clinical practice guidelines (Harris et al., 2001), and the recommendations of researchers, and nurses, who have published in the field (Cheville, McGarvey, Petrek, Russo, Taylor, Thiadens, 2003; Davis, 2001; Radina, et al., 2004). In considering content, I paid attention to tone and language, and relevance to the context of the situation in St. John's with regard to availability of management choices.

With each pamphlet, booklet section or book chapter that I assessed, I first read over the material for general content. I then applied the three assessment tools, in the same order, beginning with the SMOG formula, then the SAM assessment tool and concluding with the AHEC checklist. I recorded the scores of each evaluation on individual score sheets and clipped them to the copy of the educational material. I then read over the material again for content noting consistency and correctness, conformity with published recommendations, extent and depth of information, and innovative suggestions. I did not attach any numerical grade for content.

3.8.1 Simple Measurement of Gobbledegook (SMOG) readability formula

All readability formulas do basically the same thing: measure length of sentence and number of multi-syllabic words. The SMOG readability formula (McGraw, 1992) uses one method for texts longer than 30 sentences and another for shorter texts. Both methods involve counting the number of polysyllabic words. In longer texts, a constant of three is added to the square root of the total number of polysyllabic words. This gives the reading grade level someone must have to understand the material. In shorter texts, the average number of polysyllabic words is determined by dividing the total number of polysyllabic words by the total number of sentences and a more complicated arithmetical formula is then applied.

3.8.2 Suitability of Assessment of Materials (SAM) assessment tool

Doak et al. developed and validated SAM (Suitability of Assessment of Materials) in 1993 to evaluate print material and illustrations. Six sections (with varying numbers of factors) look at content, literacy demand, graphics, layout and typography, motivation and cultural appropriateness. Twenty-two factors are rated superior, adequate, or not suitable according to specific, usually (but not always) quantifiable criteria. The total score can be rated superior (70% - 100%), adequate (40% - 69%), and (0% - 39%) not suitable (Doak et al., 1996). The factors under content include purpose, content topics aligned to behaviour, scope, and summary or review. Under literacy demand, comes reading grade level (using any reliable readability formula), writing style, vocabulary, sentence construction, and advance organizers. Graphics include cover, type and relevance of illustrations, graphs/charts and captions. Layout looks at sequencing, placement of text and illustration together, use of white space, line length, contrast between type and paper, type of paper, typography, and subheadings. Learning stimulation and motivation look at interactive text or illustration, modelling of desired behaviour in text or illustration, and division of complex topics into small parts. Finally, cultural appropriateness looks at a match of logic, language and experience to the intended audience, and use of cultural images and examples (Doak et al., 1996).

3.8.3 The Area Health Education Centre Assessment Checklist (AHEC)

The third tool is the seventeen-item checklist for print material devised by the Area Health Education Centre (1996), in Biddeford Maine, and recommended by experts in the field of teaching patients with low literacy (Doak et al., 1996). The AHEC Assessment Checklist looks at four areas: organization, writing style, appearance and appeal. If any items on the list are unscored, the material is deemed to be difficult for readers with low literacy. The factors measured under organization are: attractive cover and core content, "need to know" information stressed first, only three or four points presented, use of headers and summaries, and a summary stressing behaviour.

Writing style measures whether it is conversational, uses active voice, little jargon and a friendly tone. Appearance assesses for lack of clutter, amount of white space, lowercase fonts, high contrast between print and paper, print size at least 12 point, serif style, and that illustrations are simple and amplify the text. Appeal assesses the material for cultural and gender and age appropriateness (Area Health Education Centre (AHEC), 1996).

These three assessment tools provide a framework for assessing presentation of educational materials, with stress on appropriate (i.e. low) reading level, engaging writing style and coherent organization of content. These tools are limited by their focus on the patient educational material; in terms of health literacy, they ignore the patient who engages or interacts with the material. In order to assess fully the value of any patient education material, we would need to assess patient response, and determine cognitive and behavioural change, in both the short and long-term. This study, however, has restricted its enquiry to the presentation of the materials alone, and thus these tools are appropriate and sufficient for my purposes.

Chapter Four Nurses' attitudes and opportunities: findings and discussion

4.1 Introduction

In this chapter, I present and discuss a group of findings related to attitudes and concerns raised by nurses in the focus groups. I begin in section 4.2, by outlining the similarities and differences among the groups. In section 4.3, I describe and discuss how time and institutional pressures limit opportunities for nurses to educate women about lymphedema. Section 4.4 discusses the issues of timing and nurses' assessment of patient readiness and how these affect opportunities for introducing lymphedema risk and management. In section 4.5, I look at nurses' changing attitudes to lymphedema. In section 4.6 I discuss nurses' concern over their knowledge base, and opportunities for further education. The discussions touch on the inherent powers and constraints imposed on nurses by the larger social and institutional context within which they perform their work, and the consequent impact on patient education.

4.2 Description of nursing practices - similarities and differences among the four focus groups

Nurses in each of the groups are responsible for patient care at a different stage of the diagnostic and treatment continuum. The Ambulatory Care and Pre-Admission Clinics share the most similar characteristics, because in both clinics nurses see patients at the beginning of the process. Nurses at all the sites, however, claimed teaching as an important part of their job. Nurses in all four groups identified common approaches to, and behaviours with, their patients.

From what the nurses told me about their practices, I concluded that they combine both formal (use of educational and management strategies) (Rankin, 2001) and informal (asking and answering questions, giving instructions, demonstrating correct procedures) teaching practices (Gregor, 2001). At the Pre-Admission and Ambulatory Care sites, nurses help prepare the patients for surgery, and help them to understand the diagnosis and options available to them. The teaching can be informational and about process. In summing up their work in the Pre-Admission Clinic, a nurse stated: "What we do with them is go over all the information regarding pre- and post- operative and discharge planning…"

Nurses at the Ambulatory Care Clinic at St. Clare's told me that when a patient first arrives, a nurse will perform a patient assessment, and schedule a mammogram if necessary. A biopsy is often done right away. When the patient returns a week later, a nurse will get the mammography and pathology reports, and bring the patient in to the surgeon. If the patient is upset, a nurse will phone a family member to come. Often nurses have to sit with a patient for half an hour. They will give the patient the Purple Lupin kit and go over it with her and a family member, explaining the contents.

Sometimes the physician will give the patient the Purple Lupin kit, and tell the patient to read specific sections pertaining to their disease or treatment. The kit contains a book and several booklets with information about breast cancer, treatment options, social services and other supports locally available, and suggested questions to ask the physician about the treatment options.

The nurses help patients in making decisions by going over the literature. They explain sentinel node biopsy, and the procedures patients will go through on their return from surgery. They may discuss some post-treatment issues such as developing a seroma, psychological concerns, and radiation treatment or chemotherapy. They respond to questions, and if they do not know the answer to a specific question, they will get back to the patient later with a response. Nurses may see sixty to seventy patients in a day, of whom only a few may be patients with breast cancer. Nurses in Ambulatory Care interact closely with surgeons, and one nurse in particular specializes in care for patients with breast cancer. She keeps a file of information about breast cancer treatment, and lymphedema, and if the other nurses need any extra information for a patient, they have access to her information files.

All patients, whether they have same-day surgery or surgery that requires a hospital stay, are automatically referred post-operatively for home-care services through Health and Community Services. Home care is a misnomer, as patients no longer all receive home care visits. Patients who are able now visit ambulatory community clinics, which are situated in a number of different locations throughout the city and surrounding regions. The community nurses routinely care for patients with a multitude of diseases, not just breast cancer: "We're jack of all trades out here. Every discipline, everything you can think of, we see it all."

With patients with breast cancer, Community Health nurses do a general assessment on the first visit to ascertain how the patient is doing at home both physically and emotionally. The visits may be daily or every second day depending on the wound drainage and physician orders. The nurses change dressings, teach patients how to empty drains, and make sure patients have received the Purple Lupin kit at the hospital. The nurses ensure that the patients have all the information including the booklet on exercises and which exercises to do and not to do until their strength returns. The nurses check for swelling and signs of infection. If this occurs they send the patient back to the surgeon who usually sees them right away, or the patient is seen in the emergency department. Community Health nurses also encourage independence in patient self-care, support exercise for patients as part of their recovery, and discuss the long-term risk of lymphedema where appropriate.

Nurses in Community Health have the least contact with physicians and by the very location of their clinics within the community are more independent. Some nurses appeared less familiar with newer surgical procedures and were not familiar with treatments for lymphedema, even the wearing of compression sleeves. Like the

Ambulatory Care Clinic nurses, they see patients with a wide variety of diseases, but unlike Ambulatory Care, there did not appear to be a nurse within the five who participated in the focus group who took a special interest in patients with breast cancer.

Nurses at the Cancer Centre, not unsurprisingly perhaps, see the greatest concentration of patients with breast cancer, about 35% of patients are treated for breast cancer. Similar to the work of nurses in the other areas, they also do a patient history at the first visit. They focus on teaching for the treatment that the patient will receive at the Cancer Centre (radiation therapy or chemotherapy), and they tend to specialize either in medical oncology or radiation oncology. During follow-up visits they will do a thorough assessment and it is during those visits that they may see patients with lymphedema. They may refer patients with lymphedema to me for specialized treatment, or to other registered massage therapists, because, as one nurse put it: " I've found that they're (massage therapists) educated in encouraging circulation to the affected limb, though not in manual lymph drainage." In the Cancer Centre, nurses interact closely with medical and radiation oncologists. One nurse in the Cancer Centre with an interest in lymphedema undertook training in lymphedema management in June 2004. She has been allocated just two afternoons a week for lymphedema patient assessment and treatment, yet a full treatment regime requires intensive, daily manual and compressive therapy to be effective.

During the process of diagnosis, decision-making, and undergoing treatment, the patient continually faces uncertainty, new information, choices and consequences of treatment. Nurses in every focus group spoke about the patients feeling overwhelmed and anxious, and about the benefit of having a family member present during the teaching encounter. A family member can be helpful not only in the moment, but also later as patients try to recall information when they are back home:

> They are usually quite good with a family member [there] and they communicate quite well. And they feel comfortable having someone they can look over to and feel good there is someone there for assistance.
>
> And we find it helpful too because usually if a patient is in … a high level of anxiety, at least if we are telling two people we feel more confident that the information is getting to the patient.

In the pre-surgery phase, nurses noted that patients are intolerant of uncertainty, both in regards to the big picture (What will the surgery reveal?), and to small details (What happens in the operating room?):

> Most, I find, they just want to get in, get the surgery over, recover, and then deal with what comes after.
>
> That's true.
>
> Especially lymph nodes and if they're facing metastatic disease and stuff like that. That's the main thing for most patients in my view. And the other, the biggest thing, is what to expect when they go to the operating room that morning. After that it's just recovery. If they have a difficult time, they just want to get it over with.
>
> If they know exactly what to expect when they're coming in, then they are more comfortable when they leave.

Based on this perception that women are anxious and only want to deal with the most imminent procedure, the surgery, nurses said they try to emphasize the positive so as to decrease anxiety. As a result, lymphedema may not be mentioned to patients, especially those who are exhibiting more signs of stress, anxiety and being overwhelmed. "We try to take a positive spin so they get through the surgery cause we don't want them more anxious cause their anxiety is going to really deteriorate their post-op recovery. So we try to get them into a positive attitude."

Nurses perceive that anxiety interferes with patient capacity to learn, comprehend or retain information. Nurses may therefore limit the amount of information they provide to patients whom they perceive as under stress. Nurses in Community Health, where they are caring for patients recovering from surgery, referred to the patients' anxiety about the continuous uncertainty:

> A lot of times they don't know what treatment they're going to receive as follow-up. … They haven't got the pathology report back yet so no decision has been made and they haven't seen an oncologist to see what they follow-up is going to be in relation to the cancer treatment.
>
> The waiting is bad, and the not knowing.

How nurses help patients who are anxious is determined by the nurses' assessment of each individual patient's coping style and readiness to discuss issues and receive information. Based on a nurse's assessment of the patient at that moment, she will decide whether or not to introduce the topic of lymphedema. "Like I said, a lot of it has to do with rapport and how much you develop it and how much they actually want to talk about, how much they're ready to talk about."

In every group, nurses said that the patient guided their interactions. Nurses spoke about following the patient's lead, and establishing rapport as being fundamental to their approach. They are aware that timing is a crucial factor in presenting information to patients:

> The timing of things is such that people can be overwhelmed. So we as nurses realize that sometimes we've got to plan our teaching in stages. As people seem to be receptive, to avail of that teaching moment. We have to go when we think they're able to receive that.
>
> Everyone is individual, and some can process the information more readily than others and you have to take that into consideration.

This descriptive review of the educative role of nurses reveals the similarities among the groups. In nurse-patient interactions, there were many commonalities. Differences between the groups were small. Nurses in Community Health have the most varied practice, and treat patients with many different diseases. They must maintain up-to-date knowledge over a very broad range of subjects. Their level of knowledge of lymphedema risk and management may be expected to be less than that of nurses working in the hospitals, who may be exposed to the most current information.

Nurses in the Dr. H. Bliss Murphy Cancer Centre see women over a longer period of time than do nurses at the other sites, and later in the treatment process. Given the earlier opportunities for lymphedema education, they might be expected to find women more knowledgeable about lymphedema. This was not the case. One nurse said: "Very few percentage of patients who come in here have prior knowledge concerning lymphedema. Very few who ask about it".

4.3 Opportunities for educating patients about lymphedema – a question of time

What are the opportunities for lymphedema education? Nurses appear to spend little time educating patients with breast cancer about lymphedema.

4.3.1.Nurses appear to spend little time on lymphedema education

Although nurses may spend quite a lot of time with patients, they are often task oriented, giving instructions, and answering questions about a multiplicity of patient concerns regarding breast cancer treatment. Nurses do not routinely discuss lymphedema with all patients. Nurses in the Pre-Admission Clinic outlined their normal intake procedure:

> They say one hour is allotted for each patient but that includes everything like organizing diagnostic tests, history and physical … organizing that and the nursing assessment and then doing the pre- and post-op teaching. … It depends on the day. To spend longer with the patient. The teaching I would say, you're talking about half an hour, forty-five minutes. On an average patient, I would think. That's pretty good but … you have to go through all the instructions like for coming into the hospital, you go here, and this is what they're going to do, then you know, some of it's more … the mechanics of it. But then we try to get into the deep breathing and the circulation exercises you know, and about any tubes and stuff like that. With the patients with breast cancer of course they have hemovacs in, so all that. But with exercise you probably get five minutes to talk about the dos and don'ts after the breast surgery. Five to ten minutes.

One nurse in St. John's described the dilemma of a busy day and a patient who wanted to have a long conversation about risk and management of lymphedema: "I don't have time to talk about it for 25 minutes. The clinic slows down, people are looking for you." The institutional routines and procedures have to take precedence or the system breaks down. Other people's needs (as established by the routines and procedures of the system) trump the needs of the patient who "likes to have a long conversation". The nurse is forced into an ethical predicament; "You can't just say this might happen, but I can't tell you more about it just yet." It is not surprising, therefore, that a nurse might choose not to bring up the topic of lymphedema because she realizes she does not have the time to devote to it that a patient requires.

4.3.2 Discussion

Nurses educating women about lymphedema risk and management appear to devote little time to this topic. Nurses may be caught in a difficult dilemma of time constraints, and competing institutional and patient demands. This may be due to absence of a standard policy, the view that lymphedema is not as important as the disease of breast cancer itself, not enough time in general to spend with patients, or insufficient knowledge on the part of nurses themselves (Davis, 2001; Radina et al; 2004).

As indicated by the nurses, competition among patients for the health professional's time exists. In the institution, the balance of power is weighted on the side of physicians and nurses who "own" the territory. A patient is a foreigner, a temporary visitor, and one among many (Freedman, 2003). In following institutional guidelines and priorities nurses exert their authority and may necessarily choose to interact with one patient while overlooking another.

Nurses work in a formally rule-based environment that reflects larger socio- cultural values (Rankin & Stallings, 2001; Redman, 2001). These larger cultural forces impact how medical institutions are run, and how nurses within the institutions accomplish their daily task. Government policies requiring balanced health board budgets, for example, may impact the number of nurses working within individual hospitals. Additionally, most patients' stay in hospital is now of short duration and both nurses and physicians are working under constant time pressure. Communication with patients and the provision of information is constrained (Saino & Ericksson, 2003: Treacy & Mayer, 2000).

This problem is not new and was identified when patient stay in hospitals was longer. Then, the argument was the same: that doctors and nurses are too busy and that the number of patients is too great. There must be some other factors not yet identified which contribute to this problem. An investigation employing the methods of institutional ethnography, whereby the researcher examines more fully the interconnections between the daily activities, professional practices, and policy making to uncover the socio-political dynamics of ruling relations could provide insight into contributing factors not yet identified (DeVault & McCoy, 2002).

4.4 Opportunities for patient education – questions of timing and patient readiness

Nurses in all four focus groups talked about the difficulty of introducing the risk of lymphedema developing (i.e. that it is an iatrogenic risk of surgery and radiation therapy).

The primary reason given was patient inability to absorb information either because of the state of the patient's emotions, or because of the influence of medications.

4.4.1 Based on assessment of patients, nurses may control information

Nurses assess patient readiness to receive and absorb information. If patients are upset at the time of diagnosis for instance, nurses will avoid mentioning lymphedema. Rather, they will emphasize the positive so that the patient will be better able to support the surgery. Nurses at both the Ambulatory Care Clinics and the Pre-Admission Clinics commented on the difficult choices women face during the time of diagnosis. "Usually that first week we see them, they're too upset to go over a lot." "A lot of them are very emotional when they come through."

Since the move to involve women more fully in decision-making about their treatment, nurses at the Ambulatory Care Clinic identified that some patients do require help in making decisions: "Years ago it was: the patients were told: this is what you have to get done. This is the way it is (chorus of agreement from other nurses). But now the decision-making really is in the patient's hands. If she wants the lumpectomy, if she wants the mastectomy, if she wants chemo, if she wants radiation."

Nurses in all groups revealed that they assess their patients carefully, and hand out information if and when they thought a woman was ready to receive it.

> Well, you read your patient. If you're got a patient with an elementary education level of less than grade three, you really got to bring yourself down and you gotta

> answer what's important to them in their minds. Because if they don't understand, there's no point in introducing it. That's what I find. Each patient is different.
>
> If a patient asks for it I'll give it [patient information sheet listing dos and don'ts] to them. I don't as a rule pass it out to everybody. Now that we have the little lymphedema pamphlet in the Purple Lupin, they do have the information. They can call us if they want to ask anything else. But it's not everybody that we give it out to. Because they're getting so much information that it's a lot to take in.

When asked how women responded to the information about lymphedema, nurses in two of the groups seemed to think that women were glad to have the information and that "most women respond well to it." However, in another setting, nurses felt that women "are just too upset to respond." In the Pre-Admission Clinic, nurses' perceived patient lack of interest in the subject of lymphedema pre-operatively: "A lot of them [women being treated for breast cancer] don't talk about lymphedema though. They don't ask a lot of questions about it." "That's because they don't know about it." Nurses interact with patients both before and after the interview with the surgeon, and sometimes accompany a woman if no family member is present. Whether, or how much, the risk of lymphedema following surgery for breast cancer is discussed in patient-physician interviews is not known.

Across the focus groups, nurses could not agree on an optimum time to introduce the subject of lymphedema risk. Nurses from one area proposed another area as the best place to introduce the topic, and vice versa. Nurses at the Cancer Centre suggested that the Pre-Admission Clinic would be the best place to introduce lymphedema education because:

> That's about the only time you're going to get them. Because right now they're not staying in overnight, not even for mastectomies. They're home. There's absolutely no time post-op unless Community Health could go in. But then post-op, there's people looking after drains, they've lost their breast. How receptive are they? I think that's the challenge, part of the challenge with lymphedema.

The Pre-Admission nurses on the other hand felt that, depending on the emotional state of the patient, the Pre-Admission Clinic was not necessarily the best place to start lymphedema education:

> There may be a time to introduce that [lymphedema education] and it may not be in this clinic [Others agree]. They may just be so overwhelmed with the diagnosis that they only need to know about preparation for surgery and the immediate things that they need to know for right after. … Maybe when physiotherapy sees them, maybe one of the nurses gently talking to them post-operatively, maybe when the public health nurse comes in to see them in surgical day care. It could be that Community Health is the right person for some people to introduce it.

Community Health nurses, while reinforcing the notion of working within the parameters of patient and family readiness to hear information, also countered the suggestion that Pre-admission was the best time to introduce the topic. They tended to find that patients did not recall well what they had been told in the hospital post-operatively, due to effects of medication:

> It's a lot to put on people who are unconscious when they are told these things. Especially with the tubes and milking them. They're shown that in hospital but some say 'I didn't know anything about that'. And if it happened or not, you have no way of knowing. They could have been loaded up with gravol and morphine.

In the Ambulatory Care Clinic where lymphedema is introduced briefly, nurses also indicated that little time is spent on it because most of the patients are too upset to respond to the information. Although there was little agreement as to the best time to introduce the topic, there appeared to be general support for multiple introductions of the information so that women and their families would become familiar with it. Nurses also referred to the role of physicians. Surgeons typically are the first to discuss treatment options and risk factors. According to nurses at two sites, some doctors are more open than others to the subject of lymphedema education.

4.4.2 Discussion

Despite apparent agreement among nurses at all the focus groups that lymphedema education for patients was important and necessary, and that they already incorporate some lymphedema guidelines into their normal care, nurses indicated that they could do more. Most interestingly, aside from the notion that it is difficult to talk about lymphedema during a first visit, there was no agreement as to when *is* the optimum time to educate patients.

Timing of educational interventions has been identified as crucial (Nicklin, 2002). Many factors affect patient education: the knowledge and skill of the educator, the educational materials, the environment, and timing are external factors; while the stress levels, coping style, state of health, motivation, beliefs, readiness, etc. are factors internal to the patient (Treacy & Mayer, 2000). While some health care professionals may lack the skill, or time to assess patient readiness to learn, it has been documented that cancer patients need information throughout the process of the disease and its treatment, and that those information needs could change over time (Luker et al., 1995; Rees & Bath, 2000; Treacy

& Mayer, 2000). Nurses did not reference any particular way of monitoring changing needs of patients. They rely on their own assessment capabilities and identified patient distress, and patient incapacity due to medications as major factors in decisions not to discuss lymphedema risk.

Multiple introductions of a topic is recommended as patients' needs for information are individual and change over time, and multiple and various forms of information giving (e.g., different health providers, verbal and mass media) are useful (Luker et al, 1995; Rees & Bath, 2000). Nurses at the various sites already reinforce information through reliance on the Breast Cancer Surgery Services Checklist, and the Purple Lupin kit. It must be noted, however, that multiple introductions would require that nurses discuss the topic of lymphedema risk at all sites. Such a practice would appear to be difficult to implement given nurses reluctance to introduce lymphedema in their own clinics when they assess women as anxious or overwhelmed with information.

This widespread reluctance among the nurses to introduce the topic of lymphedema risk at times when patients were anxious or stressed could be due to a tendency to protect the patient (Dixon-Woods, 2001; Freedman, 2003) or could be an accurate assessment of learning readiness. Nurses are rarely responsible for the first introduction of lymphedema risk. It appears from the focus group discussions that the practice of physicians on this subject is not uniform. If the initial introduction of lymphedema risk as a result of a medical intervention were to be made by a physician, perhaps the nurses would feel more comfortable. Physicians, however, have been found to be reluctant to educate women about lymphedema as an iatrogenic complication (Carter, 1997).

Freedman (2003) reported that patients were concerned by some physicians' decisions not to inform them of treatment options, which might be of benefit in limiting long term side effects. The risk of lymphedema varies according to the surgical procedure that is performed, and the amount of radiation that may be given later (Schrenk et al., 2000, Sener et al. 2001). Sentinel node biopsy (SNB), which is presumed to result in lower incidence of lymphedema, is performed in St. John's, but not by all surgeons. It has been documented, in the United States, that some physicians, who do not perform SNB, do not inform patients of the option of seeking another surgeon who does (Freedman, 2003). It is unknown if such behaviour occurs in St. John's. It should also be noted that not all patients are candidates for sentinel node biopsy (Zack, 2001). Nurses explain the procedure of sentinel node biopsy to those patients who will be receiving it, but appear to limit their discussion to a description of what to expect during the procedure:

> We also go over, if they're having a mastectomy, then they may be booked for a sentinel node biopsy. We explain that procedure to them as well. … If they're having the mastectomy, most of them get the sentinel node biopsy. I guess it depends on the surgeon too.

When asked if patients brought up the subject of lymphedema as a risk factor after their interviews with physicians, no nurse could recall any such discussions. It is possible that patients are so pre-occupied with the significance of their diagnosis and the immediate requirements of treatment decision-making that the risk of lymphedema, even if discussed, may be disregarded (Freedman, 2003). Further in-depth research involving physicians, patients and nurses is required to answer this question.

Criticisms of health care professionals on matters of judgement are problematic. Human beings are constantly making judgements; it would be difficult to act without doing so. Patients do rely on professionals to make judgements in the patients' best interests and ethical codes are written and enforced for this purpose. Yet professionals can be justly criticized if information is withheld or slanted to a certain view. By their discussion, nurses showed that they make judgements about how much information an individual patient should be given. This reflects their training both in the bio-medical sphere, and in patient assessment (Babcock & Miller, 1994; Dow & Kalinowski, 2000; Rankin & Stallings, 2001). Patient-rights exponents have criticized medical practitioners for manipulation of information, e.g. selecting, emphasizing, withholding, etc. (Dixon-Woods, 2001; Freedman, 2003). Yet other writers have shown that some patients, particularly the elderly, perceive medical information difficult to understand and may prefer less information (Jahraus, 2002). The literature does support the notion that patients with breast cancer want information and that their information needs change as they move from diagnosis through treatment (Luker, et al., 1995; Rees, et al., 2000; Rees, et al., 2001). It is not clear how health care professionals assess those changing needs and respond to them.

It may be difficult for nurses to check with patients later to ascertain if they were satisfied with the amount and type of information provided. Nurses may see a patient only once, or at most twice early in the treatment process. This may constitute an institutional barrier to continuity of care that is beyond the capacity of an individual nurse or patient to rectify. Nurses at the Cancer Centre are more likely to establish an on-going relationship with a patient than nurses in Pre-admission or Ambulatory Care Clinics. In such a situation, there may be more of an opportunity for on-going, and changing educational encounters, and informal feedback on patient satisfaction with information.

4.5 Attitudes to lymphedema are changing

Nurses report that their own levels of knowledge and attitudes to lymphedema and patient education and management are changing, as are those of some of the physicians they interact with. Nurses are more aware of the need for preventive education for women.

4.5.1 Knowledge of lymphedema and attitudes are changing

At the Pre-Admission Clinic there was quite a discussion about changing attitudes over the past ten years. One nurse had had surgery for breast cancer ten years ago. She felt that she had not got sufficient information at that time, and that even now, not enough emphasis is put on lymphedema, whereas others in the group thought that great changes had been made:

> I was told don't wear anything tight around your wrist, don't have blood pressure taken on that arm, but nobody said to me you are at risk to have swelling in your arm.

> Was there any Pre-Admission Clinic set up at that time?
>
> I was in Pre-Admission Clinic. But I think it was just when Pre-admission was getting started.
>
> Because our information is very very good now.
>
> Pre-admission then was your history, physical and blood work the doctor got you in and saw you and got your consent signed and the nurse asked you all these questions and …
>
> So we've come a long way with our clinic now. I think every single one of us puts a big emphasis …
>
> But I don't know if the emphasis is placed on lymphedema that should be placed on it. … (talking over) because once you get it . It's very hard to …
>
> Yes and I think, the emphasis wasn't placed, you know ten years ago (no, no others talking) but it is the most important thing
>
> Oh I mean our booklet on breast surgery now is very, you know. You get the physio also what we tell them
>
> And a lot of times too I don't think people understand that this is a lifelong thing. (mm) And you are never to have blood pressure taken out of that arm. You are never to have blood work taken out of that arm. They just think that it's initially until the under the arm heals (that's right). They don't realize (A: " you have to say the word never") I just say never, ever, ever, as long as you're alive are you to have that done to that arm (yeah that's right).

This illustrates how attitudes can differ as a result of experiences on opposite sides of the institutional divide. The nurse speaking from the patient vantage point is quite adamant that even now, not enough attention is given to lymphedema. The second nurse, on the other hand, seems to speak for other nurses in the clinic and defends the current program as it is implemented. Some nurses agreed that more emphasis should be put on lymphedema education.

One nurse commented on the distinction between nurses and physicians, and how her practice as a nurse has changed to incorporate lymphedema education regularly: "I think our practices are independent. What I teach the patient isn't necessarily the same as what the doctor does. But I bring it up regularly now." Nurses had a variety of experiences with physicians, and changing attitudes, regarding lymphedema education:

> A lot of physicians feel that the type of surgery they do, the patient is at minimal risk for lymphedema. Some physicians feel they don't need to talk about it.
>
> There's mixed messages from physicians … I've seen doctors not take it seriously enough. I think it's gotten better recently.
>
> I think they have different opinions.
>
> There's another one who sounds knowledgeable but some of the information I hear being said to a patient doesn't seem correct. Like a sterile needle is OK to use in an affected arm. Because it wouldn't cause an infection if the needle is sterile.
>
> My experience with these patients (patients with breast cancer) was (in the past) there was very little time spent on educating patients on lymphedema. It very often was overlooked. Partly because we as a group of nurses, we didn't know what to tell them. Doctors didn't know what to tell them. And at the time they were receiving active treatment it just didn't seem important. We are learning now, or are more aware of the fact now, that prevention is such a big part of it. Because once it starts, it's there.

4.5.2 Discussion

In every group one or more, sometimes several, nurses expressed feelings of ignorance about lymphedema and what to teach women. Opinions varied, not only among individual nurses assessing their own level of knowledge concerning lymphedema, but also nurses' assessment of the institutional programs they were responsible for implementing. It is noteworthy that the one nurse who had herself experienced lymphedema following breast cancer treatment was most emphatic about the importance of lymphedema education. She spoke from a patient's perspective and challenged the attitude of other nurses who thought that their program was greatly improved. While this nurse was initially treated ten years ago, and all agreed many improvements had been made since then, she expressed a more vigilant attitude than many of the others. Lymphedema tends to become a concern once it occurs. Coward (1999) found that women who developed lymphedema were more likely to use preventive strategies than those women who did not develop lymphedema. Women/health professionals only realized they had overlooked lymphedema after they themselves developed it (Price & Purtell, 1997).

Nurses appear more aware now of the need to educate women about lymphedema risk and management. It is not reasonable to expect every nurse to take an individual interest in lymphedema, to delve into the research, and to ascertain available community resources. Some nurses are better informed than others and a few have taken a special interest in lymphedema and willingly share their information. Nurses generally recognised that they, and other health care practitioners were, and to a lesser extent are now, lacking the knowledge base to provide adequate information to women about lymphedema. This situation appears to be consistent with that of many medical professionals across North America, and may partially be related to the lack of local treatment centres and certified lymphedema therapists (Radina et al., 2004). While nurses are more aware, they do not necessarily feel well prepared, do not necessarily have good resources, and do not necessarily feel the support of physicians. It appears from the focus group discussions that lack of institutional emphasis may also be a factor contributing to ignorance about lymphedema management.

4.6 Opportunities for education for nurses are required

Despite growing awareness about post-mastectomy lymphedema, nurses expressed concern over lack of knowledge, lack of time for self-education, and lack of staff educators. They identified these as barriers to their own education.

4.6.1 Nurses do not feel well educated on the subject of lymphedema

Lymphedema appeared to be a subject that received scant attention in basic nursing education, both for older and for more recent graduates. Nurses also articulated that they had not received much post-graduate education on lymphedema or breast cancer through in-services:

> I just graduated in 2000 and I don't recall, there was no in-depth discussion or teaching on it. Sort of touched over ... So most of mine [learning about lymphedema] has been through reading articles on my own in a magazine … and from nurses that have been there. In my other team I worked on, there were a couple of women who had been there twenty-five years. So you know, through discussion with them, getting info and tips. I haven't had a real lot of info myself from in-service or anything like that.
>
> I agree with (name withheld) as regards to nursing school. There was very little discussion with regard to lymphedema as an actual part of the pathology of your course. And very little in-servicing on the part of the organization. So there is a very great need for further education. And I'm sure things have changed in the last ten years as regards to lymphedema.

Nurses also said that they found it difficult to keep up with new developments in all the areas for which they were responsible. This was expressed in particular by Community Health nurses, who care for patients with many different diseases, other than cancer:

> You can appreciate where we come from, from a community perspective. When you're working in a hospital you either work in medicine or cardiology or oncology. Out here we're working with everything, so we're a little bit of everything and hopefully you get what you need from us. We're not going to be experts in any of the fields.

Many nurses agreed that they relied on information gathering through conferences, reading, and talking with other experienced nurses. Some nurses relied on the Internet, while others were more suspicious of that source. One nurse said she accessed the Canadian Cancer Society for information, and another stated that she got information from the Breast Cancer Retreat that is now held annually in Newfoundland.

Nurses at all locations pointed out that there was no nurse educator in their unit. In the absence of a staff educator, nurses at the Ambulatory Care Clinic, on their own initiative, set up a regular monthly time for educational sessions. Nurses identified financial pressures on the system and staff shortages as constraints. Managers were seen as supportive: "Our manager here is very supportive. If she can get someone to relieve us to go for education, she is very supportive in regards to that. But then again, there is no money. (laughter) You know, you have to find your own."

4.6.2 Discussion

Nurses at every site expressed concern over lack of time and absence of staff educators to promote and organize educational sessions. Nurses stated that they wanted consistent, reliable information for themselves that could be accessed across all sites. This need seemed to exist in an organisational vacuum with no institutional mechanism through which it could be addressed. Presumably a nurse educator would be responsible, not only for organizing in-service training, but for responding to requests for background information.

As indicated in the previous section, the level of knowledge about lymphedema varied among the nurses. There was no discussion of how nurses evaluated their own levels of knowledge. Without some formal mechanism of self-evaluation, nurses (and other health care professionals) may not recognize when the information they are using is out of date. In Community Health, for example, some nurses did not appear familiar with newer surgical techniques, such as SNB, that may impact on lymphedema occurrence. Nurses appear to rely on each other as information sources in an informal manner. Learning from others is an ad hoc process and depends on the motivation of the individual nurse and the experience and character of the other team members (Long, Kneafsey, Ryan, & Berry, 2002). There is a possibility of acquiring incorrect information by this method.

Lack of time for self-education is an institutional as well as individual issue. Without a staff position of nurse educator, the impact is felt locally, but has repercussions broadly, as many women from across the province are treated through the Health Sciences Centre and the Dr. H. Bliss Murphy Cancer Center. Without a nurse educator to initiate programs, nurses are forced to rely on their own resources, on each other, and on the occasional program that might be offered institutionally or within the unit.

Now that a nurse in the Cancer Center has been trained in combined decongestive therapy, it is possible that assessment, and perhaps management of lymphedema will take place in the Cancer Center itself. This would be a positive development for patients suffering from lymphedema, as many cannot afford the cost of private treatment. There may be institutional advantages as well. A well-educated nurse can influence her colleagues through formal and informal educational presentations and discussions.

Nurses at all the sites articulated a lack of formal, organized educational activity designed specifically for them. Lymphedema, it was my impression, was not a priority in the basic formal curriculum, nor in structured educational sessions for staff within the hospital setting. Nurses were becoming more aware of the need to educate patients about preventive and management strategies, but had to rely on their own resources or ad hoc information gathering from each other, and community support agencies to obtain the tools in order to accomplish this task.

4.7 Summary

With this chapter I reviewed the findings related to attitudes and opportunities for lymphedema education and elaborated on the implications for nurses, for patients, and for the institution. Nurses make judgements about what information to give depending on their assessment of patient readiness. Nurses could not agree on a best time to introduce lymphedema education to women, because they were concerned about patient levels of anxiety, distress or possible medication-induced confusion. Some nurses are more knowledgeable than others about lymphedema and more regularly provide patient education on this topic, while other nurses provide only very limited information, or none at all, depending on the patient circumstances. Nurses do not appear to have a formal mechanism for assessing their own knowledge base, or patient satisfaction with educational information. While, with a few exceptions, nurses reported that their level of knowledge about lymphedema is generally low, this is common among health care professionals across North America where lymphedema has traditionally been a topic of low priority. Generally nurses felt their level of knowledge has improved, and this increased awareness has resulted in some nurses making lymphedema education a more routine part of their interaction with women being treated for breast cancer.

Chapter Five Text-mediated findings and a discussion of their implications

5.1 Introduction

This chapter describes and discusses text-mediated findings, and the assessment of the educational materials nurses provide to women. In section 5.2, I introduce and discuss the implications of institutional barriers to nurses disseminating information about lymphedema risk and management. In section 5.3, I present and discuss the implications of reliance on a standard package of educational materials. In section 5.4, I describe, assess and discuss relevant sections of the standard package of educational materials and additional materials that nurses use when educating women about lymphedema risk and management.

5.2 Policy on breast cancer treatment does not include lymphedema

It is evident that across the three sites, there is no standard, co-ordinated policy or guidelines for nurses regarding the education of women with breast cancer about lymphedema risk and management.

5.2.1 Reliance on the Breast Surgery Services Checklist but no policy on lymphedema

There is a policy/guideline for standard procedures across all three institutions on care of patients with breast cancer. This was begun in 2001 with the Quality Initiatives Committee for Patients and Families with Breast Cancer and involves the use of the Breast Surgery Services Checklist. The checklist does not include specific reference to education regarding lymphedema risk, or to assessment for lymphedema. The checklist does require confirmation that patients be given the Purple Lupin kit, which provides information on all topics regarding breast cancer, its treatment, and community support. Information on lymphedema is contained within the kit.

Nurses in each focus group knew of the Quality Initiatives Committee and referred to it, though not by name. It was only in the final focus group that a nurse provided the full title for the committee and gave me a document that outlined its purpose and development (Committee, 2001). The Qualitative Initiatives Committee for Breast Cancer Patients and their Families is an interdisciplinary and collaborative venture among the Surgery Program (Health Care Corporation, St. John's), the Newfoundland Cancer and Treatment Research Foundation, and Health and Community Services, St. John's Region. The aim of the project is to provide a comprehensive care plan for patients with breast cancer to ensure continuity of care from time of diagnosis to home care in the community by instituting guidelines that are standard, best practice, and consistent across institutions. In 2001, a pilot project took place at St. Clare's site. The project included patient evaluation (Committee, 2001). On the Committee`s recommendations, a standard Breast Surgery Services Checklist was developed and put into use.

The checklist is attached to a patient's file and nurses confirm or provide the following items: information and exercises kits, consults with physiotherapy and social work, contact with Cansurmount visitors, nursing patient education, provision of temporary prosthesis, and referral to Community Health. Items not on the list (such as lymphedema risk factors or arm measurements) are not part of the routine. Several nurses independently stated that patients are no longer "slipping through the cracks." In every group, nurses commented that patients were receiving consistent care and getting "all the information" they need regarding breast cancer and its treatment. No one commented on the fact that lymphedema risk factors and symptoms are omitted from the list.

5.2.2 Discussion and implications

The most obvious result of no formal policy on lymphedema education for women is that it is ignored or given little priority. Despite their assurances that patients are getting all the information they need regarding breast cancer care, nurses articulated, directly and indirectly, that the potential risk of developing lymphedema as a result of axillary dissection or radiation therapy is not always discussed, either at the time of initial diagnosis, or following treatment. On the subject of lymphedema management, some nurses revealed complete ignorance that any effective and safe treatment strategies were available and had no knowledge of where to refer patients.

Without guidelines or policy involving health practitioners in all fields to incorporate education about lymphedema risk and management into normal practice, and without sufficient information being provided to the health care practitioners themselves, lymphedema is likely to remain unrecognized, and women uneducated and untreated. Lymphedema may have been ignored because it has been deemed unimportant compared to the more life-threatening consequences of breast cancer (Carter, 1997; Coward 1999: Freedman, 2003). Yet, for women who develop chronic lymphedema, it becomes a life-long concern and management issue, with potentially serious psychological impact (Bosompra et al, 2002; Maunsell, 1993, et al.; Radina et al. 2004).

It has been recommended in the literature that women be educated about their options at the time of diagnosis and decision-making about treatment both by physicians and nurses (Freedman, 2003; Luker et al. 1995). Communication between health care professionals and cancer patients can, at this time, be problematic (Coulter, 1998). Nurses at most of the focus groups indicated that physicians need to be involved and stressed that need. Physicians are the first to engage with patients in informed decision-making about complex treatment choices, and their words carry weight. Studies show that women treated for breast cancer want to be active participants and want to have a sense of control (Hinds et al, 1995). Women want comprehensive information, including information about "all possible side effects" (Jahraus et al., 2002, p. 272).

The Breast Surgery Services Checklist shapes the work of nurses universally across the system and ensures links to different internal and external elements (e.g. physiotherapy consults to advise women about proper exercise). While many people, including patients, were involved in the project that resulted in development of the checklist, a document, once developed, assessed and approved, can take on a life of its own. The checklist becomes a mediating and possibly restraining influence on nurses' behaviour. Nurses who were not involved in its development rely on it as the authorized and approved method of ensuring proper care. Nurses establish a routine based on the checklist and procedures become standardized and unquestioned. The nurses believe they are providing optimum care. Yet, because lymphedema education and assessment is not part of the checklist it is automatically outside of standard care and therefore not regularly given in a routine, consistent or universal fashion.

The checklist could provide a medium for incorporating standards for lymphedema care. Or another form could be created. Nurses at the Cancer Centre have discussed the creation of a form that the "patient could either keep with them, or have on the chart, with arm measurements so that they could be more aware of how important that is to monitor regularly. (pause) But we haven't got very far with it yet (haven't started it yet)." Another nurse even used the word "checklist": "Maybe if we had an educational tool, a checklist to say what has been covered and a way for a patient to actively participate by keeping a record of measurements". These nurses recognize a need and articulate a solution recommended in the literature (Harris et al., 2001; Radina, et al., 2004). Yet no policy or procedural change has occurred. The Qualitative Initiatives Committee for Breast Cancer Patients and their Families could provide the vehicle for such a change. A sub-committee or working group on lymphedema has been formed and may lead to the development of needed guidelines, and the implementation of a form, or adaptation of the checklist to implement recommended procedures. Such a procedure would need to be supplemented with education and training for the nurses and other health care professionals on assessment techniques, individualized precautionary measures and management strategies.

5.3 All nurses rely on a standard information package on breast cancer and its treatment

The second policy finding, linked to the first, is that the nurses all rely on the Purple Lupin kit as their primary source for educating women with breast cancer about all facets of the disease and its treatments, including lymphedema. They rely on physiotherapists to educate women about proper exercise after surgery.

5.3.1 Nurses rely on the Purple Lupin kit and on physiotherapists

The Breast Surgery Services Checklist on the patient's file is used to ensure, among other items, that women have received the Purple Lupin kit and have been seen by a physiotherapist. The Purple Lupin kit is usually given out in Ambulatory Care when women are booked for surgery. Nurses approve of the kit:

> The booklet is excellent because they can take it home and read it over with their families and then come back … and discuss their options. Then they have all the questions they need answered written down and then they discuss their options with the surgeon.

Nurses at Pre-Admission Clinics and Ambulatory Care reinforce the surgeon's instructions regarding what to read in preparation for decision-making regarding treatment choices. Nurses go over the literature as they help women understand the decision they will be making. Sometimes the patient will ask:

> What would you do?' And you don't know unless you're in that situation yourself. All we can do is go over the literature in the book and tell them to read up on the difference between lumpectomy and mastectomy, and let them know the final outcome, there's no difference in the final outcome whether they choose mastectomy or lumpectomy.
>
> I tell the patients sometimes to ask the doctor to highlight what they should be reading in the books. Also to point out the pamphlets, yes that's really important. But in the book itself, bring it to the hospital, put it in your bag, if you don't want to read it beforehand. If it frightens you, ask your doctor: what should I be reading in this? They read too much they get scared.
>
> They get it in the outpatient department when they see the surgeon. And so they (the surgeons) tell them which section to read for their particular cancer. I tell them not to look at anything else ("that's right" interject other nurses) except for that part. It's too overwhelming for them."

The kit contains a wealth of material and as these quotations demonstrate, nurses and physicians often guide women to read relevant sections. As one nurse commented "There's a lot of information in those books that you know that the patients probably aren't up to reading and taking in and all the rest of it." In two of the groups, nurses remarked that some physicians do not see the need to inform patients about lymphedema.

While some patients may be at very low risk for lymphedema and consequently will not be presented with that information, the nurses seemed to indicate that some physicians more broadly may not see the need to inform women about the risk of lymphedema.

In Community Health the nurses make sure that women have received the kit and been instructed in proper exercise.

> We make sure they got their kit that the hospital gave them, the Purple Lupin kit, and make sure that they`ve been given all that information and the booklet on the exercises and all that stuff, and which ones to do and not to do until their strength come. Most of them, I've got to say, that it's improved a lot.

In the Pre-Admission Clinic at the Health Sciences Centre, the physiotherapist visits women on the unit:

> We have the pamphlet in the Purple Lupin kits at the Health Sciences so we give out the Purple Lupin kits to the patients, we go over the exercises briefly with them, we call the physiotherapist and they come see the patient in the clinic now.
>
> The physiotherapist that comes to our clinic now actually gives the kit to the patient with the ball and the rope and stuff. So they spend a bit of time with the patient and that's helpful to us because we didn't know if we were doing enough with the exercises. We're not physiotherapists. I mean we go over the exercises but it's good to have that back up.

Although they rely on the kit, it was evident that some nurses were not themselves familiar with the contents. Nurses do not have their own copies of the kit. Some nurses were given an introduction to the kit but had only a very brief occasion to examine its contents. A few copies of the kit may be kept to distribute to women but not at all locations. Some nurses had read the pamphlet on lymphedema contained in the kit, while others had never seen the pamphlet.

5.3.2 Discussion and implications

In the formally rule-based environment of the medical institution, the Breast Surgery Services Checklist acts as a socially mediating force on the distribution of information and on professional-patient, and professional-professional interaction. Across the sites, nurses use the checklist to monitor what has been provided to a patient. Usually women receive the Purple Lupin kit at time of diagnosis, and nurses use the texts from the kit as a vehicle to direct their discussion with patients, and as a reference source to substantiate the information they give. Given the limitations of time and the concerns of patients with breast cancer, the kit provides a useful mechanism for focusing on essential information. It is also intended as a resource guide and source of information that women can refer to over time.

The physician's role is an important arbitrating influence on which sections of the kit women read. From the majority of the discussions, it was apparent that physicians and nurses tended to rely on the kit mainly for education about treatment choices and outcomes. Education about lymphedema as a risk factor of certain treatments did not appear to be a routine topic of discussion. When nurses spoke about how they educated women they mentioned the common list of precautions. Nurses referred to the addition of a locally produced pamphlet on lymphedema, which the kit now contains, but it was my impression that the nurses in general relied on the women themselves to read the pamphlet in the kit.

Nurses realize that patients may not read everything in the kit at the beginning of the treatment process. But they did appear confident that over time patients read the materials at home. There does not appear to be any method of evaluating whether patients are in fact reading the materials, how much information they are absorbing, or whether they are understanding it properly. One nurse in Community Health related a story of a patient who had read the section indicated by her doctor and had gone back to him with questions. "It was some contraindication with her condition to do with what she had read in the Purple Lupin. 'Where'd you get that?' he said. 'In that book you gave me to read' she said. 'Well stop reading it.' (laughter) She was taking it too literally."

This anecdote indicates the need for health care professionals to offer on-going verbal explanations, in addition to any educational materials. At the time of diagnosis, women prefer verbal explanations (Rees & Bath, 2001). A patient's ability to absorb information may vary over time, and depends upon many factors. Older patients are more likely to prefer only that information which is necessary to them (Jahraus et al, 2002) while women have been found to want comprehensive information about the disease, its treatments and side effects (Luker et al., 1995; Mills & Davidson, 2002). Patients are also constantly interacting with new health care providers as they move along the treatment continuum. Women have been found to prefer an active, collaborative role in decision-making (Stacey et al., 1999) and one study found that women tended to rely on information from other patients more than medical knowledge in making decisions (Leydon et al. 2000).

It is well documented that health care information is often written at too high a literacy level for many patients (Doak et al. 1996). Some patients may not understand even the most simply written information. By relying primarily on written information (in addition to interviews), nurses, and other health care professionals, may miss opportunities to ensure that those who are illiterate comprehend the information they have been given. Literacy experts contend that intelligent adults who are illiterate are not always easy to detect (Doak et al. 1996).

Nurses indicated that there was little patient-initiated concern about lymphedema. Patients may not understand the information they have been presented with; they may not have read the information; they may think the information does not apply to them; they may not be ready to learn or be interested in the information. Two authors have pointed out that once lymphedema occurs, interest in precautionary strategies increases (Coward, 1999; Radina et al, 2004). Some method of assessing patient readiness and patient understanding of educational materials may be warranted. The Breast Surgery Services Checklist is an attempt to ensure that all patients receive the proper information. An evaluative component to discover whether patients use or understand the information might improve the effectiveness of the educational materials that are provided.

Ideally nurses should be familiar with the contents of the Purple Lupin kit, and a copy should be in their clinics as a reference tool. When nurses have not read the material that is in the kit, it is difficult to direct patients to relevant information in answer to questions. Nurses who had questions about the role of exercise, for instance, might find answers to their questions in the materials in the kit. While good information is available, constraints of time, interest and competing demands of patients with other diseases and conditions may mean that all nurses do not necessarily access information that is available.

5.4 Superior rating for the Purple Lupin kit

5.4.1 Description and assessment of the Purple Lupin kit

The Canadian Breast Cancer Foundation financially supports the Purple Lupin kit which is a small box containing a book, several booklets and leaflets. The assessed items, as noted in section 3.8 included: Chapter 35 *Physical therapy and management of lymphedema* (Harris and Hugi, 2001) from the book, *Intelligent patient guide to breast cancer: all you need to know to take an active part in your treatment* is part of the Intelligent Patient Guide series (Olivotto et al., 2001); *Guideline 11: The management of lymphedema related to breast cancer* from the booklet, *Questions and answers on breast cancer, a guide for women and their physicians* (Steering committee on clinical practice guidelines, 2001); and the Lymphedema pamphlet, produced locally (West, 2004). Section 3.8 gives details of the assessment tools and evaluative process used. Table 1 summarizes the scores for each item.

Table 1 Summary evaluation of Purple Lupin kit contents

Item assessed	SAM rating	SMOG rating	AHEC score
Chapter 35	Superior (77%)	Unsuitable gr. 11.7	Superior (82%)
Guideline 11	Superior (73%)	Unsuitable gr. 13.3	Superior (80%)
Pamphlet	Superior (72%)	Adequate gr. 8.5	Superior (80%)

All three evaluated texts scored superior ratings using the SAM assessment tool, but among the three, only the Lymphedema pamphlet rated adequate on the SMOG readability assessment (it was very close to rating superior). The other two were rated not suitable. The patient version of the clinical practice guidelines on lymphedema had the highest reading grade level of 13.3. Despite frequent use of technical jargon in the book and booklet, and overuse of the passive voice, the general tone of all three is conversational and friendly. All three group the material using subheadings for easier understanding, but only adequately state the purpose of the text. The book chapter has an introductory paragraph in the passive voice, with many medical terms and unnecessarily polysyllabic words such as "minimized" and "eliminated". Only the book chapter is supplemented with graphics, which were all excellent, clear, relevant line drawings with captions. The Lymphedema pamphlet is a first draft and has no graphics; there was one ungrammatical phrase, and a plural ending missing from a noun. These small errors may have been corrected in a later draft.

From the point of view of accurate medical information, these texts present a mixture of the best evidence as defined by evidence-based medicine (EBM), and the self-care preventive practices recommended by clinicians and other researchers. The book chapter, 11 pages in length, naturally contains more information than the patient version of the guidelines (3 pages) or the lymphedema pamphlet (two-sided leaflet printed on letter size paper).

The book chapter promotes the use of physical therapy, and physiotherapists, so concentrates primarily on exercise. There is no caution against overuse of the arm on the affected side but the authors suggest that women wear a compression sleeve when lifting weights over 10-15 pounds. Measuring the arm before treatment begins and monitoring the arm by measurements are advocated. A short section outlines the cause of lymphedema and gives a brief but complete overview of treatment and preventive measures. Standard precautionary measures, such as avoiding blood draws in the affected arm, are included although these have been the subject of controversy. Some health care practitioners disregard this advice as it has not been subjected to rigorous scientific investigation.

The 3-page patient version of the Clinical Practice Guidelines on lymphedema covers the same information (omitting the advice about exercise, but adding a caution about air travel). An introductory paragraph explains what lymphedema is and the next section describes how it is caused. Measurement and treatment options are outlined, as well as concerns about pain and preventive, and precautionary strategies.

The lymphedema pamphlet contains the same mix of advice as the book chapter and the patient version of the guidelines. The focus here is more on self-care. The pamphlet also suggests other avenues for learning about lymphedema and references a book for women with lymphedema and a number of Internet sites.

5.4.2 Discussion and implications

It is to be expected that the materials included in the Purple Lupin kit would be of high quality as Health Canada, the Canadian Medical Association, and a successful and popular health series publisher produced them. As the assessment above shows, the book and the patient version of the guidelines are very good educational materials, both in terms of production and content. In common with many education materials produced by health care professionals, however, they are written at a high literacy level that may make them inaccessible to individuals of low literacy (Mumford, 1997; Paul et al., 2004). Experts advocate a reading level of below grade eight for health educational materials. The pamphlet provides an excellent counterpoint because it is short, written at a lower literacy level and devoted solely to the subject of lymphedema. It is also more visible because it is not contained within a larger unit and so is an important addition to the kit.

The book chapter and the patient version of the guidelines contain essentially the same information. In the patient version of the guidelines, the ethos of evidence-based medicine is evident in the section on treatment options, yet appears downplayed in the sections on self care and exercise. It is puzzling to understand the unequal handling of these issues, which may not be apparent to a lay person who is unfamiliar with different levels of evidence.

The medical tendency to maintain a paternalistic view of patients as ignorant children who must be protected from bad news and medical uncertainties has been alluded to in chapter 2 (Coulter, 1998; Dixon-Woods, 2001). Communication by doctors has been found to confuse patients through use of ambiguous terms that hint at a condition (Chapman, et al., 2003). While I did not find any studies that specifically discuss the use of the term, lymphedema, per se, I did find a tendency to confusion occurring in the educational materials of the Purple Lupin kit where "swelling" and "lymphedema" are sometimes conflated.

Swelling is a symptom of lymphedema but swelling is also a more common word. In the book, swelling is frequently used to refer to lymphedema. In chapter 22, *Hospitalization and recovery from surgery* (Olivotto et al., 2001, p.133), the authors refer to the possibility that infection in the hand or arm: "will increase the risk of complications such as permanent arm swelling. Radiation treatment to the armpit may also worsen these problems. You can take a number of precautionary steps to avoid significant arm edema (swelling) and the related pain and discomfort that can occur (see Chapter 35)." Nowhere in this passage does the word lymphedema occur, although that is the subject of the text and is part of the title of Chapter 35 *Physical therapy and management of lymphedema.* Similarly, in chapter 26 *Side effects of radiation therapy* reference is made to scarring in lymphatic channels and the possibility that arm swelling could develop. These may be examples of not using the proper word for fear of raising anxiety. Or the authors may have avoided using the word, "lymphedema", because it is yet another polysyllabic medical term. Whatever the authors' intentions, the end result is somewhat confusing.

There may be some confusion around lymphedema because it can be temporary. The National Cancer Institute identifies four patterns of acute onset secondary lymphedema (National Cancer Institute, 2003). The first occurs a few days after surgery as a result of cutting lymphatic channels, and is usually mild and transient. The second occurs six to eight weeks post-operatively possibly as a result of acute venous or lymphatic inflammation (phlebitis or lymphangitis) or during radiation treatment. The third type is erysipelas, an infection that occurs after an insect bite or minor injury, usually with in already chronic lymphedematous limb. The fourth, and most common type is insidious, with a variable onset, and frequently is seen 18 to 24 months after surgery. Transient lymphedema lasts less than six months. Chronic lymphedema can occur if early lymphedema is not successfully managed. In all cases, swelling is present. Chapter 35 does refer to both temporary and chronic lymphedema, while the lymphedema pamphlet seems to be concerned with chronic lymphedema only. Some of the confusion around "when is it lymphedema?" may occur because of the lack of clear definitions, and the possibility of two types. It is unclear whether the authors put more emphasis on the temporary nature of the swelling to reduce anxiety and prevent serious concern. Whatever their intentions, I found the book to be not entirely clear in its discussion of lymphedema, and this may contribute to confusion among patients and nurses alike.

Medical language is necessarily polysyllabic and a word like "infection" is now commonplace. Chapman et al. (2003) studied lay understanding of cancer terms and found that comprehension of the word "metastasis" had increased greatly (63% of respondents in 2002 understood that it meant that cancer is spreading) since a 1949 study where no person in the study could define metastasis. In the Lymphedema pamphlet, the word "lymphedema" is used 17 times (including subheadings). No doubt the inescapable use of the word contributed to the SMOG grade level rating of 8.5. It would be lower if "lymphedema" were replaced by "swelling". That, however, could contribute to confusion. In my view, lymphedema must be used, in conjunction with swelling and other descriptives, so that, like metastasis, it will become part of common parlance.

Finally, physical management options for lymphedema are not readily available at all sites across the island. Women from across the province often come to St. John`s to be treated for breast cancer and receive the Purple Lupin kits. When they return home there may be no physiotherapist, sequential pump, or person trained to fit compression sleeves.

For this reason, information in both the book and the booklet might not be relevant to all women's home situations. At the same time, it is important that women know that treatment options are available, even if at a distance, should they develop lymphedema.

5.5 Mixed ratings for additional patient education materials

The patient educational materials evaluated in this section are a small sample of the additional texts that nurses in St. John's may give to women with breast cancer when educating them about lymphedema. I assessed five leaflets and have grouped them into two categories: expert or patient-advocate authored texts, and unauthored texts. I use the same assessment tools indicated earlier and Table 2 provides an overview of the scores.

Table 2 Summary evaluation of patient education materials

Item Assessed	**SAM rating**	**SMOG rating**	**AHEC score**
Prevention of	Adequate (53%)	Unsuitable gr.11.7	Inadequate (36%)
18 Steps	Adequate (59%)	Unsuitable gr.11.6	Adequate (57%)
Living with	Superior (77%)	Unsuitable gr. 9.4	Superior (70%)
Do's & Don'ts	Adequate (50%)	Adequate gr. 8.5	Adequate (53%)
Untitled	Adequate (62%)	Unsuitable gr.10.6	Adequate (60%)

5.5.1. Authored texts rate more highly; unauthored texts rate poorly

The prevention of lymphoedema; general dos and don'ts is written by two of the premier researchers in the field of lymphedema from Australia (Casley-Smith & Casley-Smith, 1995). *18 Steps to prevention for upper extremities* is also a checklist of dos and don'ts, and was written by a nurse/patient advocate, and published by the National Lymphedema Network (NLN) in the United States (Thiadens, 1997). *Living with lymphedema: prevention, treatment and working towards a cure* is a pamphlet produced by a Quebec patient advocacy group (Lymphedema Association of Quebec, no date). Because the original is printed in blue and orange, the photocopy I assessed was rather grey in some areas.

Living with lymphedema: prevention, treatment and working towards a cure scored a superior rating with the SAM assessment tool and 70% on the AHEC score, while the other two leaflets scored only adequate with the SAM tool and 36% and 57% on the AHEC score. The *Living with lymphedema* pamphlet had a reading grade level of 9.4 on the SMOG scale, while the other two 11.7 and 11.6.

The Casley-Smiths' document presents its information simply as a list with no organizational subheadings. Twenty-two items cover three pages in a dense, uninviting fashion. The photocopy appears to have been derived from several generations of copies, as the text is no longer clear but beginning to blur. There are no illustrations. While the information is good, and contains clear instructions, the writing style is rather lecturing with "must" recurring throughout the text and frequent use of exclamation marks, underlining and full capitals for emphasis. Because it was written in Australia for Australian citizens, the Casley-Smiths' document refers to products that are not available in Canada.

The NLN checklist, like the Casley-Smiths' list has a rather medical tone, using "patient" rather than "person" or "woman", and "physician" more often than "doctor". The layout of the 18 items is in two columns, making it visually easier to scan than the other lists, but the print size is small and the text itself dense. Some words are highlighted by bolding or italicizing.

Living with lymphedema: prevention, treatment and working towards a cure contains the widest variety of information, attractively arranged, and grouped under headings. In addition to information about both primary and secondary lymphedema, the lymphatic system, and cellulitis, there are sections on diagnosis, treatments, exercise, nutrition and diuretics. One section emphasizes self management and care in choosing treatments. There is a 20-item checklist of preventive steps for upper and lower extremities which follows the 18 steps to prevention of the NLN (Thiadens, 1997), adding two items regarding foot care, and repeating the categorical exhortations regarding not lifting weights more than 15 pounds. More comprehensive advice is given in these instructions than the 18 steps. The rationale is given for some of the prohibitions, making them more understandable. A list of Internet sites and other resources is provided.

I evaluated two unauthored texts, a one-page list of do's and don'ts, which achieved adequate on the SAM assessment with a reading level of 8.5. The second was a three-page document with a variety of information on lymphedema (who is at risk, what a person can do, instructions on self-massage without illustrations, and self-care). This document was assessed at a grade 10.6 reading level using the SMOG scale, and the SAM score was adequate. Several sections of text were missing. The section entitled skin care listed 16 items, eight of which referred to categories other than skin care. A number of items had been circled, as though to highlight them, perhaps for a particular patient. Language in places was quite medical.

The title of the one-page list is simply *Dos & Don'ts*, and there is no reference at any point in the text to lymphedema or prevention of swelling. While the 15-item list does contain information about lymphedema, it does not identify it as such. There is also general advice that may be useful to breast cancer patients but is not relevant to care of lymphedema (e.g. keep doctor's appointments, examine the remaining breast). While both these documents scored adequate on the SAM scale, the content of each was such that I judged them overall as poor as resources for lymphedema.

5.5.2 Discussion

In the literature evaluating patient education materials, several authors comment on the poor quality of the materials provided to patients (Coulter, 1998; Mills & Davidson, 2002). These authors found that some locally produced leaflets were illegible, and some had been photocopied so frequently that the type was thickened and the text difficult to read. I found this to be the case with a few of the evaluated texts.

It is interesting that four of the five texts rated adequate on the SAM assessment scale yet two were rated poor overall because of content. This substantiates concern in the literature that while reading level and attractive presentation are important (Doak et al., 1995) and are more easily measured using validated assessment tools, content is vital (Coulter, 1998). The one-page list entitled *Dos & Don'ts* seemed to be popular among nurses at various sites, perhaps because it is simple, straightforward, and written to a grade 8.5 level. Readability experts advocate a reading level of less than grade eight for health education materials. Judging by the appearance of the photocopies I received, nurses have probably been using it for some time. But the purpose of the text is so unclear, I wonder how useful a woman would find it? A sentence or two of introduction, perhaps the phrase "what you can do to avoid or manage lymphedema" would provide a context for the prescriptive list that follows.

On the other hand, good content poorly presented can be ignored. The faults of the NLN and Casley-Smith texts were mainly in the realm of organization and presentation of the material. The contrast between these two documents and the text from the Quebec advocacy group was striking. The latter laid out the information in a very reader-friendly, easily accessible format. It would be interesting to have patients evaluate these documents to verify the findings presented here.

Within the community of clinicians and therapists treating lymphedema, the NLN list is well known in North America and is likely the most widely used. Several nurses in the focus groups referred to it. It was published in 1997 and revised in 2003, but earlier downloads do not reflect any revisions. The reference to not lifting more than 15 pounds is still part of the instructions in the 2003 version, and is printed in italics. As discussed in chapter 2, the debate about exercise as both a cause and a cure can be confusing (Radina, et al., 2004). Because the evidence regarding exercise, and possibly also lifting heavy weights, is unclear, this pamphlet (like some others) would benefit by changing the categorical reference to not lifting weights to a more conditional one that indicates some women may be at risk.

Studies indicate that women do not always follow the guidelines (Coward, 1999; Radina, et al., 2004). Lists by themselves tend to be categorical, but lymphedema prevention is an inexact art. As the controversy over exercise shows, precautionary measures recommended by clinicians may change if subjected to investigative studies. Until such studies are undertaken, however, the advice provided is the best available. The Quebec pamphlet offers the best approach by directly encouraging patients "to become your own expert". This transfers authority from the text to the person and promotes the individual in a way that the more medically oriented texts from the Purple Lupin kit do not.

5.6 Summary

This chapter has presented text-mediated findings from the study, from both the focus group discussions and from assessment of educational materials. One important barrier to lymphedema education identified through the focus groups was the absence of policy guidelines for lymphedema. Nurses use the Breast Surgery Services Checklist, which defines best practices for the care and treatment of patients with breast cancer but lymphedema is omitted from the list and consequently may be ignored. Policy guidelines, education for nurses and other health professionals, and inclusion of lymphedema into routine patient education through use of the checklist may be warranted. Nurses rely on the educational materials in the Purple Lupin kit, which were assessed as superior, but there were some concerns about language and biomedical emphasis. Nurses supplement the kit with other materials as required. One of the additional educational pamphlets nurses use offered a more patient-oriented approach by transferring authority from the text to the person. Nurses did not appear to use any mechanism for evaluation of patient response to or use of the educational materials on a regular basis.

Chapter Six Conclusion and recommendations

6.1 Introduction

This final chapter summarizes the study (section 6.2), and outlines its limitations and strengths (section 6.3). The chapter concludes with three recommendations for future research in this area (section 6.4).

6.2 Summary of study

This primarily qualitative study investigated the practice patterns of nurses in St. John's educating women treated for breast cancer about lymphedema risk and management. Twenty-five registered nurses across four sites participated in focus group discussions. The discussions were taped, transcribed and analysed according to grounded theory and themes identified. Educational materials that nurses use in educating women about lymphedema were assessed.

The results of this study revealed several interlinked, institutional level findings. First, the absence of a co-ordinated policy for nurses, or health care professionals across the three sites, regarding the education of women with breast cancer about lymphedema risk and management results in uneven educational practices. Several subsequent results are related to a lack of policy. Nurses appear to spend very little time educating patients with breast cancer about lymphedema. This may be due to the lack of a standard policy, which itself may derive from the view that lymphedema is not as important as the disease of breast cancer itself. It may be due to a reported lack time in general to spend with patients, or insufficient knowledge on the part of nurses themselves. As well, this study found that nurses are reluctant to introduce the topic of lymphedema education when they assess patients as anxious, or overwhelmed with information. According to their assessment of patient readiness to receive and absorb information, nurses control what and how much information they give to patients.

Nurses report that their own levels of knowledge and attitudes to lymphedema and patient education and management are changing, as are those of some of the physicians they interact with. Nurses are more aware of the need for preventive education for women, but at the same time, some nurses expressed concern over their lack of knowledge, and most were concerned about lack of time for self-education, and lack of staff educators. Nurses at one site emphasized the need for consistent, reliable information for themselves that could be accessed across all sites.

Finally, while it is a matter of policy for nurses (and physicians) to rely on the Purple Lupin kit as the primary source for educating women with breast cancer about all facets of the disease and its treatments, including lymphedema, there appears to be no policy to evaluate patient response to lymphedema education. While the contents of the Purple Lupin kit have been evaluated in this study quite highly, patients may not access the information about lymphedema in the kit. Patients may not understand the information they have been presented with; they may not read the information; or they may think the information does not apply to them. Some of the additional information about lymphedema, which nurses provide to women to supplement the Purple Lupin kit was rated quite highly, while two items were rated as poor.

6.3 Strengths and limitations of this study

This study is limited to investigating the role of nurses in educating women about post-mastectomy lymphedema risk and management. Women learn about lymphedema from many different sources, including physicians, physiotherapists, friends and family (Mills & Davidson, 2002). Although this study has focussed on only one group among the several different health care providers, two primary findings are at the institutional level and thus may involve other health care professionals, to some degree. While no conclusion can be made from this putative association, it does indicate a direction for further study that might not otherwise have been identified. Although this study did not investigate the perceptions of women living with breast cancer, one finding that has arisen is that it appears that women are not regularly being asked if they are satisfied with the information they receive. Again this indicates a direction for future research.

The strengths of the study are twofold. Firstly, and I think, importantly, this study provides baseline descriptive data on a to-date unexplored topic, giving a view of nursing practice patterns, nurses' attitudes and concerns, and the challenges they face. The focus group discussions ranged from highlighting nurses' attitudes about when and how to educate patients about lymphedema to institutional concerns regarding time and the provision to nurses of education about lymphedema. Some of the barriers to providing information about lymphedema to women treated for breast cancer, which this study identified, are institutional level findings, and have implications, not only for nurses, but for other health care professionals treating women for breast cancer.

Secondly, the study opened discussion on a topic that has traditionally received little attention. The result is increased awareness of lymphedema among the nurses who participated in the study. Not only awareness was increased. Through their discussions, nurses who were more knowledgeable educated those who were less informed. Following two of the focus groups, a question and answer session took place where I provided up-to-date information from the research on lymphedema risk, self care, and management strategies. Nurses in the focus groups indicated that they learn informally from each other, so it may be presumed that some of what they learned during these sessions will trickle over to other nurses with whom they work.

6.4 Recommendations for future research and nursing practice

Recommendation #1

That a broad investigation involving physicians, physiotherapists, nurses and other health care professionals explore the question of policy regarding lymphedema education.

During my investigation and analysis, I found it difficult to assess whether what the nurses told me was their actual practice. An institutional ethnographical approach could examine whether the professionals and the institutional hierarchy concur on a need to develop policy in this area, and could substantiate or clarify the findings of this study.

Recommendation #2

A study to investigate the response of women treated for breast cancer to lymphedema education provided by nurses (and physicians, and physiotherapists) within the health care system could provide answers to a number of questions and the findings could be employed to improve the effectiveness of the educational materials, or educational approaches used.

What are women's own perceptions of how they are informed by health care professionals about lymphedema? Do women seek information from other sources? Are women satisfied with the information that has been given them by health care professionals on this topic? Women's responses to such questions may vary over time, thus it would be interesting to devise a longitudinal study, that follows women for two years post surgery, or a study that surveys a number of women who are at shorter or longer remove from surgery, e.g. 6 months, one year, two year, five years, etc.

Recommendation #3

The findings of this study show that a commitment to quality lymphedema education for women treated for breast cancer may be warranted within the health care system. Policy guidelines on lymphedema assessment and patient education that are consistent across all sites could be incorporated into standard patient care through the Breast Surgery Services Checklist. This would facilitate consistency and continuity of quality patient education across the continuum of sites.

In order for nurses to provide quality patient education, however, they themselves must be well educated. A commitment to lymphedema education for patients needs to include a committment to formal lymphedema education for nurses. Formal education could be provided through regular seminars or workshops at all the sites. A copy of the Purple Lupin kit should be available at all sites as a reference tool.

A third component to quality patient education in lymphedema risk and management would be the inclusion of patients in the development and on-going evaluation of patient education materials. Patients could be involved through surveys, response cards, and interviews. Aspects of these practical recommendations could be combined with a research component.

6.5 Final words – next steps

The recommendations speak for themselves as next steps. The role of nurses is vital in the education of women regarding lymphedema, and nurses themselves expressed the desire to learn more and have more consistent and valid information. At the same time, women themselves should be consulted in the development of any educational materials for patient use.

Once again, I want to thank the nurses for their participation in this study. Without their support, co-operation and sharing of ideas and concerns, this study could not have taken place, and this thesis would not have been written. I believe that the views of nurses are vitally important in the development of lymphedema education and that this study fills a gap in the lymphedema literature. Much remains to be done in the area of lymphedema education and, as indicated earlier, there are many avenues for future research.

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Appendix A

Memorial
University of Newfoundland

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

FILE COPY

December 23, 2003

KEYED

Reference #03.183

Ms. P. Hodgson
C/o Dr. N. Beausoleil
Division of Community Health
2nd Floor, Health Sciences Centre

Dear Ms. Hodgson:

This will acknowledge your correspondence dated December 18, 2003 wherein you clarify issues and provide a copy of the revised consent form, demographic questionnaire, focus group questions, focus group information sheet, letter to registered nurse, and undertaking of confidentiality for your research study entitled "**The role of St. John's nurses in educating breast cancer patients about lymphedema risk and management**"

The Chairs of the Human Investigation Committee (HIC) reviewed your correspondence, approved the revised consent form, demographic questionnaire, focus group questions, focus group information sheet, letter to registered nurse, and undertaking of confidentiality, as submitted and granted ***full approval*** of your research study. This will be formally reported to the full Human Investigation Committee, for their information at the meeting scheduled for **January 8, 2004**.

Full approval has been granted for one year.

For a hospital-based study, it is **your responsibility to seek the necessary approval from the Health Care Corporation of St. John's and/or other hospital boards as appropriate**.

This Research Ethics Board (the HIC) has reviewed and approved the application and consent form for the study which is to be conducted by you as the qualified investigator named above at the specified study site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to the Tri-Council Policy Statement and applicable laws and regulations.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,

Sharon Buehler

Sharon K. Buehler, PhD
Co-Chair
Human Investigation Committee

Richard S. Neuman, PhD
Co-Chair
Human Investigation Committee

SKB;RSN/jjm

C Dr. C. Loomis, Vice-President (Research), MUN
Mr. W. Miller, Director of Planning and Research, HCCSJ

St. John's, NL, Canada A1B 3V6 • Tel.: (709) 777-6974 • Fax: (709) 777-7501 • email: hic@mun.ca • www.med.mun.ca/hic

Appendix B

Undertaking of Confidentiality

I understand that as a participant in this focus group, I am participating in a discussion that will be kept confidential.
I agree not to disclose or discuss anything that is discussed during the focus group.
I will keep confidential the names of the other participants.

Name Date

Appendix C

Consent Form

Faculty of Medicine, Schools of Nursing and Pharmacy of Memorial University of Newfoundland; Health Care Corporation, St. John's; Newfoundland Cancer Treatment and Research Foundation

Consent to Take Part in Health Research

TITLE: The Experience of St. John's Nurses in Educating Breast Cancer Patients about Lymphedema Risk and Management

INVESTIGATOR: Pamela Hodgson, graduate student in Community Health

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researchers will:

- **discuss the study with you**
- **answer your questions**
- **keep confidential any information which could identify you personally**
- **be available during the study to deal with problems and answer questions**

If you decide not to take part or to leave the study this will not affect your work situation in any way. Taking part in this study is completely voluntary.

Introduction/Background:
The role that nurses play in caring for women treated for breast cancer is a vital one. Patient education is an important aspect of nursing care. In providing direct patient care, nurses have an opportunity to educate women about the potential risk of developing post-mastectomy lymphedema. At this time, however, there is no standard protocol. Nurses are left on their own to assist women in understanding the risks and management of lymphedema. This study will explore the experience of nurses in educating breast cancer patients about lymphedema through the use of focus groups. The findings of the study could provide information to develop materials for post-mastectomy lymphedema education and protocol in risk management.

2. Purpose of study:

The purpose of the study is to examine nursing practices by giving nurses an opportunity to discuss their concerns and any difficulties they encounter in providing women with education on the topic of lymphedema risk and management.

3. Description of the study procedures and tests:

You will be one of 5 - 8 people in a focus group. You will be asked to sign an oath of confidentiality to keep confidential the participants and the discussion. I will distribute a short questionnaire just before starting the focus group. This will ask questions about demographics and about the information you give women about lymphedema risk and management. The people in the focus group will be asked to talk about the kinds of concerns you discuss with breast cancer patients, how you inform women about lymphedema risk and management, and what materials you use. The focus group discussion will be audio-taped and transcribed. You will be offered a chance to review the transcript for feedback and editing before analysis begins. You will receive a summary of the conclusions. After the focus group has ended, I will ask if you are willing to share the educational material you provide to women. I will collect what materials you offer.

4. Length of time:

Each focus group will last between an hour and an hour and a half.

5. Possible risks and discomforts:

The length of time of the focus group may cause some small inconvenience, but I will try to arrange each group in a location and at a date and time that is agreeable to all participants.

Participation is entirely voluntary and will not affect your work situation in any way. Nursing managers will not be advised of who attended and who did not. Everything discussed will be kept confidential.

6. Benefits:

It is not known whether this study will benefit you.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. Questions:

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is:

Principal Investigator's Name and Phone Number
Pamela Hodgson, MSc student, 754-5393 or 754-0443

Natalie Beausoleil, PhD, MSc supervisor, 777 8483
Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Office of the Human Investigation Committee (HIC) at
709-777-6974
Email: hic@mun.ca

Signature Page

Study title: Lymphedema Risk and Management: Educating Breast Cancer Patients, The Experience of Nurses in St. John's

Name of principal investigator: Pamela Hodgson

To be filled out and signed by the participant:

Please check as appropriate:

I have read the consent [and information sheet]. Yes { } No { }

I have had the opportunity to ask questions/to discuss this study. Yes { } No { }

I have received satisfactory answers to all of my questions. Yes { } No { }

I have received enough information about the study. Yes { } No { }

I understand that I am free to withdraw from the study Yes { } No { }

- at any time
- without having to give a reason
- without affecting my work situation

I understand that it is my choice to be in the study and that I may not benefit. Yes { } No { }

I agree to take part in this study. Yes { } No { }

______________________________ ______________________

Signature of participant Date

______________________________ ______________________

Signature of witness Date

<u>To be signed by the investigator:</u>

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

______________________________ ______________________

Signature of investigator Date

Telephone number: ____________________

Appendix D

Sample thank you letter

Pamela Hodgson
95 Monkstown Road, St. John's NL A1 C 3T7
phone/fax 709 754-0443

Date
Salutation

I want to thank you very much for setting up the opportunity for me to conduct a focus on March 22, 2004 for my master's thesis on the experience of St. John's nurses educating breast cancer patients about lymphedema.

I want to thank you for your kind efforts in contacting xx nurses from various clinics in the region and arranging for their attendance. Five was a good number and I was pleased that everyone's voices came out clearly on the tape. Thank you also for providing coffee for everyone.

Please convey my thanks and appreciation to the nurses who participated. I know how busy nurses are these days, and I am grateful for the time you gave and the information you shared.

I will be sending you a summary of my findings after I have completed all the focus groups.

Sincerely,

Pamela Hodgson

cc. Natalie Beausoleil, PhD. Community Health, Memorial University of Newfoundland

Appendix E

Focus Group Information Sheet

Rationale
Post-mastectomy lymphedema is a chronic disease that affects a significant number of women, about one in four treated for breast cancer, and is one of the most feared consequences of breast cancer treatment. In the past, lymphedema risk and management has been a neglected topic. New developments in surgical techniques may result in lower incidence of lymphedema, but education of women on risk and management of lymphedema remains an important issue. I am interested in this topic for my master's thesis.

Purpose
The purpose of the focus group discussion is to examine this topic from the nursing perspective. Focus groups will be held in three different sites: St. Clare's Hospital, the H. Bliss Murphy Cancer Centre and at Health and Community Services, St. John's Region.

Voluntary participation
Participation in a focus group is completely voluntary and anyone has the right to withdraw at any time without prejudice.

Time and place
Each focus group will last at most one and a half hours, and will take place at a location, date and time convenient to the participants. Nurses willing to participate should call Pamela Hodgson to arrange a mutually agreeable time and place.

Potential risks
There is no risk associated with participation in this focus group. Your nursing manager will not know who attends or who does not.
Protection of privacy and confidentiality
During and after the study is completed, privacy and confidentiality will be maintained. All participants will agree to keep confidential both who participated and what is discussed. At the beginning of each focus group, I will obtain consent to audiotape and later transcribe the discussion. Participants will be offered the opportunity to review the transcribed data. Anonymity of participants will be maintained when presenting a summary of the discussion or publishing findings. Each unit that participates will be sent a summary of the discussion.
This project will not succeed without your involvement. I hope you will take the time to participate in the focus group.
Contact: Pamela Hodgson: home 754-5393 answering machine cuts in if I am unavailable; office 754-0443 leave message any time

Appendix F

Letter of Introduction

Dear Registered Nurse,
I am a graduate student in Community Health at Memorial University of Newfoundland, with an interest in post-mastectomy lymphedema risk and management.

The role that nurses play in caring for women treated for breast cancer is an important and vital one. In providing direct patient care, nurses have an opportunity to educate women about the potential risk of developing post-mastectomy lymphedema. To my knowledge, there is no standard educational material available, so nurses are left on their own to assist women in understanding the risks and management of lymphedema.

For my thesis project, I wish to explore this topic with a small number of nurses and am writing to invite you to participate in a focus group to discuss post-mastectomy lymphedema risk and management. I hope to learn from your knowledge and experience.

I hope to meet with nurses who have a range of experience and are willing to discuss their practices, concerns and any difficulties they encounter in providing women with education on this topic

The focus group discussion will take place at a time and location convenient to the participants, ideally at your place of work. The focus group will last an hour, or perhaps an hour and a half. An attached information sheet provides more detail.

This project has been approved by your supervisor, the Human Investigations Committee at Memorial University and the Research Proposal Approval Committee of the Health Care Corporation of St. John's. Participation in the project is **entirely voluntary** and you can withdraw at any time.. Your work situation will not be affected whether you participate or not. All participants will sign an oath of confidentiality and consent form and agree to keep confidential both who participates and what is discussed.
If you are interested in participating in this project, please contact me at the number below. If you wish to discuss this with my supervisor, please contact Dr. Natalie Beausoleil at 777 8483. I look forward to hearing from you and thank you for considering this proposal.

Sincerely,

Pamela Hodgson 754-0443 work 754-5393 home

Appendix G

Demographic Questionnaire

Place a tick in the appropriate box or boxes.

Demographic questions will not be used to identify you in any way.

1. Age in years: ☐ 20 – 29 ☐ 30-39 ☐ 40-49 ☐ 50-59

2.Level of nursing education ☐ R.N. ☐ B.N ☐ M.N.

3. Number of years working as a nurse:

☐ 5 or less ☐ 6-10 ☐ 11-15 ☐ 16-20 ☐ over 20

4. Number of years working in this setting:

☐ 5 or less ☐ 6-10 ☐ 11-15 ☐ 16-20 ☐ over 20

Appendix H

Semi-structured focus group discussion questions

What are some of the post-breast cancer treatment concerns you commonly discuss with your patients?

If lymphedema risk and management is a topic that is a concern to a woman, what aspects do you talk about? Do concerns about physical, psychosocial, physiological impact arise?

If lymphedema as a topic is not a concern, do you introduce it? How do you introduce it? What do you talk about?

How do women respond to this information?

What educational materials on this topic do you use? Where do you get your information?

What aids or hinders you in providing education to women on this topic?

How have you learned about lymphedema? Do you feel well trained? What other information would you like?

How can we better address lymphedema issues in patient management?

Are there any other questions or topics I haven't asked that you would like to introduce?

Are you willing to provide me with a copy of any educational information you use? I am interested in comparing what materials are used here with educational materials available elsewhere or with guidelines for such information.

Appendix I

List of educational materials assessed

1. Purple Lupin Kit
    a) Chapter 35: Physical therapy and management of lymphedema, *Intelligent patient guide to breast cancer*
    b) Guideline 11: The management of lymphedema related to breast cancer, *Questions and answers on breast cancer, a guide for women and their physicians*
    c) Lymphedema pamphlet
2. Dos and don'ts
3. Prevention of lymphedema: general dos and don'ts
4. 18 steps to prevention for upper extremities
5. Living with lymphedema: prevention, treatment and working towards a cure
6. Untitled 3 page information about lymphedema