

1-1-1997

Lymphoedema following surgery for breast cancer

Jacqueline Lord
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LYMPHOEDEMA FOLLOWING SURGERY FOR BREAST CANCER

By

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A thesis submitted in partial fulfilment of the requirement for the award of Master of
Nursing

at the School of Nursing, Edith Cowan University

Date of submission: January, 1997

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Dedication

This thesis is dedicated to the memory of Professor Robert Van Dongen whose application to life, and undying confidence in my ability to undertake academic study, provided the stimulus for me to pursue this project. I miss you Bob.

Acknowledgments

This thesis could not have been completed without the support and encouragement of family, friends and colleagues. My appreciation and gratitude is extended in particular to Professor Anne McMurray for her support during the early stages of the development of this thesis and to Bronwyn Jones and Phillip Della, my supervisors for their patience, encouragement and confidence in my ability to complete this project. A special thanks is extended to Elaine Pascoe, for statistical guidance and to Dr. Patricia Percival for her most constructive comments in the final preparation of the thesis.

To my children, Sean and Wayne, thankyou for not minding when study took precedence over pleasure and for the all those cups of coffee. To my friend Dr. Jaye Martin, thankyou for the many hours in the library organising and sorting information with me and for your valuable input and advise relating to cancer.

Finally, I would like to thank Dr. Bruce Haynes. You are the most frustratingly annoying person I know; when I wanted to “quit” or said “I can’t” you always found a way to make me think, answer my own questions, then achieve what I said I couldn’t. Without your caring and support this thesis would not have been completed. Thankyou for being you!

Abstract

Lymphoedema of the ipsilateral upper limb is one of the most significant long term complications of the surgical treatment of breast cancer and may be described as a life sentence of bodily disfigurement. The resultant cosmetic disfigurement, physical discomfort and reduced physical mobility combined with the psychological sequelae, far exceeds the original expectations of the breast surgery patient (Tobin, Lacey, Meyer, and Mortimer, 1993). It is estimated that one hundred thousand women in Australia have developed lymphoedema (or will develop it before they die) as a result of mastectomy and radiotherapy alone (Casley-Smith, 1992).

In breast cancer patients, lymphoedema can follow radical surgery including lymph node dissection, fibrosis due to radiotherapy or it can represent late recurrence of malignant tumour in the axilla occluding lymphatic pathways (Ellis & Calne, 1983).

This descriptive correlational study focussed on describing the experiences of women with lymphoedema following surgery for breast cancer and identifying whether or not its occurrence is related to the type of surgery undergone, chemotherapy, radiotherapy and Tamoxifen therapy in a convenience sample of women (n=144), who had had surgery for breast cancer.

There was an 81.3% response rate to the questionnaire (n=117). The majority of the respondents were from an urban sector of Western Australia with a mean age of fifty three (53) years. Data were supplemented by information from participants' responses to open ended questions which were then quantified.

Data analysis using descriptive statistics and chi-square identified the following: The prevalence of lymphoedema, attributed to diagnoses by the respondents doctor, was

found to be 20%. Mastectomy was found to be the most commonly performed surgical procedure with approximately 43% of all women undergoing some type of adjunctive treatment for their breast cancer. Whilst some women with lymphoedema were undergoing adjunctive treatment there was no standardised treatment method demonstrated. A statistical significance was demonstrated between the formation of lymphoedema and the use of Tamoxifen therapy, a finding not previously reported in the literature.

The impact of lymphoedema on the quality of daily living experienced by the women was reflected by reports of low self esteem, financial hardship, inability to undertake usual hobbies and restriction and/or inability to perform many of the normal daily tasks.

A large proportion of the women (approximately 66%) reported that they were provided with insufficient information with regards to their treatment regime and the possible complication scenario resulting for the interventions.

Declaration

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signature

Date 8/7/97

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CHAPTER 1

Introduction

Lymphoedema of the ipsilateral upper limb is one of the most significant long term complications of the surgical treatment of breast cancer. It is estimated that one hundred thousand women in Australia have developed lymphoedema (or will develop it before they die) as a result of mastectomy and radiotherapy alone (Casley-Smith, 1992). The condition is distressing and unpleasant for the patient and frustrating for the surgeon. It not only causes cosmetic disfigurement, physical discomfort and loss of functional ability of the limb, but also has an associated psychological sequelae (Tobin, Lacey, Meyer, and Mortimer, 1993).

In breast cancer patients, lymphoedema can follow radical surgery including lymph node dissection, fibrosis due to radiotherapy or it can represent late recurrence of malignant tumour in the axilla occluding lymphatic pathways (Ellis & Calne, 1983).

Lymphoedema

Lymphoedema is swelling resulting from failure of the drainage system to adequately reabsorb and transport protein rich fluid away from the tissues, an excess of fluid reaching the tissues or both. There are two types of lymphoedema, primary and secondary (Casley-Smith, 1992). This study is concerned only with the occurrence of secondary lymphoedema as it occurs following surgery for breast cancer.

Lymphoedema - The Pathophysiology

To enable an understanding of lymphoedema it is essential to first have knowledge of the normal physiology of the lymphatic system. The lymphatic system which is a system of lymphatic vessels and nodes that serve to transport tissue fluids back to the venous system and form a protection against diseases (Granda, 1994). The lymphatic system functions in three ways:

1. it returns tissue fluid resulting from blood filtration, to the blood stream;
2. it serves as a transport route for absorbed intestinal fat to the blood; and
3. it assists by way of its lymphocytes (lymph cells, formed in the lymph nodes, lymphatic organs and bone marrow) in providing an immunity against disease (Van De Graaff & Fox, 1989, p.710).

Lymphatic vessels have valves similar to those in the venous system that prevent back flow of fluid. Pressure obtained from constant massage by skeletal muscle contractions, intestinal movements, and other body movements keep the lymph moving in one direction. The insufficiency of the lymph vascular system results in the formation of lymphoedema (Van De Graaff & Fox, 1989).

Lymphoedema is swelling resulting from failure of the drainage system to adequately reabsorb and transport protein rich fluid away from the tissues. Damage through irradiation or removal of part of that system, ie. the lymph nodes, as is the case with many types of breast surgery, is thought to contribute to the formation of lymphoedema. Factors reported in the literature as contributing to the occurrence of lymphoedema include the type of surgery performed, radiotherapy, chemotherapy, the removal of all the axillary lymph nodes and Tamoxifen therapy (Markowski, et al., 1981; Mattheiem,

Bourgeois, Delcorde, Stegen, and Frühling, 1989; Badr El Din, Coibion, Guenier, Nogaret, Lorent, Van Houtte, Tueni, and Mattheiem, 1989).

Psychological Effects

Apart from any physical problems, many patients with lymphoedema suffer psychological sequelae, such as embarrassment about their appearance, feelings of isolation, marital and family problems. Tobin et al.'s (1993) study specifically addressing this issue substantiated the psychological sequelae and results revealed that patients with lymphoedema showed greater psychological morbidity at formal psychiatric interview, impaired adjustment to illness, greater impairment of physical functioning and psychosocial maladjustment. The relationship between lymphoedema and the interventions discussed was explored and the impact that lymphoedema has on patients' quality of daily life was examined by assessing the patients ability to perform daily requirements to their own satisfaction.

Background Of The Study

Breast cancer is diagnosed in more than half a million women around the world each year prompting a global focus on early detection and treatment (Dow, 1995). Little attention however is paid to complications of intervention modalities.

Chronic swelling of the arm, lymphoedema, is for many the seemingly forgotten complication of breast cancer surgery. Chronic lymphoedema has been widely reported as a debilitating complication of breast cancer since the early 1900's and when it does occur has the potential to have a large impact on the women's quality of daily living.

However, according to Farncombe, Daniels and Cross (1994), data relating to the incidence and prevalence of lymphoedema associated with breast cancer is contradictory and misleading and comparison between studies is further complicated by there being no recognised definition of lymphoedema (Kissin, Querci della Rovere, Easton & Westbury, 1986). Various studies allude to the formation of lymphoedema following surgery for breast cancer as having an association with the types of surgery performed and the type of adjunct treatment modalities (Britton & Nelson, 1962; Haagensen, 1971). Whilst there appears to be a number of factors contributing to the formation of post surgical lymphoedema, the reality is that a number of women who have had breast surgery are destined to have a life sentence of bodily disfigurement far beyond their original expectations.

Such realisation provided the initial stimulus to undertake this study as well as the researcher's professional experience with women suffering the complications of breast cancer.

Globally the incidence of lymphoedema following breast surgery and adjunctive treatments in breast cancer patients, has not been determined. Regardless of the incidence, the impact upon such patients is even less well defined. Williams, (1993) whilst investigating management of lymphoedema from a community-based approach, suggests that the development of clinical and education services is hindered by an ignorance by the health professional as to the depth of the problem and ineffective management of lymphoedema.

As controversy exists (Kissin et al., 1986; Markowski et al., 1981) as to the definition of lymphoedema, for the purpose of this study subjects were only included who had been medically diagnosed as having 'lymphoedema'.

Significance Of The Study

This study takes place against a background of radical changes of focus on issues relating to women's health as seen by the global promotion of screening for the early detection of breast cancer (Dow, 1995). It acknowledges the need for research to promote women's health issues and ensure a continuing quality of care.

Identification of the prevalence of lymphoedema following breast surgery and the impact it has upon the patients' quality of daily living, may enable early intervention aimed at limiting the degree of disability, both physical and functional.

The findings of the study justify health educators incorporating the current information related to post-surgical lymphoedema into the curricula for health professionals, so that they may provide appropriate anticipatory guidance for patients and their carers.

The findings of this study support the view that a well informed client enhances patient centred decision making which, according to King and Coman (1993) assists with compliance and monitoring of treatment. The treatment scenario of lymphoedema is intensive and long term and to be effective requires specialised knowledge and skills (King & Coman, 1993) consequently the cost effectiveness of treatment programs must be established when initiating management of lymphoedema.

Policy formation focusing on identified needs of those with lymphoedema as a sequelae of breast surgery will allow efficient utilisation of limited resources.

Purpose Of The Study

The purpose of this study was to describe the experiences of women with lymphoedema and the relationship of its occurrence with type of breast surgery, chemotherapy, radiotherapy and axillary node clearance, in a convenience sample (n=114) of Western Australian women who had undergone surgical treatment for breast cancer. The study identified the treatment modalities for lymphoedema being employed in the community and explored the effect of lymphoedema on the patients' self perceived quality of daily living.

The following questions were addressed:

1. What is the frequency of occurrence of lymphoedema in a convenience sample of women in Western Australia, who have undergone surgery for breast cancer?
2. Is there a relationship between the occurrence of lymphoedema (as diagnosed by the patients doctor), and:
 - a) the type of surgery performed;
 - b) the adjunctive treatment of radiotherapy;
 - c) the adjunctive treatment of chemotherapy;
 - d) the adjunctive treatment of tamoxifen therapy?
3. What are the treatment modalities for lymphoedema being employed in the community?
4. What is the patients' perception of the impact of the presence of lymphoedema on the patients' self perceived quality of daily living?

Definition Of Terms

Lymphoedema: A high protein oedema (swelling), is caused by a defect in the lymphatic transport capacity (Casley-Smith, 1992, p.2).

This study investigated secondary lymphoedema occurring post surgery for breast cancer, which, according to Ellis and Calne (1983), occurs from the obstruction of the lymphatic flow resulting in the accumulation of fluid in the tissues. For the purpose of this study a patient is deemed to have lymphoedema only if a medical diagnosis has been made.

According to McMurray, "Morbidity refers to the number of people in a population affected by a disease or condition. Morbidity is described in terms of incidence and prevalence.

Incidence refers to the number of new cases of the disease or condition occurring during a specified period of time.

Prevalence measures the amount of morbidity; that is, the total number of cases, both new and old, occurring in a population at a particular time" (1993, p.191).

Lymph nodes, according to Van De Graaff and Fox, 1989, "are small, oval bodies enclosed within fibrous connective tissue capsules....Lymph nodes usually occur in clusters in specific regions of the body" (p.711).

Other key terms used in the study include axillary node clearance; being the removal of the lymphatic nodes from within the axilla; chemotherapy, the prevention or treatment of a disease by "chemical reagents that have a specific and toxic effect upon the disease-causing microorganism" (Taber & Thomas, 1985, p.309); radiotherapy,

which is the “treatment of disease by application of roentgen rays, radium, ultraviolet and other radiations” (Taber & Thomas, 1985, p.1449).

Tamoxifen therapy involves the use of the drug Tamoxifen which blocks the effect of oestrogen on cells thus stopping the cell’s growth. The cancer stops growing even though the cancer cells are not killed by the drug. Tamoxifen is most effective in tumours that are oestrogen receptor positive (National Health and Medical research Council [NHMRC] 1996, p.50). “Tamoxifen protects against the recurrence of breast cancer and reduces a women’s risk of heart disease” (NHMRC, 1996, p.51).

‘Phantom Breast’ as used in this study, refers to a “psychological phenomenon frequently occurring in amputees; the patient feels sensations, and often pain, in the missing limb” (in this instance ‘missing breast’) (Osol et al., 1973, p.594).

Mastectomy, as defined by Osol et al., is the “excision or amputation of the breast” (1973, p.466). The procedure of mastectomy is undertaken by several methodologies, (Halsted’s radical mastectomy, modified radical mastectomy, simple mastectomy and Wide local excision (Lumpectomy) are methods referred to in this study).

Halsted’s Radical Mastectomy evolved in 1882 and involved excision of the “entire breast together with the pectoralis major muscle and all of the axillary nodes” being “excised in continuity” (Haagensen, 1986, p.866).

Modified radical (Patey) mastectomy involves preservation of the pectoralis major muscle with the “intersection of pectoralis minor is detached from the coracoid process to allow easier access to the axilla....Less cosmetic disturbance is produced than in the classical radical mastectomy but a similar axillary lymph node dissection is possible” (Watkins & Thomas, 1989, p.122).

Simple Mastectomy involves excision of the entire breast, “none of the underlying muscles are removed or divided and only the lower axillary contents are biopsied” (Watkins & Thomas, 1989, p.122).

Wide local excision (lumpectomy) involves removal of the tumour only which should be “excised with a 1 cm margin of surrounding normal breast tissue and the excision margins should be free of tumour when subsequently examined histologically” (Watkins & Thomas, 1989, p.122).

Thesis Organisation

The study presents an argument for the development of the research in **Chapter 1**. The theoretical framework selected to guide this study is discussed and illustrated. **Chapter 2** consists of a review of the relevant literature pertinent to the development of lymphoedema following surgery for breast cancer. **Chapter 3** discusses research methodology of the study, addressing the design, selection of the sample, instrumentation, ethical considerations data analysis and limitations. **Chapter 4** details the analysis of the collected data whilst **Chapter 5** concludes the study with a discussion of the implications of results and suggestions for further research.

Theoretical Framework.

The framework used in this study is the 'Web of Causation Model'. Krieger (1994) states that the concept of the 'web of causation' was first introduced by epidemiologists Brian MacMahon, Thomas F. Pugh, and Johannes Ipsen in the 1960's to encourage epidemiologists to explore the possibility of multiple causes and effects of disease and to consider interaction between all possible routes for the prevention of disease (p.890).

The model is appropriate for this study which analyses the relationships between several variables and the development of lymphoedema following breast surgery. The study further examines the patients self reported satisfaction with treatment modalities and the impact that living with lymphoedema has on the patient. According to McMurray, (1993, p.189) the web of causation model best illustrates the theory of multiple causes of disease, the model was used to demonstrate the complex interrelations between the variables and the development of lymphoedema.

McMurray further asserts that the web allows the interrelationships to be examined in order to determine viable interventions (1993, p.189), therefore, enabling early intervention strategies to be implemented to control the advancement of lymphoedema. The concept of the web is that it forms a network of strands that intersect frequently. The intersections representing specific risk factors or outcomes, and the strands symbolise the pathways that cause the problem (Krieger, 1994), thus reflecting the complexity of factors reportedly associated with the development and subsequent living with lymphoedema.

The web illustrates lymphoedema as influenced by many factors including host susceptibility (see Figure 1). These factors include the exposure to surgery,

radiotherapy, chemotherapy and Tamoxifen therapy and such trigger factors as infection, delayed wound healing, airline flights, recurrent disease, burns, cuts and insect bites. The environment also influences the disease process by exposure to the physical, biological, chemical and social elements. Consequently it is prudent to utilise this theoretical concept thus allowing simultaneous consideration, of the diverse aspects related to the host, agent and the environment.

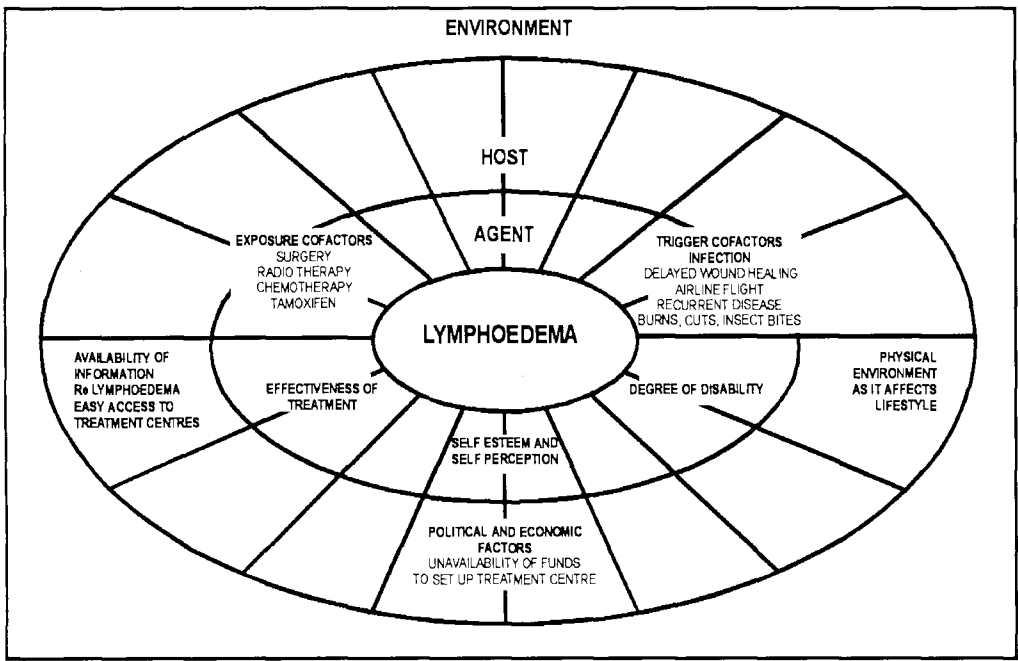


Figure 1. The web of causation model, illustrating factors associated with Lymphoedema

(Adapted with permission from McMurray, 1993, p.190).

CHAPTER 2

Literature Review

Review of the literature provides an account of the prevalence of lymphoedema following surgery for breast cancer and identifies factors of concern for patients and their carers. In general, literature focuses predominantly on the treatment modalities of breast cancer whilst neglecting complications resulting from the surgical intervention or the morbidity status. For many sufferers of breast cancer, it is in fact complications of the treatments that dictate their quality of life and their ability to function within society.

Surgical Modalities

Literature which discusses the medical outcomes resulting from surgical management of breast cancer is somewhat limited and tends to understate problems or potential problems.

Historically, the Halsted procedure was the treatment of choice for breast cancer. The Halsted procedure was first performed at Roosevelt Hospital in the United States of America in 1882. The Halsted surgical procedure “sacrificed all of the skin and subcutaneous tissue over the breast except for a triangular portion of the skin overlying the anterior axillary fold. The entire breast together with the pectoralis major muscle and all of the axillary nodes were excised in continuity” (Haagensen, 1986, p. 866). Halsted first reported oedema of the arm following surgery for breast cancer in his final paper on breast cancer published in 1922. Halsted reported the formation of oedema to be related to wound closure technique that was faulty (Haagensen, 1986). Initially

lymphoedema research studies reported varying degrees of incidence rates. The incidence of lymphoedema following the Halsted procedure has been reported in the literature to range between 6.7% to 62.5% (Handley, 1908; Lobb & Harkins, 1949). Kissin et al. (1986) assert the large variation in the incidence range of lymphoedema during the Halsted era is related to the non-existence of a standardised definition of lymphoedema.

The early research studies provide background information on the incidence of lymphoedema related to the Halsted procedure and the studies report on the incidence rates and detail the medical intervention, however comparison between studies is difficult because of changes in treatment modalities and lack of definition of lymphoedema (Kissin et al. 1986).

The management of breast cancer has undergone significant changes in concept as a result of a greater understanding of cancer biology and its history (von Rueden, 1994).

Treatment modalities have progressed from a single treatment of radical mastectomy to a more flexible approach whereby breast-conserving strategies are utilised. The major change in treatment modality over the past ten years has been the reduction in the radical nature of surgery. This modification has led to a decrease in the amount of surrounding tissue and chest wall excised (Haagensen, 1986).

Current surgical interventions, for the management of breast cancer, include procedures aimed at isolating the tumour and defining the tumour boundaries in an attempt to reduce the amount of breast tissue resected. Hook wire or fine wire localisation breast biopsies are of particular benefit for management of suspicious breast lesions that are detected by mammography but are not able to be palpated by the clinician (Allen, Thompson, Stuart, Gill, Walton, Karczenski, Hoffman & Peel, 1994).

Used as a diagnostic tool to determine the pathology of any breast abnormality before embarking on major surgery, or the less radical treatment of lumpectomy the hook wire procedure is instrumental in determining the need for, and type of intervention necessary.

Mattheiem et al. (1989) posit the use of modified radical mastectomy in conjunction with extensive removal of axillary lymph nodes in the surgical treatment of breast cancer. They believe this technique of management avoids the need for axillary irradiation and therefor reduces the risk of developing lymphoedema.

Mokbel, Ahmed, Nash and Sacks (1995) reviewed the records of 317 patients who had had needle localisation and excision (lumpectomy) of the mammographic lesion for radiologically detected, nonpalpable suspicious breast abnormalities. Surgical re-intervention was necessary for 50 of the patients studied, nine of the patients requiring mastectomy. Despite the trauma to the patient of having to undergo two surgical procedures to treat the cancer the authors suggest:

“that mastectomy, which results in cure rates exceeding 98%, is an over treatment for this lesion, and radiotherapy should be recommended following an adequate local excision” (Mokbel et al., 1995, p. 227).

The recommendation towards breast tissue conserving management, is supported by many studies (Howe, Monsees, Destouet, Seib, Dehner, & Kraybill, 1995; Goff, Molloy, Debbas, Hale & Jaques, 1995; Page, Dupont, Rogers, Jensen & Schuyler, 1995). These studies whilst containing logical, statistical reasoning for this treatment modality, have not addressed the patient’s perspective. Silverstein (1995) in his commentary on reexcision operations that may result from this surgical management, acknowledges the

dilemma faced by the general surgeon and plastic surgeon however, the dilemma posed for the patient is not considered.

There is no standard method of management of breast cancer. Surgical management, according to Marchant (1994) is dependent upon a number of factors, and believes the lesion size and histology together with the skill and experience of the management team, together with the patient's preference for management as influencing factors in the decision making process.

Literature reveals that no consensus as to surgical management exists, however it is evident that a shift to a more breast-conservative approach to management is being practised.

Yilmazer, Aydiner, Ozkan, Aslay and Bilge (1994) undertook a comparative study of women undergoing total mastectomy and breast conserving therapy. The study compared the body image, self esteem and social support. Forty (40) women were included in each group. The outcomes of the conservative approach to surgical management of breast cancer found that the women had a more positive body image, however only a negligible difference was demonstrated with regards self-esteem and social support (p.238). This study underpins the importance of body image faced by the patient when faced with the dilemma of breast cancer treatment.

The psychosocial aspect of treatment modalities needs to be included in the presentation of possible appropriate treatment methodology to provide a holistic approach to patient management.

Incidence Of Lymphoedema

Extensive literature searches revealed a dearth of recent studies reporting the incidence of lymphoedema of the arm following less radical treatments for breast cancer. Farncombe et al. (1994) assert that the “available data concerning the incidence and prevalence of lymphoedema associated with breast cancer is contradictory and misleading” (p. 269).

In 1986 Kissin et al. studied two hundred (200) patients, at the Royal Marsden Hospital, London, who had had surgery with or without radiotherapy for breast cancer. Like most researchers of lymphoedema, they faced the problem that no standard definition of lymphoedema existed, therefore, found it impossible to compare their study and conclusions with from previous studies. The aims of the Kissin et al. study were to compare the incidence of lymphoedema as judged by subjective observation with objective measured differences in arm circumference and volume; to identify independent risk factors for late lymphoedema; and to compare the incidence of lymphoedema after different treatments for breast cancer (p. 580).

Kissin et al.'s (1986) subjective measurement was taken from patient and observer impressions based on three categories: no difference, moderate lymphoedema, and severe lymphoedema. The physical measurement (objective measurement) to determine the severity of the lymphoedema, was ascertained by measuring the circumference and the volume of each arm 15cm above and 10cm below the lateral epicondyle. The study found that subjective lymphoedema (assessed by observation) was present in 14% of patients studied, whereas objective lymphoedema (actual measurement) was present in 25.5% of the studied population. The difference between the incidence figures could be related to the patients' and researcher's perception of what constitutes lymphoedema.

Kissin et al. (1986) identified that the risk factors contributing to the development of lymphoedema were the extent of axillary surgery, axillary radiotherapy, and pathological nodal status. They further suggest that two types of lymphoedema can occur post surgery; early lymphoedema, which appeared to be transient and occurred during the first two months, and resulted from acute overload of the lymphatics and possible wound healing delays, and late lymphoedema which appeared to be associated with a number of variables such as axillary radiotherapy, late infection and the extent of axillary node clearance. This finding concurred with other studies such as that of Haagensen (1971) reported finding late lymphoedema occurring any time after six months from the initial treatment and was often progressive. Kissin et al. (1986) emphasised that the focus of the most recent literature was predominantly on breast tissue and texture conservation and that most failed to address the “swollen, painful, lymphoedematous arms” (p. 584) resulting from surgery for breast cancer.

Markowski et al. in 1981 studied retrospectively the incidence of lymphoedema in a group of fifty eight (58) women who underwent radical or modified mastectomy for breast cancer in a county hospital in the United States. Following surgery the women underwent a specific treatment program of hand and arm care, occupational and physical therapy. The treatment was aimed at reducing post-mastectomy complications and preventing the formation of lymphoedema and its related complications. After twelve months of follow-up objective measurement was undertaken. Circumferential measurements were taken of both upper extremities at 5 sites: 21cm and 11.5 cm above the olecranon, and 7.5cm, 14cm and 24cm below the olecranon. The diagnosis of lymphoedema was made when the circumference at more than one measured site in the affected extremity was 1.5cm or greater than that of the corresponding site on the

nonaffected extremity (p. 450). Results indicated that 60% had no lymphoedema, 22.4% slight lymphoedema, 5.2% moderate lymphoedema and 3.4% severe lymphoedema. This was in spite of the fact that 39% of the women had received radiotherapy and 48% had delayed wound healing.

Markowski et al. (1981) suggested that their own study foreshadows the potential benefits of close follow-up and specific treatment of mastectomised patients with the aim of minimising the complication of lymphoedema. Markowski et al.'s (1981) study supports the findings of Healy in 1971 who reported that 55% (n=45) of patients who received no instructions for an appropriate post-mastectomy exercise program developed lymphoedema, in contrast with an incidence of 33% (n=53) in patients who received exercise instruction and followed them.

A review of postoperative morbidity following pre-operative irradiation was undertaken by Badr El Din et al. (1989). The group reviewed the medical files of one hundred (100) patients. Such findings substantiate the need for early detection of lymphoedema and the need to alert both patients and health professionals of the necessity to be informed of the symptoms associated with lymphoedema and the treatment methods available to the patients. The dearth of research limits guidelines for educating health professionals and carers toward a holistic approach to patient care.

It would then seem pertinent to conclude that supervised exercise programs, patient and carer education need to be an integral part of post mastectomy therapy.

Predisposing Factors

Factors contributing to the formation of lymphoedema are widely quoted, however controversy remains as to the actual cause. Kissin et al. (1986) demonstrated a correlation between radiotherapy and lymphoedema, however, they failed to show significant relationship between delayed wound healing and lymphoedema as had been earlier demonstrated by Nelson (1966) and Britton and Nelson (1962). Comparison between Kissin et al. (1986) and other recent studies, including Markowski et al. (1987) is difficult, as each study used different parameters to measure lymphoedema.

Treatment And Treatment Modalities

Wedgwood and Benson (1992) believe the management of primary breast cancer to be controversial and attest to there being minimal focus being placed on complications resulting from the surgical interventions despite these complications being well documented. The study of one hundred and forty eight (148) women who had had surgery for breast cancer between 1985 to 1987 assessed complications both in the early and late stages after surgery. They found that early complications occurring were predominantly infection (10%) and lymphocoele/seroma (25%). These findings compare with results reported in other studies. The late complications of lymphoedema and frozen shoulder, due to pectoralis major muscle wasting, constituted the majority of complications contributing to long term disability. Wedgewood and Benson (1992) believed these two complications “may have an appreciable impact on quality of life” (p. 316).

Hornsby (1995) compared two treatment methodologies (compression sleeve and massage and exercise) used in the management of lymphoedema. Her study defined

lymphoedema as “the presence of an excess of 200ml fluid in the affected arm, compared with the unaffected arm” (p. 127). The study investigated twenty five (25) patients who attended the follow-up breast clinic at the Wessex Cancer Centre in Southampton with lymphoedema following treatment for breast cancer. The women were randomised into experimental and control groups. All subjects were instructed in self massage and specific exercise routines and advised on lymphoedema and skin care. The experimental cohort was fitted with a compression sleeve and requested to wear it day and night. Participants were asked to monitor the effect that Lymphoedema had on their ability to perform activities of daily living and their pain levels.

Results from the study indicated a reduction in swelling in the experimental group in twelve of the fourteen patients compared to only four of the eleven patients in the control group, hence demonstrating the efficacy of the compression sleeve in conjunction with massage and exercise as an effective treatment modality.

Hornsby (1995), in her comments on the study asserts patients glean a positive psychological benefit from attending treatment centres and alludes to patients being less accepting of their limitations resulting from their treatment for breast cancer and more motivated towards treatment methodologies.

Psychological Implications

It has been reported that for many patients the physical problems associated with lymphoedema are surpassed by the psychological sequelae. Healy (1971) in his paper on the Role of Rehabilitation Medicine in the care of patients with breast cancer, states that the “physician must go beyond the physical deformities and consider the many psychologic, social, economic, and vocational problems besetting a cancer patient and

his family” (p. 1666). Healy reports on a study of two hundred and seventy one (271) women treated for breast cancer. In the study 40% (108) women developed lymphoedema and of the women with lymphoedema 95% (103) reported being self-conscious about their physical appearance. Embarrassment about their appearance, feelings of isolation, marital and family problems are paramount to the overall well-being of the lymphoedema patient.

A study by Tobin et al. (1993) specifically addressed these issues. It was revealed that patients with lymphoedema showed greater psychological morbidity at formal psychiatric interview, impaired adjustment to illness, greater impairment of physical functioning and psychosocial maladjustment.

Hardy (1991) advocates the undertaking of studies evaluating the quality of life and physical self-image of women with post-mastectomy lymphoedema, to ascertain a holistic approach to management of this potentially debilitating complication.

Razavi and Delvaux (1995) concur with Hardy and in their study on quality of life for the cancer patient viewed from a psychiatrists perspective, emphasise the prevalence of psychosocial problems and psychiatric disturbances that have been reported in relation to cancer and believe that this “underlies the need for comprehensive psychosocial support....to preserve, restore or enhance quality of life” (p.S25). The issues addressed above are compounded when the patient has both cancer and lymphoedema.

Identification of the factors contributing to the formation of lymphoedema and education of health professionals and patients on the early detection and management intervention for lymphoedema is relevant to outcomes. Awareness of the impact that lymphoedema may have on the patient and her family will enable policies and strategies

to be developed to circumvent and/or limit the physical, psychological and economical cost involved with the management of lymphoedema.

Summary

Review of the literature highlights the problems associated with defining the incidence of lymphoedema, as no standard objective measure has been utilised. Research to date of the incidence of lymphoedema relates to the identification of new cases and their management. Research that identifies the prevalence of lymphoedema following surgery for breast cancer and identifies the needs for existing cases is pertinent. The establishment of intervention and education strategies for health professionals to approach patient management from a team perspective are needed.

A study of Lymphoedema involving prevalence, treatment, management and patients' quality of daily living was thus indicated.

CHAPTER 3

Methods.

Design

A descriptive correlational study was undertaken.

This approach is appropriate as conflicting evidence exists as to the prevalence of Lymphoedema following breast surgery and its relation to a variety of pre-disposing factors. Data were supplemented by information from participants' responses to open ended questions which were then quantified.

Sample

Inclusion/Exclusion Criteria

Women were included in the study if they had had surgery for breast cancer however, women were included in the category of having lymphoedema, only if they stated that they had been diagnosed as having lymphoedema by their doctor.

The convenience sample consisted of women who responded to an advertisement in the state wide newspaper, the West Australian. The advertisement invited women who had had surgery for breast cancer to participate in this study (Appendix 1). Although a local data base of women who had had breast surgery exists, the researcher was unable to be access this data source ($n = >4,000$ for a ten year period).

Women who met the criteria for inclusion (having had surgery for breast cancer) were requested to register their interest in participating in the study by leaving their

name and telephone number or name and address on an answering machine. The researcher contacted by telephone all respondents who left a telephone number. The purpose of the study was explained and all participants were guaranteed strict confidentiality and anonymity. The sample size was dictated by the number of respondents (n=144).

Instrumentation

Development Of The Questionnaire

The questionnaire was designed to gather data from cancer patients who had had surgery, looking at psychological responses as well as physical effects. The questionnaire was designed by the researcher following a review of the available literature, discussions between the researcher, surgeons performing surgery for breast cancer and members of the Lymphoedema Support Group.

The first section of the questionnaire collected background information on the respondents; age, distance from Perth, year of diagnosis, year of surgery and pre-surgical treatment. The second section of the questionnaire comprised questions generated by the researcher to ascertain the type of surgery undergone and any adjunctive treatment given. This section also examined alterations to the participants perceived quality of daily living. A section of the EuroQol[®] Health Questionnaire Version 10 (October, 1990), was utilised, by permission (see Appendix 3), to gather information relating to quality of daily living. The EuroQol[®] Health Questionnaire component was utilised as it explores a wide range of domains looking at degrees of severity within each domain. Other disease specific measures such as the Karnofsky Performance Status Index could

be used, however Kind (1987) believed the alternative instruments to be essentially for ordinal measurement that distinguished between states and provided no information regarding relative values. The EuroQol^c measure is essentially descriptive producing a cardinal measure that generates numeric information (p.18). The instrument is purposeful in defining unique health states such as experienced by those with lymphoedema.

Section three of the questionnaire pertained to the incidence of participants who had acquired lymphoedema following surgery, treatment and support modalities.

In order to reduce respondent error, instructions were provided on the first page of the questionnaire. Each of the major sections reminded the respondents of the appropriate method for question completion.

Generation of the questionnaire involved several stages:

Content Validity

The appropriateness of the content of the questionnaire was initially verified by colleagues with practical knowledge of lymphoedema following surgery for breast cancer, the Lymphoedema Support Group and Nurse Academics.

Content validity was ensured by having the instrument content validated by a team of experts. The researcher sought content validation from four experts from relevant fields.

The following experts assessed the content validity of the tool:

1. A Senior Haematology/Oncology Registrar at Royal Perth Hospital.
2. A General Surgeon who undertakes breast surgery at Royal Perth Hospital.
3. A Breast Cancer Nurse Counsellor with many years of experience in oncology nursing.

4. A clinical psychologist who has for many years counselled patients with cancer.

The questionnaire, together with a copy of the research proposal was given to each expert who was requested to comment on the content of the questionnaire. The comments of the group resulted in the exclusion of one question and the addition of another. The questionnaire was then piloted to test that the women understood the questions included in the questionnaire.

Pilot Study

The questionnaire was piloted to test the clarity of the questions.

The pilot subjects (n=10) were randomly chosen from the sample and were excluded from the final analysis. Random numbers were generated using the Epistat Statistical Program. The subjects were asked to identify any problems they had completing the questionnaire as well as any suggestions they might have for improving the questions. The questionnaire was also reviewed by a Nurse Researcher and several nurse academics. The questions required modification to the wording and one section of a question was deleted as it was repetitive and had potential to cause confusion for the participants.

The piloting of the questionnaire enabled the researcher to:-

- (1) refine the data collection and analysis plan
- (2) test the instrument to be used in the major study
- (3) gain some experience with the subjects, methodology and instrumentation as suggested by Ort (1981, p.49) in Brink & Wood, (1989, p.288).

The final questionnaire incorporating the above changes, was used in the study, and is provided in Appendix 6.

Ethical Considerations

The proposed study was considered by the University Ethics Committee and clearance given prior to implementation.

Participation in this study was by informed consent. Information was provided in written form with the questionnaire and further explained by telephone to participants who requested a return call from the researcher after expressing interest in the study.

Completion and return of the questionnaire represented consent to participate in the study.

Confidentiality in the handling of data collected is the responsibility of the researcher. The researcher and the research supervisors have sole access to data storage systems. Data collected from the returned questionnaires was coded, therefore, individuals could not be identified. All records, including the master copy (kept separate from questionnaires) of the coded data, is concealed and will be held at the researchers residence for five years following completion of the study. Stored data did not contain any information that could be used to identify the participants. No names are used in the reporting of the data and all data is reported in such a way that it does not identify individuals.

According to Brink & Wood, studies involving human subjects have the potential to revive sensitive issues hence require provision for therapeutic intervention should this be necessary during the process of data collection (1989, p.116-7). Debriefing and counselling for the participants who required it was made available by the Lymphoedema Support Group (see appendix 4). The counselling service is a confidential service

therefore no information has been provided by the Lymphoedema Association as to whether or not their service was utilised. All potential participants were informed that participation was voluntary. The letter sent to the participants is attached in Appendix 5.

Procedure.

An advertisement was placed in the West Australian Newspaper requesting women who had had surgery for breast cancer to participate in a study. All interested women were requested to leave their name, address and/or telephone number on an answering machine at the researcher residence. The researcher then contacted all women who responded to the advertisement, explained the purpose of the study and guaranteed complete confidentiality should they wish to participate in the study. Women who agreed to participate were informed that a questionnaire would be sent to them for completion.

The printed questionnaires, a letter of introduction that included a restating of the purpose of the study, guarantee of strict confidentiality and anonymity, together with a replied paid response envelope, were mailed to each of the respondents. A private mail box was hired at the local Post Office for the return of the completed questionnaires. The post box was cleared daily by the researcher.

Statistical analyses were performed on the useable, returned questionnaires.

Statistical Analysis

The questionnaires were numbered and coded on receipt. A code book was prepared listing the codes associated with the various aspects of each question as recommended by Polit & Hungler (1983, p.499). Quantitative data were entered into a Statistical Package for the Social Sciences (SPSS for Windows Release 6.0.1) file for analysis.

Responses to open ended questions were coded, categorised and quantified on a statement by statement basis for each response. Statements were compared to ensure mutual exclusivity for categorisation as suggested by Polit and Hungler (1983). The categories were agreed to by a reference group.

The initial quantitative analysis included descriptive statistics presenting frequencies, means and standard deviations. The output of these basic statistics helped highlight coding errors and provided a general overview of the data.

Cross-Tabulation was used where necessary, data were grouped and recoded to allow statistical analysis to be undertaken. Chi square was used to examine the data in the contingency tables for the differences between variables, and Phi employed to determine the level of association. The level of statistical significance was $p = <0.05$.

Limitations

Although the participants are representative of the larger population of women who have had surgery for breast cancer this study was restricted to women who responded to the newspaper advertisement and consented to participate. Originally this study was designed with anticipated access to a more random sample ($n \geq 4,000$ for a ten year

period) by accessing the names on the local Breast Cancer Register. However, due to unforeseen circumstances this was not possible, therefore the sampling framework needed to be changed to a convenience sample. This limitation was for convenience of access to participants by the researcher in the restricted time frame. Such limitation may result in generalisations beyond the sample being viewed cautiously, in particular the frequency of lymphoedema.

CHAPTER 4.

Findings

The purpose of this study was to describe the experiences of women with lymphoedema and the relationship of its occurrence with type of breast surgery, chemotherapy, radiotherapy and axillary node clearance, in a convenience sample (n=114) of Western Australian women who had undergone surgical treatment for breast cancer. Subsidiary questions were directed at identifying differences between geographical location, possible incidental relationships and age indicators. The study findings are presented in accordance with the research questions.

In this study, data were analysed using the Statistical Package for the Social Sciences (SPSS for Windows, Release 6.0.1). Open-ended questions were grouped, and coded to allow analysis.

Research Respondents

Questionnaires were sent to 144 women who had expressed interest in participating in the study, 117 were returned giving a response rate of 81.3%. Three (3) questionnaires were not included in the analysis as the respondents had had multiple surgery to the same breast, thus making it difficult to ascertain if the outcomes were as a result of the initial or subsequent surgery.

Demographic Characteristics

The age range of the participants was from 29 to 79 years (\bar{x} = 53 years). The standard deviation was 9.83.

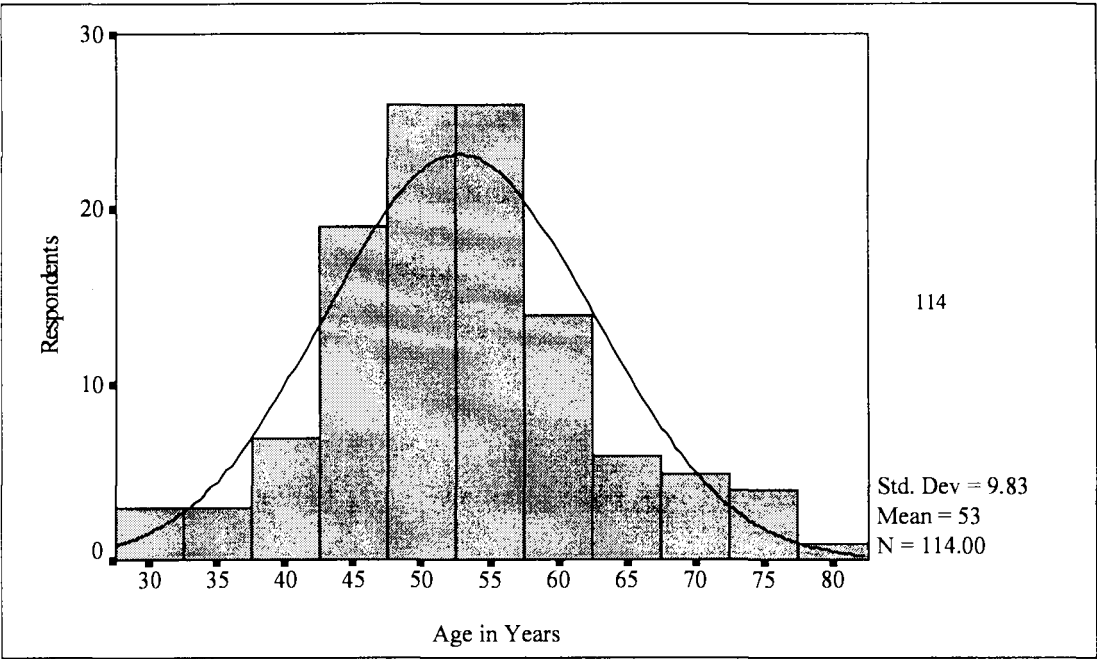


Figure 2. Age Distribution of respondents.

The majority of the participants (85%) resided in the urban sector, which included the Perth metropolitan region and an area within 250 kms from Perth. The 250 km radius was chosen as residents living a distance greater than this qualify under the government regulation for a rural travel allowance, Patient Assistance Travel Scheme (PATs), to attend medical treatment at a major centre. Only two (1.7%) respondents with lymphoedema were from the rural areas, therefore, the results of this study are not generalisable to a rural population (see Frequency Tables Appendix 7).

The Frequency Of Lymphoedema Following Surgery For Breast Cancer

The first question of this study was to determine the frequency of lymphoedema in a group of Western Australian women who had undergone surgery for breast cancer.

The respondents were first asked if they had had swelling in their arm on the affected side since having surgery for breast cancer. Fifty seven (50%) of the respondents reported having had swelling at some time following their surgery. The length of time that the women had had their swelling varied from less than six weeks to longer than ten years. (see Table 1).

Table 1

Summary Of The Length of Time Swelling Lasted And The Occurrence of

Lymphoedema

Time	Number (n=57)	Diagnosis of Lymphoedema
0-6 weeks	14	3
7 weeks - 6 months	5	1
7 -12 months	8	5
2 - 3 years	9	6
4 - 5 years	4	1
6 - 7 years	2	2
8 - 9 years	1	1
> 10 years	4	2
Unsure	1	0
Missing Data	9	2

Twenty eight of the women who reported arm swelling following their surgery had had their swelling for a period longer than six months. This, according to literature (Hardy, 1991; Kissin et. al., 1986) should indicate to the physician a diagnosis of lymphoedema. However, only seventeen of the women in this category had been reportedly diagnosed as having lymphoedema. Two of the women who had reported swelling for longer than ten years had not been diagnosed with lymphoedema. The lymphoedema prevalence found in this study was 20% (n=23).

Predisposing factors to Lymphoedema

Question two sought to identify relationships between lymphoedema (as diagnosed by the patient's doctor) and the type of surgery performed, radiotherapy, chemotherapy, and tamoxifen therapy.

To answer this question, from the descriptive data, it was first necessary to establish the frequency and type of surgery undertaken and the frequency of women having adjunctive treatment.

To complete the fulfilment of the underlying assumptions for Chi-square contingency table analysis and demonstrate statistical inference between the variables, recoding and grouping of the variables was undertaken. The 'type of surgery' variable was regrouped into mastectomy and conservative surgery, and 'post surgical' chemotherapy, radiotherapy and Tamoxifen therapy variables were regrouped to show the responses of 'no' and 'not sure' as one category within the each variable. The researcher, from professional experience, believed that should a patient have undergone chemotherapy and radiotherapy then they would most certainly have been aware of the treatments as

both treatments are specific and unique. The regrouping of the Tamoxifen therapy variable was to provide consistency for comparison.

Chi-square analysis of the contingency tables was undertaken (see Tables 8 - 11).

Lymphoedema And Type Of Surgery

As shown in Table 2, the most frequently used type of surgery was mastectomy (n=80, 70%).

Table 2

Summary Of The Type Of Surgery Performed

Type of surgery	Number (n=114)	%
Radical Mastectomy	43	37.72
Modified Radical Mastectomy	30	26.32
Simple Mastectomy	7	6.14
Wide Local Excision	4	3.5
Lumpectomy	30	26.32

Part of question 2 investigated whether there would be a greater number of women in the group having developed lymphoedema if they had first undergone mastectomy rather than conservative surgery.

The null hypothesis (H_0) being that no relationship exists between each of the variables tested. The level of significance was $p<0.05$ and the degrees of freedom (d.f.) was 1.

Table 3

Contingency Table Showing The Development Of Lymphoedema By The Type of Surgery Undertaken

Type of Surgery	Lymphoedema	Lymphoedema	Row Total	%
	No	Yes		
Mastectomy	65	14	79	69.3
Conservative	26	9	35	30.7

Chi-Square	Value	DF	Significance
Pearson	.96211	1	.32666

The results of Chi Square (χ^2) analysis did not to show significant relationship between the type of surgery undergone and the development of lymphoedema.

Lymphoedema And Radiotherapy

Forty three (37.7%) of the women underwent radiotherapy following their breast surgery, nine of these women had had pre-surgery radiotherapy, however none had been diagnosed as having developed Lymphoedema.

Table 4

Summary Of Women Undergoing Radiotherapy Following Surgery

Response	Number (n=114)	%
Yes	43	37.7
No	62	54.4
Not sure	8	7.0
Missing data	1	0.9

Table 4 shows that forty three women had radiotherapy following their breast surgery. Of these forty three women twenty six (22.8%) had radiotherapy to both the breast and the axilla.

Table 5

Site Of Radiotherapy

Response	Number (n=114)	%
Breast	43	37.7
Axilla & Breast	26	22.8

The second part of question 2 investigated whether there would be a greater number of women in the group having developed lymphoedema if they had undergone a course of radiotherapy following their surgery for breast cancer.

Table 6

Contingency Table Showing The Development Of Lymphoedema By Radiotherapy

Radiotherapy	Lymphoedema		Row Total	%
	No	Yes		
Yes	31	12	43	37.7
No	60	11	71	62.3

Chi-Square	Value	DF	Significance
Pearson	2.56264	1	.1094

Again, Chi Square (χ^2) did not to show a significant relationship between the development of lymphoedema and the women having undergone a course of radiotherapy.

Lymphoedema And Chemotherapy

Forty (35.1%) of the participants underwent a course of chemotherapy following their surgery. Three of the forty women underwent chemotherapy pre-surgery - neither of the women who had chemotherapy pre and post surgery developed Lymphoedema.

Table 7

Summary Of Chemotherapy Following Surgery For Breast Cancer

Response	Number (n=114)	%
Yes	40	35.1
No	60	52.6
Unsure	13	11.4
Missing data	1	0.9

The third part of question 2 investigated whether there would be a greater number of women in the group having developed lymphoedema if they had had chemotherapy following their surgery for breast cancer.

Table 8

Contingency Table Showing The Development Of Lymphoedema By Chemotherapy

Chemotherapy	Lymphoedema		Row Total	%
	No	Yes		
Yes	35	5	40	35.1
No	56	18	74	64.9

Chi-Square	Value	DF	Significance
Pearson	2.25414	1	.13326

No significant relationship could be demonstrated by Chi Square (χ^2) between the development of lymphoedema and the women having chemotherapy.

Lymphoedema And Tamoxifen Therapy

Forty eight (42.1%) of the respondents indicated that they had received Tamoxifen therapy. Thirty eight (33.3%) of the respondents use Tamoxifen as an ongoing treatment.

Table 9

Summary Of Tamoxifen Therapy

Response	Number (n=114)	%
Yes	48	42.1
No	53	46.5
Not sure	12	10.5
Missing data	1	0.9

Table 10

Summary Of Length Of Time On Tamoxifen Therapy

Response	Number (n=114)	%
Not Taking Tamoxifen	64	56.1
Ongoing treatment	38	33.3
10-30 weeks	4	3.6
52 weeks	1	0.85
100-130 weeks	3	2.7
131-160 weeks	1	0.85
Missing Data	3	2.6

The fourth part of question 2 investigated whether there would be a greater number of women in the group having developed lymphoedema if the women were taking Tamoxifen following their surgery for breast cancer.

Table 11

Contingency Table Showing The Development Of Lymphoedema By Tamoxifen

Tamoxifen Therapy	Lymphoedema No	Lymphoedema Yes	Row Total	%
Yes	33	15	48	42.1
No	58	8	66	57.9

Chi-Square	Value	DF	Significance
Pearson	6.31387	1	0.01198

Chi Square (χ^2) analysis showed a significant relationship between the development of lymphoedema and women taking Tamoxifen $\chi^2 (1) 6.31 p .011$. Of the twenty three (20%) of the total sample who developed lymphoedema, fifteen were on Tamoxifen. The question as to whether or not the women had undergone a combination of adjunctive treatment methods was not addressed in this study.

Lymphoedema Treatment

The third question asked was to identify the treatment methodologies being employed in the treatment of lymphoedema. The women were given a list of common treatments and asked to indicate the type of treatment they were receiving. Treatments methodologies undertaken that were not specifically listed on the questionnaire were categorised and coded from the responses.

Twenty five women reported undergoing some form of treatment for the swelling in their arm that occurred following their surgery for breast cancer. Seven of the women receiving treatment had not been diagnosed as having lymphoedema.

The most frequently used treatment ($n=12$), involved combination therapy using a pump plus massage, bandages and sleeves either in combination or singularly.

Table 12

Summary Of Treatment Methodologies

Treatment type	Swelling - no diagnosis	Diagnosed 'Lymphoedema'
No treatment	20	3
Compression sleeve	2	2
Massage	3	2
Surgery	0	1
Pump & massage	1	3
Pump & sleeve	0	1
Pump/sleeve/massage	0	3
Pump/bandage/massage	0	1
Squeeze tennis ball	2	3
Missing data	6	1

The Impact Of Lymphoedema On The Perceived Quality Of Daily Living

The fourth question of this study was to determine from the patients' perspective, the impact that living with lymphoedema had on their quality of daily living.

The following results focus on women who have been diagnosed as having lymphoedema, however, for interest and comparison results have been included from women who have reported having swelling following their surgery but have not been diagnosed as having lymphoedema. These results are enclosed in square brackets [].

Three (13.04%) women reported requiring assistance to walk, one (4.35%) [1] expressed concern about her ability to self care and five (21.74%) [10] women reported that they had difficulty performing their normal duties daily duties. Sixteen (69.57%) [11] having to endure a moderate amount of pain on a daily basis. A moderate anxiety level was felt daily by seven (30.43%) [9] women whilst one (4.35%) indicated to be extremely anxious at all times. Nine (39.13%) [11] women believed that their health was at the time of the study better than it had been twelve months previously, however one (4.35%) [1] woman reported that her general health state was much worse than previous.

The women were asked to indicate the type of limitations that lymphoedema had placed on their ability to perform daily requirements. The data were categorised and coded into four major categories: financial, self esteem, ability to undertake hobbies and restriction of the tasks they could perform. The following figure presents a summary of the limitations to normal daily activity as presented in this study.

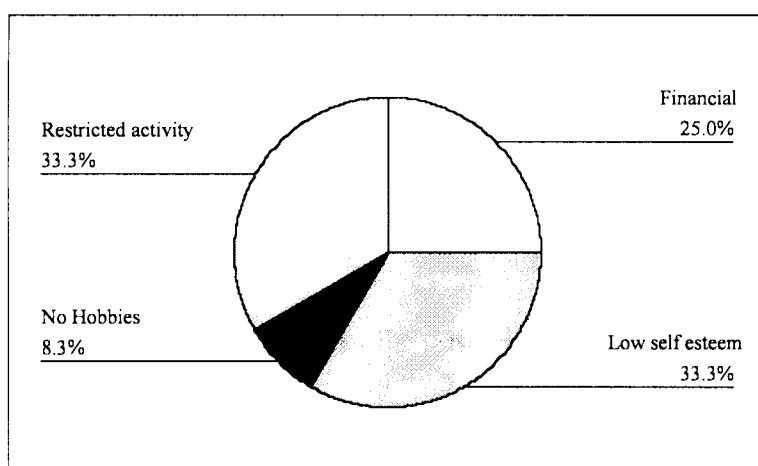


Figure 3. Reported factors affecting quality of daily living.

The purchase of compression sleeves together with the cost of treatment programs placed a huge financial burden upon the family thus limiting available resources for other sometimes necessary purchases. Shopping for personal clothing was a task few of the women looked forward to. Garments needed to be several sizes larger than the women would normally purchase to accommodate their swollen arms. This often placed the clothing design into an expensive category, nondescript category or the too difficult to acquire category. The resultant outcome of this usually enjoyable activity for women, was a reported low self esteem (n=6). Women in this study who normally undertook hobbies such as handicraft, painting and sewing described a difficulty in performing their hobby as the compression sleeve worn to manage their lymphoedema was uncomfortable and restrictive. Pain and swelling in the arm was presented as a major concern for women with lymphoedema in this study as it was said to limit their ability to stretch and lift and perform duties that required constant movement such as ironing.

Post- Hoc Analysis Concerning Patient Education

A serendipitous finding in this study relates to the information reportedly provided to the women before having surgery for their breast cancer. The women were asked if they believed that they had been provided with enough information to prepare them for their surgery; if they were told of the possible complications following surgery and if they were given information specifically relating to lymphoedema following surgery. Analysis of the responses are presented in the following section.

Pre-Surgery Patient Education

The pre-surgery education questions asked in this study aimed to determine the knowledge that the women perceived they had with regards to the treatment they were to undergo for their breast cancer and the possible complications of that treatment.

The women were asked to provide responses to three questions regarding pre surgical information given to them. Written comments made by the respondents, either as part of the questionnaire or as an addition to the questionnaire were analysed by content analysis.

The women were firstly asked if they believed that they had been given enough information to prepare them for their surgery? One patient commented:

“I feel strongly that at initial diagnosis the surgeon should use a tape and give it to the patient. Once you hear breast cancer, the brain stops working. My husband was with me and he could not take it in either. Please help me to help others. The cancer foundation won’t help”
(No. 101).

The general theme evolving from analysis of the comments was one of a great need for the provision of information in a form that patients can absorb it once they have overcome the initial shock of having been diagnosed with breast cancer.

Another stated:

“I don’t remember as I was completely shattered mentally at the time”
(N0. 8).

All the participants maintained that they were too overwhelmed with the diagnosis of breast cancer to absorb information necessary to prepare them for the sequelae following their surgery.

Thirty four (29.8%) of the women indicated that the information provided did not adequately prepare them for surgery. Of this group of women twenty developed swelling of their arm following surgery and eight of the twenty were diagnosed as having post surgical lymphoedema.

Secondly, it was asked if they were informed of the possible complications following their surgery? Fifty nine (51.8%) of the women reported having no knowledge of the possible complications resulting from their surgery. Thirty six of these women developed swelling of their arm following their surgery with eighteen of the women being diagnosed as having developed lymphoedema.

Thirdly the women were asked if they were told that they may develop lymphoedema after their surgery? Statements such as:

“at the time of my surgery I knew nothing about lymphoedema. I heard about it 9 yrs. later when I joined B.C.S.S. [Breast Cancer Support Service] (No.6)”

and

“I would like to have been told post-op about the possibility of lymphoedema and what to do about it if it occurred. My GP told me to buy a sports bandage from the chemist (No. 65).”

Seventy six (66.7%) denied having been informed of the possibility of developing lymphoedema. Forty two of the women in this category did develop arm swelling following surgery and twenty one of these women were diagnosed as having developed lymphoedema. Only twenty three women in this study stated that they had had their swelling diagnosed as lymphoedema, therefore such a result indicates that only two women with lymphoedema had been pre-warned of the possibility of developing

lymphoedema following their surgery. The women's feelings seem to be summarised with this response,

“Drs should warn patients straight after breast operation, give written information to be absorbed. My Drs were impossibly silent on many subjects and should not be allowed to continue in this manner. Even now with secondary cancer every bit of knowledge and support from them is a battle. I am still dependent on the Cancer Foundation for information (No. 116).”

Summary of Results

There was an 81.3% response rate to the questionnaire, however, three (3) questionnaires were not included in the analysis as the respondents had had multiple surgery, therefore, it would be difficult to ascertain if the outcomes were as a result of the initial or subsequent surgery. The majority of the respondents were from a urban sector of Western Australia with a mean age of fifty three (53) years.

From the questionnaire the following findings were identified: The prevalence of lymphoedema, stated to be diagnosed by the respondents doctor, in a group of Western Australian women who had undergone surgery for breast cancer was found to be 20%. Mastectomy was found to be the most commonly performed surgical procedure with approximately 43% of all women undergoing some type of adjunctive treatment for their breast cancer. Participants may have undergone a combination of adjunctive treatments however this study did not address combination adjunctive treatment. Whilst some women with lymphoedema were undergoing treatment there was no standardised treatment method demonstrated.

The impact of lymphoedema on the quality of daily living experienced by the women was reflected by reports of low self esteem, financial hardship, inability to undertake usual hobbies and restriction and/or inability to perform many of the normal daily tasks.

A large proportion of the women reported that they were provided with insufficient information with regards to their treatment regime and the possible complication scenario resulting for the interventions.

CHAPTER 5

Discussion And Conclusions

The focus of this study was to describe the experiences of women with lymphoedema following surgery for breast cancer and the relationship of its occurrence with the type of breast surgery undergone, chemotherapy, radiotherapy and Tamoxifen therapy. Subsidiary questions identified geographical location, incidental relationships and age indicators. The findings depict a global picture of experiences for the women who have developed lymphoedema as a result of breast cancer and the subsequent treatment methodology as outlined in the 'Web of Causation' theoretical framework.

A comprehensive discussion of the study findings is presented in this chapter.

Background Information

All the participants in the study had undergone surgery for breast cancer, however the type of surgery and adjunctive treatment modalities differed. Respondents (n=3) who had undergone multiple surgery on the same breast were omitted from the analysis as it would be difficult to determine if the outcomes were as a result of the initial or subsequent surgery.

Demographic Characteristics

The age of the participants ranged between 29 and 79 years with a mean age of 53 years. Residence of the respondents was geographically diverse, however, the majority of the respondents resided in the urban sector. Only two (1.7%) of the respondents with

lymphoedema were from the rural sector; the study results therefore reflect the urban population and cannot be generalised statewide.

Frequency Of Lymphoedema

In this study lymphoedema was not measured, patients were assumed to have lymphoedema if they stated that a diagnosis had been made by their consultant or General Practitioner.

Kissin et al. (1986) suggested that lymphoedema can occur post surgery in two formats: a transient type that occurs during the first two months, resulting from acute overload of the lymphatics and possible wound healing delays, and a late onset lymphoedema that appears to be associated with a number of independent variables such as axillary radiotherapy, late infection and the extent of axillary node clearance.

In the present study fifty seven (50%) of the total sample of women had indicated having had swelling after surgery. Thirty three women still had their swelling after six weeks, thus indicating that some women had experienced a transient swelling following their surgery. Results of this study concurred with Kissin et al's (1986) findings. Of particular interest in this study was that only twenty three (20%) of the total sample of women who had reported having had arm swelling after their surgery had actually had their swelling diagnosed as lymphoedema. Perhaps this may reflect a lack of knowledge on behalf of the patient that swelling following surgery is a complication resulting from the surgical intervention and as such requires management. If the patient has not been pre-warned of the possible sequelae to surgery she may have accepted the arm swelling as being an expected outcome of breast cancer surgery and therefore not sought medical intervention.

The frequency of occurrence of lymphoedema found in this study (20%) is consistent with findings in Kissin et al.'s 1986 study (11-25%), however it is much lower than that reported in 1981 by Markowski et al. (53.4%).

Variation in prevalence could possibly be due to there being no uniform measurement for lymphoedema. Reporting of large variations in the prevalence of lymphoedema suggests a need to establish a universal measurement tool to enable comparative studies of lymphoedema to be undertaken. A precise definition of lymphoedema would assist practitioners in the diagnosis of lymphoedema and enable implementation of treatment in the early stages.

Relationship Between Lymphoedema, Surgery And Adjunctive Treatments

The research investigated the existence of a relationship between lymphoedema and the surgery type undergone for breast cancer and the adjunctive breast cancer treatments following surgery

This study found mastectomy (62.5%) to be the most commonly used primary surgical intervention for the treatment of breast cancer. Forty three (37.7%) of the women underwent radical mastectomy, thirty (26.3%) had a modified radical mastectomy and seven (6.1%) had a simple mastectomy.

Forty three (37.7%) of the women underwent radiotherapy following their breast surgery. Twenty six (22.8%) of the women had radiotherapy to both the breast and the axilla. Chemotherapy was part of the treatment for forty (35.1%) of the women and forty eight (42.1%) of the women in the sample were taking Tamoxifen following their surgery. Combination adjunctive treatment methods were not addressed in this study.

No statistical significance could be demonstrated in this study between the women who fell into the category of having been diagnosed as having lymphoedema by their doctor and the type of surgery undertaken, radiotherapy and chemotherapy. This is in direct contrast to literature. Granda, (1994) reports on a study by Brismar and Ljungdah where it was reported that the combination of radical surgery and radiotherapy increased the risk of the development of lymphoedema. The Brismar and Ljungdah study asserted a higher frequency of lymphoedema in patients who had had radical mastectomy (51%) than women who had modified radical mastectomy (19%). The study found that patients who were subjected to both radical mastectomy and radiotherapy incurred the highest incidence of lymphoedema. Granda contrasted these results with those reported by Hoe, Iven, Royle and Taylor in 1992, where a considerably low incidence of lymphoedema in patients who had undergone axillary clearance and radiotherapy was established. Granda alludes to a lower incidence of lymphoedema development if a more conservative surgical intervention is undertaken. However, unlike Granda, this study did not investigate combination treatment modalities.

Kissin, et al. (1986) however, stated that the independent risk factors contributing to the development of lymphoedema were the extent of axillary surgery, axillary radiotherapy, and pathological nodal status. The researchers believe that the “extent of surgery to the breast” was of no significance in the development of lymphoedema (p.585). The Kissin et al. study demonstrated a correlation between radiotherapy and lymphoedema, and did not include the type of surgery undertaken as a causative factor.

Eleven women who had had a mastectomy reported having had their swelling following surgery diagnosed as lymphoedema. Of particular interest was that all eleven women were taking Tamoxifen. Literature does not allude to an association between the

development of lymphoedema with mastectomy and the adjunctive treatment of Tamoxifen, and this study did not investigate multiple factors relating to the formation of lymphoedema, however, this study did find a statistically significant relationship between lymphoedema and Tamoxifen. Women in this category had reported some degree of delayed wound healing or trauma to their arm on the affected side following their surgery. Both arm trauma and wound healing delay are reportedly associated with the development of lymphoedema (Kissin et al., 1986; Markowski et al., 1981), therefore the development of lymphoedema in this group may be due to the arm trauma and wound problems and unrelated to the use of Tamoxifen. In view of the significant finding it would be pertinent to undertake further studies that involve a larger sample to determine if a relationship does exist between lymphoedema formation, mastectomy and Tamoxifen.

Both these findings are not consistent with results published in current literature, therefore demand wider investigation. Replication of this study using a larger, probability sample would be prudent.

Lymphoedema Treatment

The third question aimed to identify the treatment methodologies being employed in the treatment of lymphoedema.

This study found that a 'combination treatment' modality (n=12) was mostly followed by the women to control their lymphoedema. This method comprised of the use of a pump plus massage, bandages and sleeves, either in combination or singularly. Studies reporting on effective treatment methodologies concur with this study's findings.

(Farncombe et al., 1994; Casley-Smith, 1992) as to the most commonly utilised treatment modality.

Of considerable concern is that twenty of the fifty seven women who reported having swelling post-surgery did not undergo any form of treatment for their swelling. Three of these women had been diagnosed as having lymphoedema.

It is well recognised that if lymphoedema is not treated it will gradually worsen (Casley-Smith, 1992; Kissin et al., 1986). Effective treatment requires long term compliance (Farncombe et al., 1994; Casley-Smith, 1992), therefore the ability to access treatment and treatment compliance by the patient could possibly be dictated by social circumstance. Literature supports the need to educate women regarding their treatment modalities and prepare them for outcomes together with the possible consequences of non-compliance (Farncombe et al., 1994; Tobin et al, 1993; Casley-Smith, 1992).

Markowski et al., in 1981 studied retrospectively the incidence of lymphoedema in a group of 58 women who underwent radical or modified mastectomy for breast cancer in a county hospital in the United States. Following surgery the women underwent a specific treatment program of hand and arm care, occupational and physical therapy aimed at reducing post-mastectomy complications and “prevention of lymphoedema and its related complications” (p.450). Healy (1971), reported that 55% of patients who received no instructions for an appropriate post-mastectomy exercise program developed lymphoedema, in contrast with an incidence of 33% in patients who received exercise instruction and followed them. Healy’s study demonstrates the need for compliance and pre-education.

The Australian health care system does not recognise lymphoedema as a problem requiring long term, expensive treatment as evidenced by the non allocation of

Diagnostic Rating Group (DRG) funding by the current Government. Treatment is available in the public hospital system, however, is limited and access to such treatment in today's economic climate dictates lengthy waits.

Further investigation to determine the reasons why women do not undertake treatment is recommended. Identification of the problems preventing women from seeking treatment for their lymphoedema will enable the health professional to formulate policy to correct the identified barriers.

The Impact Of Lymphoedema Has On Perceived Quality Of Daily Living

It was hypothesised that the development of respondents lymphoedema following surgery for breast cancer would have an impact on perceived quality of daily living. Morbidity resulting from the development of lymphoedema has reportedly greatly affected the quality of daily living for women in this study both physically and psychologically. The swelling and pain caused by the lymphoedema reportedly caused women to restrict the activities (33.3%) normally undertaken. Five (21.74%) women reported that they had difficulty undertaking their normal daily duties. Tobin et al. (1993) concurred with this finding and found the situation to be similar when related to the women's ability within the workplace.

The psychological sequelae following the development of lymphoedema according to Tobin et al. (1993) is multidimensional in that in many incidences swelling had occurred suddenly and without warning and more often than not during a period of time when the women were actually using their arm. The women then blame themselves for the development of the swelling.

The cosmetically displeasing body image resulting from lymphoedema can create negative self-esteem for the women. This was found to be the case in thirty three percent of the women studied in this project. The women found that they were self-conscious in company and resented the restrictions placed on their pleasure activities such as tennis and craft. Such feelings, can according to Tobin et al. (1994), result in the withdrawal from social interaction.

In addition, the cost of treatment and compression garments placed a huge financial strain on some families (25%) and the women reported feeling a burden to the family for needing to redirect much needed resources to the purchases of their treatment thus creating further anxiety for the women.

Granda (1994) proports that patient education of preventative and treatment measures can minimise the trauma for women affected by lymphoedema. Where no availability of technological resources such as pumps exists, patients can be educated in personalised interventions to self care, thus providing enhancement for “women’s autonomy and their ability to prevent, monitor and manage lymphoedema” (p.234). Granda sees the education of the women as part of the nursing management of patients who are to undergo surgery for breast cancer.

Post-Hoc Analysis Concerning Patient Education

A serendipitous finding of this study resulted from personal communication with all the participants. Direct questioning and unsolicited comments together with anecdotal notes attached to the returned questionnaires highlighted a dearth of patient education provided to women either before, during or after their treatment for breast cancer. This study included a question on the patients satisfaction with information provided to them

pre-surgery, however it was a casual inquiry and the researcher had not expected the responses returned.

Nine (39.13%) of the women diagnosed with lymphoedema (n=23) indicated that the information provided about lymphoedema before surgery was inadequate. Information about the complications of surgery, support groups and coping mechanisms were reported as deficits in their preparation for surgery. The general theme that evolved from the analysis of the comments indicated a great need for the provision of information in a form that patients can absorb it once they had overcome the initial shock at having been diagnosed with cancer. This was much evidenced in one women's statement regarding information:

"I don't remember as I was completely shattered mentally at the time"

(No.8).

Such a void in the patient's preparation has specific implications for nursing and identifies an issue that requires addressing by the nurse when discharge planning for the patient following surgery.

"Quality of care and quality of life are patient-centered, whereas medical education tends to be disease centered.....to optimise quality of care" (Heyrman, 1995, p. S11) a holistic focus model of management involving the patient, health professional and the carers is necessary.

This study has found the prevalence of lymphoedema to be 20% in the sample investigated. A statistical significance was demonstrated between the formation of lymphoedema and Tamoxifen therapy, a finding not previously reported in the literature. Women expressed an overwhelming need to be better informed as to the sequelae relating to their treatment modalities for their breast cancer so as to prepare themselves

and their families for quality life after surgery. These findings dictate an urgent need for further investigation into the needs of women undertaking surgery for breast cancer and the effective management of the “seemingly forgotten complication” (Farncombe et al., 1994) of lymphoedema both physically and psychologically.

Conclusions, Implications and Recommendations

Although the participants in this study are representatives of the larger population of women who have had surgery for breast cancer this study was restricted to women who responded to the statewide newspaper advertisement. The limitation was for convenience of access to participants by the researcher in the restricted time frame. Such limitations may result in generalisations beyond the sample being viewed cautiously.

There remains a global urgency to establish a universal measurement tool to enable comparative studies of lymphoedema to be undertaken. True statistics relating to prevalence can not be gathered until this measurement is addressed.

In view of the findings relating to the possible association between mastectomy and Tamoxifen therapy in the scenario leading to the development of lymphoedema, it is recommended that further investigations on a wider scale be undertaken.

Due to the time and number of constraints, issues confronting women in the rural sector were not identified nor addressed. Many communities in Western Australian are geographically isolated. This isolation disadvantages rural women in that treatment centres are usually centralised and consequently requires dislocation of patients with

breast cancer from their family and the social support systems in order to undergo treatment in centralised centres. Research identifying concerns for women with lymphoedema in the rural sector could have significant practical benefits to those living in remote rural settings with limited access to advice, counselling and treatment centres.

It seems pertinent to investigate the possibility of barriers preventing women from seeking treatment for their lymphoedema in view of the findings of this study.

Identification of any barriers, perceived or real, will enable the health professional to formulate policy and infrastructure to address any problems.

It is suggested that studies with a focus on patient centered decision making regarding treatment options/surgical choice and sequelae of possible post-operative complications be implemented. The implications of identifying deficits in the knowledge of the patient and health professional provides an avenue for implementing programs aimed at supporting and enhancing a positive attitude and preventing adverse psychological sequelae.

In light of the findings of this study it is prudent that researchers should replicate this study using a larger probability sample.

Implications For Nursing

The study findings have implications for nursing, particularly in the domain of nursing practice and the role of the nurse as counsellor.

Nurses, together with other health professionals, must accept responsibility for ensuring that patients are fully conversant with, and capable of understanding the knowledge and information required for them to make informed judgements regarding their treatments.

Nurses can play a vital role in providing women with the ability to prevent, monitor and manage complications that may develop. To this extent discharge planning needs to incorporate preventive health practices relating to the complication sequelae for patients following surgery for breast cancer.

Recommendations For Further Research

Findings from this study indicate that further studies should:

1. Develop a universal measurement tool for lymphoedema.
2. Investigate the role Tamoxifen has in the formation of lymphoedema.
3. Identify appropriate education methods to ensure that women are fully aware of the complications associated with surgery for breast cancer.
4. Identify appropriate discharge plans that providing women with the ability to prevent, monitor and manage complications that may develop following surgery for breast cancer.

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Appendix 1



HAD SURGERY FOR BREAST CANCER?

I'd like to hear about your experiences.

My name is Jacqueline Lord, a Master of Nursing student at Edith Cowan University. I'm interested in what happens AFTER breast cancer surgery. I invite you to participate in this study. All information will be held in strict confidence.

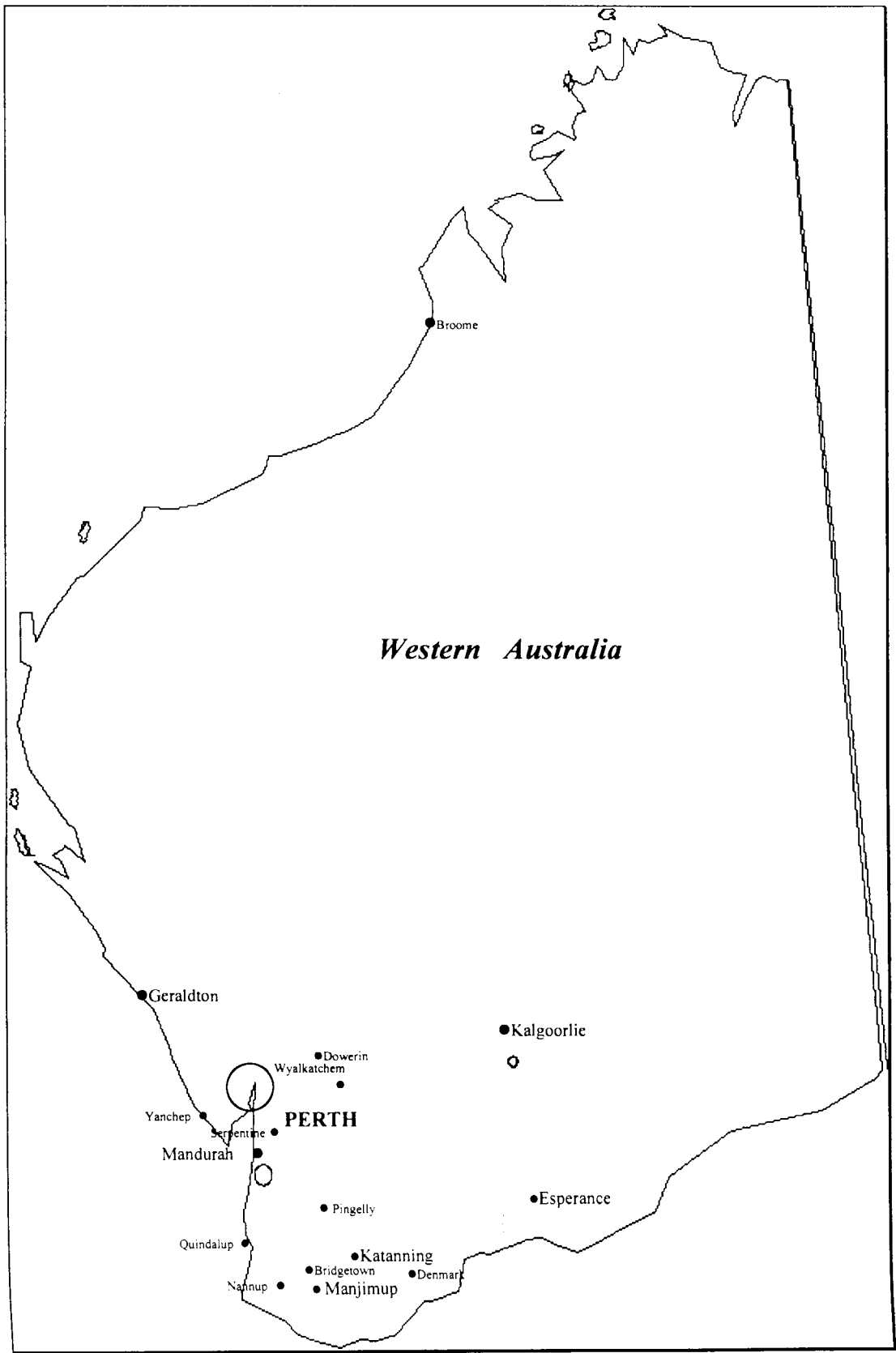
Please telephone me on (09) 448 5901.



**EDITH COWAN
UNIVERSITY**
PERTH WESTERN AUSTRALIA

100-100-100

Appendix 2
Map Of Western Australia Showing Geographical Location Of Respondents



Appendix 3.1

10th August, 1995

Mr Frank de Charro

THE NETHERLANDS

Dear Sir,

Following discussions with Professor Alan William, University of York, I write to you supplying the following information.

I am a Master of Nursing student at Edith Cowan University in Perth, Western Australia. My research interests lie in the area of Cancer and cancer related disorders. My thesis research is on 'Lymphoedema following surgery for Breast Cancer.' I am investigating several aspects related to the topic, one being the 'Quality of daily living' of these women. To assist me in gathering data, I will use page 2 of your Health Questionnaire, noting that it has been previously used and validated in the field of Cancer Research.

At the completion of my Master Degree I will be only too happy to provide you with any feedback you require through implementation of the questionnaire. It is envisaged that 500-1000 subjects will be involved in the study.

I would welcome any enquiry you may have regarding my research and it would be greatly appreciated if you could provide by return fax(09 224.2255) confirmation (for University records) that the Euroquol Health Questionnaire is 'Public Domain.'

Thankyou for assistance.

Yours faithfully,

Jacqueline Lord

Appendix 3.2



ERASMUS UNIVERSITEIT ROTTERDAM

FACULTEIT DER
RECHTSGELEERDHEID
Burg. Oudlaan 50

Dr. Jacqueline Lord

Western Australia

Centre for
Health Policy and Law
EuroQol Group Business Management

Uw Brief

Ons kenmerk

Datum

95/RC/444

17 August 1995

Onderwerp

Faxnummer

Doorkiesnummer

EuroQol

010-452 5303

010-408 1545

Dear Dr. Lord,

Thank you for your fax of 10th August 1995.

I am happy to confirm that the EuroQol instrument is in the public domain and may be used freely providing that it is not being used for commercial purposes.

I was very interested to hear about your research. Please could you provide us with a brief outline of the project for our user records.

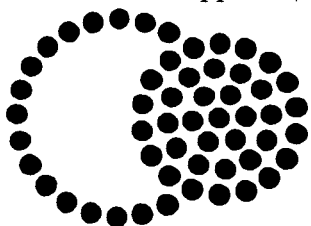
The EuroQol User Guide is in preparation and should be available in the Autumn. I have added your name to the mailing list and will send you a copy.

If you need any further information, please do not hesitate to contact me.

Yours sincerely,


dr. Frank de Charro

Appendix 4



The Lymphoedema Association of Western Australia

334 ROKEBY ROAD, SUBIACO, WESTERN AUSTRALIA 6008
TELEPHONE: 381 4515 FACSIMILE: 381 4523

17 March 1995

Ms J Lord

Dear Ms Lord

Please note that any of the participants in the study of lymphoedema following breast surgery who require debriefing or counselling will receive such counselling from the Lymphoedema Support Group.

Carol Bishop
President

Appendix 5

September, 1995

Dear Respondent

My name is Jacqueline Lord and I am a Master of Nursing Student at Edith Cowan University.

Thankyou for responding to my invitation to participate in my research into the complications following surgery for breast cancer.

My primary interest lies in the complication of Lymphoedema, however after discussions with many who have responded to my invitation to participate in this study, I have found other issues that are of concern to women who have had surgery for breast cancer. It is hoped that the needs of the group will be reflected in the results of the study.

Little is known about the prevalence (number of cases) of lymphoedema, how women cope with lymphoedema or possible causes. Consequently, few guidelines exist to help nurses and others assess and support the needs of this group of women.

I request your assistance in gathering information that will support the development of recommendations for policy and guidelines for women suffering complications as a result of breast cancer surgery.

Your participation is completely voluntary and you will be providing consent by completing the enclosed questionnaire. All completed questionnaires should be returned in the reply paid envelope. All results from the research will be reported in group ratings and no individual will be identified.

Your comments regarding the questions and/or any difficulties completing the questionnaire would be greatly appreciated. Should you require any further information please feel free to contact me on: (0 or during business hours.

Thank you for considering to participate.

Yours faithfully,

Jacqueline Lord
Researcher

Appendix 6

QUESTIONNAIRE

INSTRUCTIONS

In general each question will require you to either tick a box, circle an answer or provide missing information. Specific instructions will be provided when necessary.

BACKGROUND INFORMATION

1. What is the year of your birth?

19

2. Do you live more than 250 Kilometers from Perth?

☐ Yes ☐ No

3. In what year were you diagnosed with Breast Cancer?

19

4. Prior to Breast Surgery did you have any of the following?

Chemotherapy ☐ Yes ☐ No

Radiotherapy ☐ Yes ☐ No

5. In what year did you have Breast Surgery for the Cancer?

19

6. Has the Cancer in your Breast re-occurred?

☐ Yes ☐ No

7. If yes, what year did this occur?

19 ☐ ☐

8. Have you had any secondary Cancers, in other parts of your body (Metastases)?

☐ Yes ☐ No

9. If you have had a secondary Cancer in what year did this first occur?

19 ☐ ☐

BREAST SURGERY DETAILS

The following questions are related to your Breast Surgery and will require you to tick the most appropriate box.

10. What type of Breast Surgery did you have?
(Please tick the appropriate box/es)

TYPE OF SURGERY	LEFT SIDE	RIGHT SIDE	BOTH SIDES
Radical Mastectomy			
Modified Radical Mastectomy			
Simple Mastectomy			
Wide Local Excision			
Lumpectomy			
Hookwire Excision			

g) I can't remember? ☐

11. Did you have any Lymph Nodes removed from under your arm pit?

☐ Yes ☐ No ☐ Don't know / not sure.

12. If you had Lymph Nodes removed, could you state how many?

☐☐ Number of Lymph Nodes.

☐ Don't know

13. Did you have Radiotherapy after your surgery?

☐ Yes ☐ No ☐ Don't know / not sure.

14. If you had Radiotherapy could you provide the following information?

a) Radiotherapy to your Breast ☐ Yes ☐ No

If yes in what year? 19 ☐ ☐

b) Radiotherapy to your Axilla (Arm Pit) ☐ Yes ☐ No

If yes in what year? 19 ☐ ☐

15. Did you have TAMOXIFEN (Genox or Nolvadex) post Breast Surgery?

☐ Yes ☐ No ☐ Don't know / not sure.

If yes in what year? 19 ☐ ☐

For long did you have TAMOXIFEN _____

16. Have you had Chemotherapy after your breast surgery?

☐ Yes ☐ No ☐ Don't know / not sure.

17. The initial year of Chemotherapy?

19 ☐ ☐

18. Subsequent years of Chemotherapy?

19 ☐ ☐

19 ☐ ☐

19 ☐ ☐

19. How long did you have Chemotherapy after your surgery?

☐☐ Years ☐☐ Months ☐☐ Weeks

20. Did you have wound healing problems after Breast Surgery?

☐ Yes ☐ No ☐ Don't know / not sure.

If yes, please explain:

21. Were you given exercises after your surgery?

☐ Yes ☐ No ☐ Don't know / not sure.

If yes, did you do the exercises ☐ Yes ☐ No

If yes, for how long? ☐☐ Years ☐☐ Months ☐☐ Weeks

What type of exercises were you given?

22. Were you given enough information before your surgery to prepare you for surgery?

☐ Yes ☐ No

23. Were you told of the possible complications you may have after your surgery?

☐ Yes ☐ No

24. Were you informed before your Breast Surgery that you may get Lymphoedema after surgery?

☐ Yes ☐ No ☐ Don't know / not sure.

POST (after) BREAST SURGERY

25. If you have had a mastectomy, did you experience any feelings of your breast being still there ('phantom breast') after your surgery?

☐ Yes ☐ No ☐ Don't know / not sure.

26. If YES, was the feeling associated with pain?

☐ Yes ☐ No ☐ Don't know / not sure.

27. Following treatment for your Breast Cancer did you get/have any of the following:

Infection ☐ Yes ☐ No ☐ Don't know/not sure.

Injury to arm ☐ Yes ☐ No ☐ Don't know/not sure.

If you injured your arm what type of injury occurred and in what year?

Broken Arm ☐ Yes ☐ No ☐ ☐ Year

Burns to Arm ☐ Yes ☐ No ☐ ☐ Year

Cuts to Arm ☐ Yes ☐ No ☐ ☐ Year

Insect Bites ☐ Yes ☐ No ☐ ☐ Year

Other please specify:

HEALTH QUESTIONS

The following questions relate to your health state. Please place a circle around at least one number in each group below. Please indicate which statement best describes your own health state today. (P2 from the Euroqol Health Questionnaire).

28. Your mobility or movement?

1. I have no problems in walking about.
2. I am able to walk without a stick, crutch or walking frame.
3. I am confined to bed.

29. Your own self-care?

1. I have no problems with my own self-care.
2. I have some problems washing or dressing myself.
3. I am unable to wash or dress myself.

30. Usual activities?

1. I have no problems performing my usual activities.
(Work, Study, Housework or Family Activities)
2. Some problems with performing my usual activities.

Please describe the problems:

3. I am unable to perform my usual activities.

31. Your pain/discomfort level?

1. I have no pain or discomfort.
2. I have moderate pain or discomfort
3. I have extreme pain or discomfort.

32. Your anxiety / Depression level?

1. I am not anxious or depressed.
2. I am moderately anxious or depressed.
3. I am extremely anxious or depressed.

33. Compared with my general health over the past 12 months, my health state today is:

1. Better
2. Much the same
3. Worse

34. Have you had swelling in the arm on the affected side since surgery?

☐ Yes ☐ No

If yes how much?

A little ☐ Yes ☐ No

A moderate amount ☐ Yes ☐ No

A considerable amount ☐ Yes ☐ No

If you answered 'NO' to the above question please return your questionnaire now in the envelope provided. Thank you for your participation in this study.

LYMPHOEDEMA

This section of the questionnaire relates to Lymphoedema which occurs after surgery for breast cancer causing swelling of the arm, limited movement and pain.

35. How long after Breast Surgery did you notice swelling in you arm?

Please tick the most appropriate box:

- | | |
|--|---|
| <input type="checkbox"/> 0 - 6 weeks | <input type="checkbox"/> 4 - 5 years |
| <input type="checkbox"/> 7-12 weeks | <input type="checkbox"/> 6- 7 years |
| <input type="checkbox"/> 13 weeks - 6 months | <input type="checkbox"/> 8- 9 years |
| <input type="checkbox"/> 7-12 months | <input type="checkbox"/> 10 years or longer |
| <input type="checkbox"/> 2 - 3 years | |

36. Has the swelling been diagnosed as lymphodema?

☐ Yes ☐ No ☐ Don't know/not sure.

37. How long has the swelling lasted?

<input type="checkbox"/> 0 - 6 weeks	<input type="checkbox"/> 4 - 5 years
<input type="checkbox"/> 7-12 weeks	<input type="checkbox"/> 6- 7 years
<input type="checkbox"/> 13 weeks - 6 months	<input type="checkbox"/> 8- 9 years
<input type="checkbox"/> 7-12 months	<input type="checkbox"/> 10 years or longer
<input type="checkbox"/> 2 - 3 years	

38. What symptoms did you notice (if any) in addition to the swelling?

39. Have you had treatment for your Lymphoedema?

(Note: Not all of the listed treatment methods may be appropriate for your condition.)

☐ Yes ☐ No ☐ Don't know/not sure.

If yes which of the following treatments have you had?

(Please tick the relevant box)

Bandages ☐ Yes

Compression Sleeve ☐ Yes

Compression pump ☐ Yes

Massaging the arm ☐ Yes

Surgery ☐ Yes

Physiotherapy ☐ Yes

40. What things seem to affect the Lymphoedema?

a) Make it worse?

b) Help or relieve?

41. Has your Lymphoedema affected your Daily Living?

☐ Yes ☐ No ☐ Don't know/not sure.

If yes in what specific way?

GENERAL KNOWLEDGE

42. Do you feel that you have been given enough information about Lymphoedema?

☐ Yes

☐ No

☐ Don't know/not sure.

If 'NO', what further information would you have found helpful?

43. Are you aware of the Lymphoedema Association?

☐ Yes

☐ No

If you would like more information about Lymphoedema please contact the Lymphoedema Association.

Thank you for your assistance.

Appendix 7

SUMMARY OF FREQUENCIES

Category	Number distributed	Number returned	Returned %
Main Study	144	117	81.3

Three (3) questionnaires were not included in the analysis as the respondents had had multiple surgery therefore it would be difficult to ascertain if outcomes were as a result of the initial or subsequent surgery therefore n=114 for the purpose of analysis.

DEMOGRAPHICS

Question 1

Age distribution		
Mean	Minimum	Maximum
52.77	29	79

Question 2

Geographic distribution		
Category	Frequency (n=114)	Sample %
Urban	99	86.2
Rural	13	11.4
Missing data	2	1.8

Question 3

Year of diagnosis			
Year	Number (n=114)	Respondents %	Non respondents %
1950-1989	35	30.7	24.3
1990	4		
1991	7		
1992	18	67.5	53.5
1993	20		
1994	18		
1995	10		
Missing data	2	1.8	1.4

Question 4.

(Prior to breast surgery did you have chemotherapy/radiotherapy?)

Chemotherapy/radiotherapy before surgery				
Response (n=114)	Chemotherapy		Radiotherapy	
	#	%	#	%
Yes	4	3.5	9	7.9
No	107	93.9	103	90.4
Missing data	3	2.6	2	1.8

Question 5.

Year of surgery		
Year	Number (n=114)	Respondents %
1950-1970	2	1.71
1971 - 1980	9	7.69
1981 - 1990	26	22.22
1991 - 1995	74	63.25
Missing data	6	5.13

Question 6

Recurrence of breast cancer (n=114)				
Yes	%	No	%	Missing data
7	6.1	104	91.2	3

Question 7

(If yes, what year did this occur?)

Response	Number (n=114)	Respondents %
No Recurrence	105	92.1
1985-1990	3	2.7
1991-1995	4	3.5
Missing Data	2	1.7

Question 8

Metastases (n=114)				
Yes	%	No	%	Missing data
7	6.1	105	92.1	1.8

Question 9

(If you have had a secondary cancer in what year did this first occur?)

Response	Number (n=114)	Respondents %
No recurrence	105	92.1
1970-1990	3	2.7
1991-1995	4	3.5
Missing data	2	1.70

Question 10

(What type of surgery did you have?)

Type of surgery	Number (n=114)	Respondents %
Radical Mastectomy	43	37.72
Modified Radical Mastectomy	30	26.32
Simple Mastectomy	7	6.14
Wide Local Excision	4	3.5
Lumpectomy	30	26.32

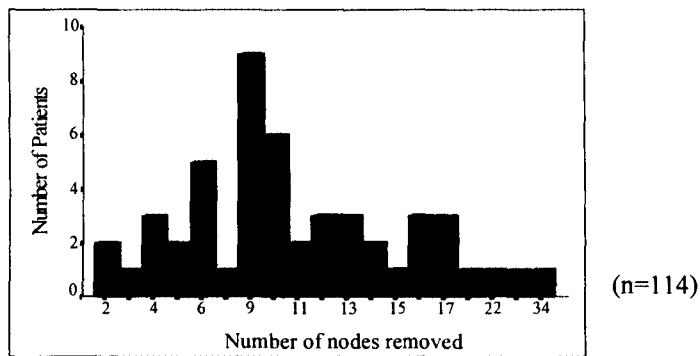
Question 11

(Did you have any lymph nodes removed from under your armpit?)

Response	Number (n=114)	Response %
Yes	103	90.4
No	9	7.9
Not sure	2	1.7

Question 12

(Number of Lymph nodes removed?)



Question 13

(Did you have radiotherapy after your surgery?)

Response	Number (n=114)	%
Yes	43	37.7
No	62	54.4
Not sure	8	7.0
Missing data	1	0.9

Question 14

(If you had radiotherapy please indicate the site of radiotherapy)

Response	Number (n=114)	%
Breast	43	37.7
Axilla	26	22.8

Question 14.1.

Year of post surgery radiotherapy to breast.

Year	Number (n=114)	% Respondents
No radiotherapy post surgery	70	61.4
1965-1970	2	1.75
1971 - 1980	4	3.51
1981 - 1990	7	6.14
1991 - 1995	30	26.3
Missing data	1	0.9

Question 14.2.

Year of post surgery radiotherapy to axilla.

Year	Number (n=114)	% Respondents
No radiotherapy post surgery	86	75.44
1950-1970	3	2.63
1971 - 1980	4	3.51
1981 - 1990	4	3.51
1991 - 1995	15	13.16
Missing data	2	1.75

Question 15

(Did you have Tamoxifen post surgery?)

Response	Number (n=114)	Response %
Yes	48	42.1
No	53	46.5
Not sure	12	10.5
Missing data	1	0.9

Question 15 Time

(For how long did you have Tamoxifen?)

Response	Number (n=114)	Response %
Not Taking	64	56.1
Ongoing treatment	38	33.3
10-30 weeks	4	3.6
52 weeks	1	0.85
100-130 weeks	3	2.7
131-160 weeks	1	0.85
Missing Data	3	2.6

Question 15 - Year

Response	Number (n=114)	Response %
No tamoxifen	64	56.1
1986-1990	9	6.9
1991-1995	39	34.21
Missing data	1	0.9

Question 16 Chemotherapy

(Have you had chemotherapy after your breast surgery?)

Response	Number (n=114)	Response %
Yes	40	35.1
No	60	52.6
Unsure	13	11.4
Missing data	1	0.9

Question 18

(The initial year of chemotherapy.)

Response	Number (n=114)	Response %
Not chemotherapy	72	63.2
1955-1980	2	1.8
1981-1985	1	0.9
1986-1990	7	6.10
1991-1995	30	26.3
Missing data	2	1.8

Question 18

(Subsequent years of Chemotherapy - 1st subsequent year)

Response	Number (n=114)	Response %
No chemotherapy	106	93.0
1980-1990	2	1.8
1991-1995	5	4.3
Missing data	1	0.9

Question 18

(2nd subsequent year of chemotherapy)

Response	Number (n=114)	Response %
No chemotherapy	111	97.4
1995	1	0.9
Missing data	2	1.7

Question 18

(3rd subsequent year)

No respondents were on this phase of chemotherapy.

Question 19

(How long did you have chemotherapy after your surgery?)

Response	Number (n=114)	Response %
No chemotherapy	73	64.0
3-12 weeks	4	3.5
13-24 weeks	34	29.8
25-36 weeks	1	0.9
37-48 weeks	1	0.9
Missing data	1	0.9

Question 20

(Did you have wound healing problems after your surgery?)

Response	Number (n=114)	Response %
Yes	17	14.9
No	96	84.21
Unsure	1	0.9

Question 20.1

(If yes to Question 20 please explain type of healing problem.)

Response	Number	Response %
No problems	94	82.5
Infection	5	4.4
Infection and swelling	8	7.0
Wound breakdown leaving bad scarring	6	5.3
Radiotherapy burn	1	0.8

Question 21

(Were you given post operative exercises?)

Response	Number (n=114)	Response %
Yes	79	69.3
No	34	29.8
Don't know	1	0.9

Question 21.1

(If you were given exercises did you do the exercises?)

Response	Number (n=114)	Response %
No exercises given	35	30.7
Yes	78	68.4
No	1	0.9

Question 21.2

(If yes, how long did you do the exercises for?)

Response	Number (n=114)	Response %
No exercises done/given	36	31.6
1-10 weeks	31	27.2
11-20 weeks	14	12.3
21-30 weeks	12	10.5
31-50 weeks	3	2.6
51-60 weeks	7	6.1
> 61 weeks	5	4.4
Missing data	6	5.3

Question 21.3

(What type of exercises were you given?)

Response	Number (n=114)	Response %
No exercises	34	29.8
Arm exercises	46	40.3
Shoulder exercises	2	1.8
Arm & shoulder exercises	2	1.8
Finger and arm exercises	16	14.0
Swimming	1	0.9
Physiotherapy	8	7.0
Own exercises	3	2.6
Missing data	2	1.8

Question 22

(Were you given enough information before your surgery to prepare you for surgery?)

Response	Number (n=114)	Response %
Yes	78	68.4
No	34	29.8
Missing data	2	1.8

Question 23

(Were you told of the possible complications you may have after surgery?)

Response	Number (n=114)	Response %
Yes	54	47.4
No	59	51.8
Missing data	1	0.9

Question 24

(Were you informed before your Breast Surgery that you may get Lymphoedema after Surgery?)

Response	Number (n=114)	Response %
Yes	33	28.9
No	76	66.7
Not sure	5	4.4

Question 25

(If you have had a mastectomy, did you experience any feelings of your breast being still there ['phantom breast'] after your surgery?)

Response	Number (n=114)	Response %
Yes	26	22.8
No	48	42.1
Don't know	3	2.6
Missing data	37	32.5

Question 26

(If yes, was the feeling associated with pain?)

Response	Number (n=26)	Response %
Yes	9	34.6
No	16	61.5
Don't know	1	3.8

Question 27

(Following treatment for Breast Cancer did you get/have any of the following?)

Infection?

Response	Number (n=114)	Response %
Yes	12	10.5
No	98	86.0
Missing data	4	3.5

Question 27.1

Injury to Arm?

Response	Number (n=114)	Response %
Yes	11	9.6
No	93	81.6
Not sure	1	0.9
Missing data	9	7.9

Question 27.2

Broken Arm?

Response	Number (n=114)	Response %
Yes	1	0.9
No	99	86.8
Missing data	14	12.3

Question 27.2.1

Year of Broken Arm?

Response	Number (n=114)	Response %
No breaks	109	95.6
1989	1	0.9
Missing data	4	3.5

Question 27.3

Burns to arm?

Response	Number (n=114)	Response %
Yes	1	0.9
No	99	86.8
Missing data	14	12.3

Question 27.3.1

Year of Burns?

No data was given for the one patient who indicated having been burnt.

Question 27.4

Cuts to arm?

Response	Number (n=114)	Response %
Yes	2	1.7
No	3	2.6
Missing data	109	95.6

Question 27.4.1

Year of cuts?

Response	Number (n=2)	Response %
1992	1	50.0
Missing data	1	50.0

Question 27.5

Insect Bites?

Response	Number (n=114)	Response %
Yes	5	4.4
No	96	84.2
Missing data	13	11.4

Question 27.5.1

Year of Bites?

Response	Number (n=5)	Response %
1987-1990	2	40.0
1991-1995	2	40.0
Missing data	1	20.0

Question 27.6

Other happenings to arm?

Response	Number (n=114)	Response %
No other happenings	104	91.2
Arm pain	1	0.9
Radiation burns & skin breakdown	1	0.9
Bruising	1	0.9
Shoulder problems	2	1.7
Arm weakness & shoulder pain	1	0.9
Missing data	4	3.5

Question 28

(Your mobility and movement?)

Response	Number	Response %
No problems	108	94.7
Walk with assistance	4	3.5
Missing data	2	1.8

Question 29

(Your own self Care?)

Response	Number	Response %
No problems	107	93.9
Some problems	4	3.5
Missing data	3	2.6

Question 30

(Usual activities?)

Response	Number (n=114)	Response %
No problems	87	76.3
Some problems	25	21.9
Missing data	2	1.8

Question 30.1

(Other problems not listed?)

Response	Number (n=114)	Response %
No other problems	85	74.6
Stretching, lifting, reaching	6	5.2
Constant moving eg. Ironing	8	7.0
Increased pain and swelling	5	4.4
Arm weakness	4	3.5
Other disease conditions	1	0.9
Can't do anything	1	0.9
Missing data	4	3.5

Question 31

(Your pain/discomfort level?)

Response	Number (n=114)	Response %
None	59	51.8
Moderate	44	38.6
Extreme	2	1.8
Missing data	9	7.8

Question 32

(Your anxiety/depression level?)

Response	Number (n=114)	Response %
Nil	76	66.7
Moderate	31	27.2
Extreme	3	2.6
Missing data	4	3.5

Question 33

(Compared with my general health over the past 12 months, my health state today is:)

Response	Number (n=114)	Response %
Better	42	36.8
Same	63	55.3
Worse	7	6.1
Missing data	2	1.8

Question 34

(Have you had swelling in the arm on the affected side since surgery?)

Response	Number (n=114)	Response %
Yes	57	50.0
No	56	49.1
Missing data	1	0.9

Question 34.1

(If yes, how much?)

Response	Number (n=114)	Response %
Nil	57	50.0
Little	37	32.5
Moderate	13	11.4
Considerable	4	3.5
Missing data	3	2.6

Question 35

(How long after Breast Surgery did you notice swelling in your arm?)

Response	Number (n=114)	Response %
No swelling	51	44.7
0-6 weeks	16	14.0
7-12 weeks	9	7.9
13 weeks - 6 months	2	1.8
7-12 months	11	9.7
2-3 years	10	8.8
6-7 years	3	2.6
Missing data	12	10.5

(The following questions were analysed using only respondents who answered YES to Q.34)

Question 36

(Has the swelling been diagnosed as lymphoedema?)

Response	Number (n=57)	Response %
Yes	23	40.4
No	22	38.6
Not sure	6	10.5
Missing data	6	10.5

Question 37

(How long has swelling lasted?)

Response	Number (n=57)	Response %
0-6 weeks	14	24.6
7-12 weeks	3	5.3
13 weeks - months	2	3.5
7-12 months	8	14.0
2-3 years	9	15.8
4-5 years	4	7.0
6-7 years	2	3.5
8-9 years	1	1.8
>10 years	4	7.0
Missing data	9	15.8
Unsure	1	1.8

Question 38

(What symptoms did you notice (if any) in addition to the swelling?)

Response	Number (n=57)	Response %
Nil	28	49.1
Discomfort	5	8.8
Pain	6	10.5
Pain & discomfort	2	3.5
Swelling	1	1.8
Numbness	5	8.8
Pain & numbness	4	7.0
Missing data	6	10.5

Question 39

(Have you had any treatment for your lymphoedema?)

Response	Number (n=57)	Response %
Yes	25	43.9
No	25	13.9
Missing data	7	12.3

Question 39.1

(If yes which of the following treatments have you had?)

Response	Number (n=57)	Response %
No treatment	24	42.1
Compression sleeve	4	7.0
Massage	5	8.8
Surgery	1	1.8
Pump & massage	4	7.0
Sleeve/pump	1	1.8
Sleeve/pump/massage	3	5.3
Bandage/sleeve/pump	3	5.3
Bandage/pump/massage	1	1.8
Squeeze tennis ball	5	8.8
Missing data	6	10.5

Question 40.1

(What things seem to affect the Lymphoedema?)

Response	Number (n=57)	Response %
Nothing	3	5.3
Overuse	16	28.1
Airflights	3	5.3
Weather	5	8.8
Weather & overuse	4	7.0
Inactivity	3	5.3
Airflights & overuse	1	1.8
Hormones	1	1.8
Missing data	21	36.8

Question 40.2

(What helps or relieves your lymphoedema?)

Response	Number (n=57)	Response %
Nothing	8	14.0
Rest	2	3.5
Elevation	2	3.5
Rest & elevation	5	8.8
Pressure sleeve/treatment	12	21.1
Exercise	3	5.3
Cool weather	1	1.8
Medication - lymphod	1	1.8
Rest & treatment	1	1.8
Missing data	22	38.6

Question 41

(Has your Lymphoedema affected your daily living?)

Response	Number (n=57)	Response %
Yes	10	17.5
No	31	54.4
Not sure	2	3.5
Missing data	14	24.6

Question 41.1

(If yes, in what specific way?)

Response	Number (n=57)	Response %
Decreased self esteem	6	60.0
Prevention from doing heavy duties	3	30.0
Unsatisfactory treatment	1	10.0

Question 42

(Do you feel that you have been given enough information about Lymphoedema?)

Response	Number (n=57)	Response %
Yes	18	31.6
No	28	49.1
Not sure	5	8.8
Missing data	6	10.5

Question 42.1

(If No, what further information would you have found helpful?)

Response	Number (n=57)	Response %
Information on complications	11	39.3
Support groups	2	7.1
General information	6	21.4
Coping mechanisms	1	3.6
Missing data	8	28.6

Question 43

(Are you aware of the Lymphoedema Society?)

Response	Number (n=57)	Response %
Yes	26	45.6
No	22	38.6
Missing data	9	15.8