



Life, Love, Lymphoedema

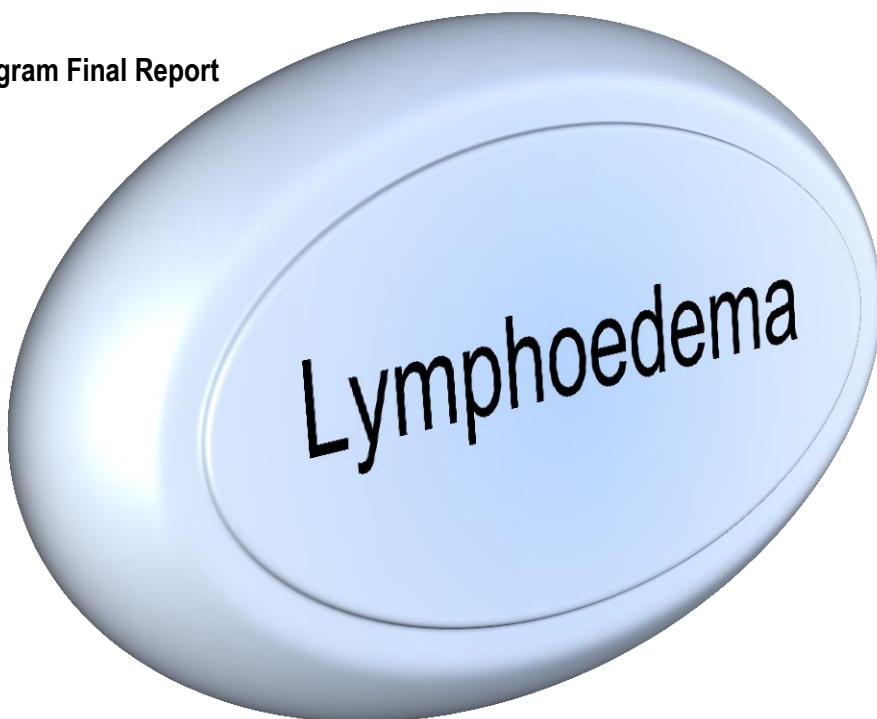
Let's Get On With It

A Rural Cancer Patient Experience

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ABBREVIATIONS

BCRL Breast Cancer Related Lymphoedema

ALND Axillary Lymph Node Dissection

SNB Sentinel Node Biopsy

BMI Body Mass Index

CLT Complex Lymphatic Therapy

ISLHD Illawarra Shoalhaven Local Health District

ALA Australian Lymphology Association

QoL Quality of Life

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ABSTRACT

Background: Rural Cancer Survivors often have limited access to medical follow up. With best practice management of lymphoedema strongly linked to early detection and intervention, this cohort of patients require the knowledge of lymphoedema, prevention strategies, local service availability and the self-efficacy to seek assistance. This qualitative research project seeks to explore the rural cancer patients' experience of living with lymphoedema.

Methods: Phenomenology was used to explore participants' life experiences learning of lymphoedema and living with lymphoedema. The participants were randomly selected from a small rural lymphoedema clinic, having attended in the last 12 months. Semi structured interviews were used to capture participant experiences of living with lymphoedema.

Findings: Eight semi structured in-depth interviews were conducted and transcribed verbatim. Three broad themes emerged; Life, Love, and Lymphoedema. These participants reported living very full and active lives, well supported by family, friends and the community. Despite this, they felt support from the medical fraternity was inconsistent. Access to a publicly funded ongoing lymphoedema service for review was a welcome safety net, enabling them to confidently seek reassurance and treatment if required.

Conclusion: This study focuses on the experiences of rural cancer patients. The findings add to the rich growing body of qualitative research giving insight into the daily lives of cancer survivors. Mixed methodology research may assist in developing an assessment tool to include the more holistic social paradigm of healthcare; assisting in identifying those most at risk of lymphoedema distress following treatment for cancer. Further dissemination of evidence based information regarding lymphoedema is required for clinicians caring for those at risk of and with lymphoedema.

Key words: Lymphoedema, Quality of Life, Survivorship, Qualitative, Lived Experience, Cancer

EXECUTIVE SUMMARY

Why was this study done?

It's not all about numbers. As an experienced generalist Physiotherapist venturing into the domain of Lymphoedema Management and cancer rehabilitation some seven years ago, it was obvious fairly quickly that symptoms and distress in lymphoedema, like many other chronic disorders is not always matched by objective findings. A patient with a hugely swollen limb may attend for a garment measure almost as an inconvenience, as there are many more important life issues to for them to attend to. This could be followed by someone with a minimally (objective measure by therapist) swollen limb most distressed that lymphoedema was stopping them from attending to their grandchildren. Obviously these are two extremes in presentation.

In the biomedical model of healthcare, treatment success is usually measured in lymphoedema management with percentage reductions, supply of a garment, with some attention to improvements in function and symptomatic relief. Remembering that a limb is attached and belongs to the person is sometimes overlooked. Lymphoedema and its implications are interpreted and imposed upon oneself differently, possibly depending on social construct – the how and why people make sense of things.

This study aims to explore what it is like to live with lymphoedema, how it affects people on a daily basis, the life experience, and in doing so enable service delivery review from a more holistic viewpoint.

What did this study find and what does this study mean?

The findings of this study are reported under three main themes; Life, Love and Lymphoedema. For the most part the participants were living full and busy lives, confidently managing their lymphoedema with the knowledge they could seek review with the lymphoedema therapist if required. The participants were well supported by loved ones and the community. Despite this, they felt frustrated that at times information and support from the medical team was inconsistent, inaccurate or absent.

This study shows that a group of rural NSW cancer survivors with lymphoedema who have access to a lymphoedema service are doing well. These patients could teach us more about which specific skills and resources have assisted them to adjust to life beyond cancer and lymphoedema.

The research evidence base for lymphoedema risk and management guidelines have undergone a monumental shift from avoidance behaviour to proactive lifestyle behaviour change. Consensus suggests we should be hesitant to label all swelling in those at risk as lymphoedema, a chronic condition. Emerging evidence suggests that early swelling often resolves without treatment. Complicating this further is the knowledge that early intervention is likely to improve outcomes. Obviously it is complex and contextualising the evidence is important, although difficult given knowledge bases amongst professionals are inconsistent. Most likely this is adding to the perception that health professionals have not got their act together.

How was the study conducted?

This qualitative project was approached from the relative perspective where an individual exists in a social world and so thinks and experiences situations from the unique individual perspective. Phenomenology was the methodology chosen as it is powerful for understanding the subjective experience and allows the opportunity to explore a wide range of patient experiences, behaviours and motivations.

To collect the data, open ended questioning was required and semi-structured interviews were used. Purposive sampling ensured both upper and lower limb lymphoedema patients that had accessed the Physiotherapy department in either Milton or Shoalhaven Hospitals were invited to participate. Systems to prevent coercion issues were implemented as the researcher/interviewer was known to the participants. Eight interviews were undertaken, recorded and then transcribed verbatim by the researcher.

Data Analysis involved reading and rereading the transcriptions, using open coding to organise, construct and deconstruct ideas into categories and themes, always remaining true to the data. Preliminary findings were presented at the Australasian Lymphology Conference in April 2014 enabling likeminded clinicians to brainstorm themes and ideas.

Where to from here – future recommendations?

At the local level the Physiotherapy department at Shoalhaven District Memorial Hospital (SDMH), with outreach to Milton-Ulladulla Hospital will continue to provide a surveillance model of care for the education, monitoring, assessment and treatment of cancer patients at risk of lymphoedema in the Shoalhaven. The psychosocial model of healthcare giving consideration of the whole person, not just the limb will continue to be employed. Education of local clinicians and the community will continue emphasising present research evidence in a pragmatic way.

At the department level, it is suggested a review of services currently available would be appropriate to ascertain present service availability and funding support, with barriers for both therapists and clients identified. This may assist to provide strategic direction in the management of lymphoedema in NSW in a fair and equitable manner. The knowledge base across all clinicians involved with patients at risk of and with lymphoedema requires review. This information would guide the department in the development of targeted learning modules.

At an academic level, mixed methodology research including social paradigms will assist in moving away from the biomedical healthcare model. Further research into groups of cancer survivors with lymphoedema presently coping well would assist in identifying personal skills and attributes that may assist in the development of tools to help those that don't.

INTRODUCTION

The rural health directorate of the Illawarra Shoalhaven Local Health District (ISLHD) encompasses the Shoalhaven Local Government Area, on the South Coast of New South Wales. It is bounded by the towns of Berry in the north, Kangaroo Valley and the Great Diving Range to the west, and North Durras some 143kms south.

Within the physiotherapy department at SDMH, in Nowra, the lymphoedema service operates, staffed by one fulltime lymphoedema trained Physiotherapist. When reflecting upon the service needs of this community, anecdotal evidence suggests significant variation in the physical and psychosocial needs of individuals with similar diagnosis and lymphoedema presentation. Patient symptoms, distress, and function do not always match objective data. Lymphoedema trained therapists tend to focus on limb volumes, which may not give a true picture of patient perceived treatment outcomes or the level of support they require.

Early intervention in the treatment of lymphoedema is considered best practice (1), however identification and referral is not always timely. Knowledge of lymphoedema in both the medical and patient population is inconsistent. This project sets out to explore the lived experience of lymphoedema, of patients receiving treatment in a rural setting, in order to increase our knowledge and understanding of this complex health issue. This will assist in future health service delivery decisions.

BACKGROUND

Lymphoedema has been reported as the most feared complication of the surgical treatment for breast cancer (2-4). It is a chronic condition characterised by a progressive swelling, and may involve the head and neck, upper or lower limbs, breast, chest, pelvis, or genitals. The swelling occurs when protein-rich fluid accumulates in the interstitial spaces of predominantly the skin (5). Lymphoedema is classified as primary or secondary. Primary lymphoedema occurs when lymph nodes and lymph vessels are either abnormal or absent. It is a rare inherited disorder. Secondary lymphoedema is a condition commonly encountered following the treatment for cancer as a result of removal or damage to lymph nodes and vessels from surgery, and radiotherapy. This study focusses on secondary lymphoedema following cancer treatments. It is reported to have far reaching effects on physical and psychosocial well-being, as well as overall quality of life (QoL) (6).

The incidence of lymphoedema following cancer treatment is conservatively reported to be 20%, but this varies with malignancy. Breast Cancer Related Lymphoedema (BCRL) of the arm incidence is more than one in five, possibly as high as 42% (7-12), and overall lower limb lymphoedema following cancer surgery incidence suggests 19.6%. Lower limb swelling following gynecological surgery for cancer was 21.8% for cervical and 24.9% for vulvar cancer (13). The incidence of lower limb swelling following uterine cancer has been reported as high as 37% (14). The actual incidence may well be much higher as research models lack consistency in classification and definition of lymphoedema, and length of surveillance (7, 13). Further to this early research evidence is emerging of a possible genetic predisposition to lymphoedema following lymph node surgery but remains in its infancy (15).

The Australian Institute of Health and Welfare (AIHW) suggests that approximately 128,000 new cancers will be diagnosed this year (16), with around 41% having a 20% risk of lymphoedema. This equates to 52,000 people at risk. With drastically improved cancer survival rates this equates to an ever increasing number of people at risk of or with lymphoedema.

Lymphoedema is associated with many physical and psychological challenges affecting quality of life and general well-being. Limb swelling, tightness, heaviness, numbness, joint restriction, skin changes, pain, and increased risk of infection are among the physical consequences (12, 17-19). Also reported is the effect on social, emotional, body image, appearance, and sexuality dimensions of lymphoedema survivors (20). Specific treatment aims at minimising the lymphatic load on a compromised lymph transport system and involves healthy lifestyle choices for risk reduction and complex lymphatic therapy (CLT) for the management of lymphatic overload. Complex lymphatic therapy is a two part process of treatment followed by maintenance and includes skin care, bandaging, massage and exercise, with bandaging being replaced by compression garments in the self-management maintenance phase (21, 22). Further to this, musculoskeletal issues of joint range and function, muscle strengthening and cardiovascular fitness need addressing, along with psychosocial assessment.

Present assessment and treatment guidelines for the management of lymphoedema are underpinned by the principle that lymphoedema is an incurable condition. Early identification and treatment is paramount in achieving best outcomes (1). Early identification requires an adequate level of knowledge within the medical team – surgeons, general practitioners, nurses, allied health practitioners, and oncologists; ensuring patients are educated with the right information at the right time. Appropriate and timely referral to a lymphoedema therapist is required and clearly this is lacking (6, 19, 23, 24). Recent research reports that up to 78% of cancer survivors (at risk of lower limb lymphoedema) being unsure of or having never heard about lymphoedema (19). This may in fact be more of a problem of timing, rather than information void, as too much too soon (*information*) is a well-documented research finding (25-29). Less immediate, less urgent, less life threatening information may not be appreciated or even recalled by these patients (29).

Rurality has generally been associated with poorer health outcomes (16, 30). Cancer patients living in rural areas are more likely to present at later stage of diagnosis and possibly have delays in receiving treatment. Surgery options may be restricted resulting in more invasive surgery, and treatment options also limited (23, 24). Increased risk for lymphoedema is associated with this and BCRL risk is increased fourfold with axillary lymph node dissection (ALND), compared with sentinel node biopsy (SNB). There is also strong evidence for increased risk associated with increased BMI and sedentary lifestyle (7).

Inequalities in rural areas are well documented in the domains of physical and daily living, and barriers in accessing treatment for cancer patients (23, 31-35). Poor coordination of care, and the need to source one's own support networks have also been reported (36). Across Australia there is a wide variation in service availability and significant barriers are reported when accessing lymphoedema management, where 20% of patients with lymphoedema were unable to access a therapist in major cities, compared with 25% and 44% in inner regional and outer regional areas of Australia respectively. Other barriers included cost, distance to travel and not knowing where to get help (32).

Quantitative research investigating lymphoedema has focused on reporting the incidence, occurrence, severity and distress related to symptoms, through their effect on health related QoL, using self-report QoL surveys (18, 23, 37-41). Inequalities in QoL when living with lymphoedema have been more closely related to age rather than rurality, with younger people generally fairing worse (given they are likely to be diagnosed with more aggressive cancer requiring more intensive initial and adjuvant treatment), those who had high amounts of stress, and those who had less confidence handling stress (including their own health). Those with poorer social structure also report poorer QoL (23). Breast cancer patients most vulnerable are reported to be younger, more likely to be in the workforce and have increased responsibilities in the home. They also have fewer life experiences for coping (38). This provides insight into which groups of survivors need closer surveillance as they may well be likely to encounter more survivorship issues, given the provision of reassurance helps patients adjust to illness (27, 28).

This data gives us invaluable information on lymphoedema symptoms however it does not explore the effect of lymphoedema in cancer survivors on a daily basis – the lived experience. Qualitative studies have been undertaken investigating the lived experience of lymphoedema (6, 34, 42-47). Interviews were used for data collection in all but one study, in which case diary entries were used. Of the seven studies examined five explored BCRL exclusively, with the other two including lower limb lymphoedema. The vast majority of participants were Breast Cancer Survivors – 118 of a possible 128. There is an obvious absence of research in the domain of lower limb lymphoedema. All reported the consistent thread of abandonment by medicine, loss of normalcy, body image disturbances, constant searching for treatment options, information void and inconsistency. Financial burden and poor access to services was also a predominant finding. Every study concluded there is a great need for lifting the profile of lymphoedema amongst those caring for this cohort of cancer survivors, improving the awareness and management of the physical and psychosocial aspects of living with lymphoedema.

To date there is little evidence of research into the lived experience of lymphoedema for rural cancer survivors in Australia. Increasing our knowledge in this area will assist in establishing an evidence base for improving care, whereby patient accounts and recommendations should not be underestimated (36).

The purpose of this study was to explore the lived experience of lymphoedema in the bush, to learn more about how lymphoedema affects cancer patients on a daily basis living outside metropolitan areas, in an attempt to identify any key areas and ideas for improved lymphoedema service design to improve outcomes for this cohort of people.

THEORETICAL FRAMEWORK

This qualitative research project uses a constructivist approach to inform the research, acknowledging the relativist perspective, where an individual exists in a unique social or life world and as such interprets thoughts and experiences from an individual perspective (German Philosopher Edmund Husserl (1859-1938))(48).

The strategy chosen to investigate the lived experience of the participants is Phenomenology. This methodology is powerful for understanding the subjective experience and allows the opportunity to explore the diverse range of participant experiences, behaviours and motivations, increasing the complexity and depth of the researchers understanding and hence knowledge (49). It allows the researcher to consider both the *what* of the experience and the *how* of the experience (48). As a clinician (experienced Lymphoedema Physiotherapist) the novice researcher was an inherent, active component of the knowledge generated. Constant reflexivity was required, taking care to put aside, or at least acknowledge personal subjectivity in order to accurately uncover the core or meaning of the participants' experience.

Lester suggests that adding an interpretive dimension to phenomenological research allows it to inform, support or challenge policy and action (50), meeting the study objectives.

METHOD

Sample

The southern Shoalhaven on the South Coast of NSW was the location for data collection. The Australian Standard Geographical Remoteness Area classes this area as Inner Regional.

Purposive sampling was used to achieve maximum variability, helping to understand a wide range of what happens and what things mean. Recruitment was via a sample of rural cancer patients that had had lymph node dissection with consequential risk of lymphoedema, identified from the Shoalhaven and Milton Lymphoedema Physiotherapy Clinic records. Patients were identified having attended the clinic in the preceding 12 months, and had completed chemotherapy and radiotherapy if required. They may or may not have developed lymphoedema. Surgery may or may not have occurred in the Illawarra Shoalhaven Local Health District (ISLHD). The sample was to include both male and female adult patients of mixed diagnosis, and it was hoped to achieve 50/50 recruitment of breast cancer and non-breast cancer patients, including both upper and lower limb lymphoedemas.

A list of 30 potential participants (initially identified by the researcher and de-identified by way of number) was given to the independent assistant. Initial contact with 10 random potential participants was via post - the patient information sheet seeking willingness to participate. The researcher was unaware of which patients were contacted, apart from those that replied, preventing coercion issues. Willing participants were provided with the consent form by mail to review prior to meeting for the interview, and an interview time was organised, in a place convenient to participant. Participants were encouraged to have a carer or support person present if they chose.

Recruiting for interviews was ceased once a wide range of rich data was collected, sufficient to answer the research question, with an upper limit of 10 interviews in order to stay within the constraints of the research work and timeframe.

Prior to commencement of recruitment, ethics approval was sought from University of Wollongong Human Research Ethics Committee and granted, approval number HE13/256.

Data Collection

With informed consent obtained, data collection commenced by way of semi-structured interviews using open ended questions. This allowed for open data collecting, remaining flexible to pursue new leads as they emerged.

In the interview, participants were asked questions related to their cancer journey, their knowledge of lymphoedema, learning about lymphoedema, and the impact of lymphoedema on their lives; how lymphoedema affected their life on a daily basis. During the interview the researcher clarified thoughts and ideas with the participants. Interview duration was 45-75 minutes. The interviews were recorded using a digital audio recording device, transcribed verbatim manually, and checked for accuracy by the researcher within two weeks of the interview. The recordings were then deleted. The transcripts were de-identified, coded, and analysed for emergent themes. The transcribed data is stored electronically and password secured.

A field note journal was kept and was also included in the analysis to assist in the interpretation of data collected and to encourage reflexivity on the part of the researcher.

Data Analysis

As an experienced Physiotherapist, whose clinical reasoning skills have been very much shaped by random controlled trials and evidence based practice, this was by far the most challenging experience albeit rewarding for the novice researcher. The interview process was very humbling, with participants willingly sharing at times very private thoughts and reflections around topics and times of great confrontation and confusion.

Dickie (51) suggests that when analysing data in qualitative research the researcher should report an accurate and honest account of the process. Subjectivity is thought of as a strength of qualitative analysis (52, 53) and the challenge is “not to get it all wrong”. This analysis aims to achieve both and in the process stay true and faithful to the data.

The process of data analysis commenced immediately upon typing the transcripts verbatim. Typing and rereading was an opportunity to think. First impressions were gathered along with ideas around what the participants did not talk about – or want to expand upon.

The process continued with the highlighting of phrases, writing key points in margins, and making notes to self. Sticky notes helped organise key points around headings, organising and reorganising. Flow diagrams were constructed and deconstructed defining categories. Calculated chaos (54, 55) helped define the questions to guide the analysis (51). Interested colleagues were then “talked at” (51) allowing the opportunity to organise ideas into coherent themes. Preliminary findings were presented by the researcher at the Australasian Lymphology Conference in April 2014, also giving an opportunity to engage other likeminded clinicians, eager to brainstorm and verify the findings.

FINDINGS

Recruitment into the study was not difficult with six responses for interview within four days of the initial mailout. The initial six responses were from women, with upper limb lymphoedemas also being over represented. The second mailout was specifically to men, and women with lower limb lymphoedemas. A further two interviews were undertaken with a large amount of rich data collected. Maximum variation was not achieved as no males responded to the invitation to participate, however women with both lower and upper limb lymphoedemas were represented. All had lymphoedema except one, with her being at risk of BCRL. The time since diagnosis of both cancer and lymphoedema varied (Table 1), and the severity of lymphoedema ranged from mild to moderate. Although participants received their initial diagnosis locally, most were required to travel for surgical intervention. Oncology consultations involved travel to tertiary hospitals, and radiation interventions took place there also.

Two participants were still in the paid workforce, with several others providing childcare for grandchildren or caring for ageing partners. There was a range of socioeconomic and educational background.

The participants were very enthusiastic about being involved, and eager to have their stories heard. All participants except one insisted on meeting at the hospital for the interview, the other taking place in their own home and on that one occasion a support person was present. These women felt very comfortable meeting at the hospital and were concerned with practical and time considerations for the researcher rather than themselves; this group all lived outside the “local” township where the hospital was situated, and involves a 40-140 km round trip to access the lymphoedema service.

Table 1 Participant characteristics

Participant Characteristics	
Participants	n=8
Age	Mean=67yrs Range 53-84yrs
Cancer Diagnosis	
Breast	n=5
Gynecological	n=2
Other-Sarcoma	n=1
Time elapsed since Ca diagnosis	Mean=10.5yrs Range=1-23yrs
Duration since L/O diagnosis	Mean=7.6yrs Range=6mths-22yrs

NB 1 participant was at risk of L/O, but hadn't developed L/O

Three broad themes of Life, Love and Lymphoedema have been chosen to present the findings.

Life

The findings suggest that these women generally do not live as or consider themselves disabled people. Lymphoedema is not something that is going to stop them from living busy and fulfilling lives.

The participants all reflected on their cancer journey with a strong sense of survival. They have through their life journeys endured many challenges and this was no different to any other. Lymphoedema is a constant reminder of the places they have been, the confronting mortality issues associated with cancer and its treatments. Disfiguring and extensive surgery rendered them vulnerable to fear and panic, when at times they were very much unaware of their prognosis. Each woman talked of life events – some losing life partners and children unexpectedly in tragic circumstances, significant personal or family health battles and the corresponding economic issues, the experience of which has assisted them in developing the skills to tackle head on further challenges.

Each problem you come to you work your way through. It just...we'll get through this and go on. That's the way I am approaching it. The main thing is to keep trying....whatever. I wanted to live. Janet

The women repeatedly reported that although they had a swollen limb it was not going to stop them from getting on with life. For them lymphoedema fell into perspective within the “big picture” of life, whereby perhaps there is a shift in these people’s thinking.

You know it doesn't worry me. I'm still alive that's what I keep thinking. There are a lot of people worse than me. I've seen people with both Legs (lymphoedema present). The lymphoedema hasn't held me back from doing anything. I still do everything I want. You just deal with it. You haven't got a lot of choices. Joan

This shift response suggests patients with a favourable prognosis may in fact change their appreciation in QoL given their past experiences or close call with cancer. Beatty et al in their Australian study reported cancer survivors with a new perspective on and appreciation for life, with an improved inner strength and ability to cope (56). De Viries (34) reported patients with lymphoedema following melanoma reported higher QoL scores than the normal population, and long term cancer survivors in Australia also reported higher levels of QoL, than the general population, reporting “no issues, doing well”, and “no need for help” (57, 58). Interestingly in these studies there was no association of rurality and unmet needs. This sub-group of survivors could provide valuable insight into ways people cope (58), possibly with transferability to those developing lymphoedema.

The women expressed a strong sense of self and feel confident to tackle healthcare systems if required. All found their cancer diagnosis and consequential experience extremely confronting and frightening. Communication with surgeons and oncologists was reported as disappointing with results, prognosis and ongoing care sometimes delayed and clear information not forthcoming. Survival instincts resulted in new levels of personal assertiveness which also fostered some level of personal control.

You can fight for your own healthcare. You need to.....We need to fight; we need to fight for ourselves. Joanne

Although this personal sense of control ebbs and flows, with external support self-belief is fostered allowing them to complete tasks and reach goals. Psychologist Albert Bandura suggests persons with high self-efficacy (the belief you can perform well) are more likely to face difficult tasks as something to be mastered rather than avoided (59). The participants all confidently tackle life, knowing at times some things need modification to allow for their lymphoedematous limb, all the while knowing they can seek assistance as or if required. Participants spoke of ways they have managed the ongoing problem of lymphoedema describing coping mechanisms helping them adapt both to changed appearance and physical limitations. This allows them to contribute to the family in a way they can manage that is also meaningful for them.

I want to help move stuff, heavy stuff, but I can't do it. That to me was....I used to thrive on doing physical things.....but because I can't do that anymore I feel like I'm not helping. So I got to help with other things, so I clean. Cause I can't lift, it's my way of helping. Jenny

It is evident that personal resilience is high in this group of women. Resilience is a complex concept, but is generally described as the notion of overcoming adversity, and the associated growth and adaption following significant stressors. There are most certainly personal attributes and environmental issues at play, and these are central to resiliency (60).

Love

Significant Others

The women spoke of a strong personal support crew and included partners, friends, and work colleagues. This support encompasses many dimensions and includes the physical, emotional and spiritual domains. The women spoke of circumstances whereby those closest to them assisted

"we clawed our way back (Joan)" and "we didn't shirk anything (Jill)"

In the initial stages a protective cocoon was formed by these people, providing the scaffold for both physical and spiritual recovery. The optimism these structures provided was clearly evident, and permeated through to the patient giving them the confidence and support to consider and achieve some sense of personal autonomy.

Support Groups

All women that had attended support groups spoke very positively of the many benefits they provide. Clearly it helped to know they were not dealing with the issue alone. The group provided a forum whereby the women could exchange ideas and experiences with experts on the ground, those who also walked their walk.

I didn't realize that other people had it. It was through talking with other people and getting their experiences ofyeah you get swelling worse in the summer and that, so I could expect that that would happen. Janice

This source of information was considered very credible. The friendships and support forged in these unusual but similar circumstances were treasured by their owners. For those with lower limb lymphoedema internet chat rooms provided a source of reassurance as there are no support groups for these people locally. The virtual support group is a particularly helpful resource for those isolated by distance or health reasons, and requires further investigation.

Medical Team

Ladies reported interactions with the medical team as varied as they were numerous. They expected to find health professionals both supportive and caring. The participants did by no means have straight forward, coordinated episodes of care. Some interactions with doctors were described as

"casual", "lacksadaisy", "rude", "I was brushed aside", and "dismissive" Joan, Janice, Joanne, Jill

when patients were seeking cause and diagnosis of a swollen limb. They expressed concern, frustration and at times anger that the medical team was not supportive, caring, consistent or knowledgeable.

You weren't treated as a person, just a number. You are a whole person not just a limb. You need to be able to work with somebody that cares about you. Everybody is a somebody. Joanne

The women acknowledge that surgeons, medical oncologists, radiation oncologists and therapists are busy people but as health professionals it is our duty to promote patient autonomy by developing respectful, bilateral relationships enabling patients to develop and exercise self-governance skills both within and beyond health care visits (61). Regular contact with health professionals can help normalize the effects of lymphoedema and how it affects daily function, consistent with similar research into the side-effects of cancer and its treatments (56) whereby patients described the need for this support rather than interventions to reduce side-effects. The women are not looking for scape goats or to lay blame regarding the presence of lymphoedema but in fact welcome validation of their concerns regarding Lymphoedema and its effects on their lives.

There were however many times that the medical team was supportive and caring.....and accommodating. Confidence in the medical team certainly had a positive effect on outlook, particularly when the future looked bleak. Trust in a team leader is pivotal in successful negotiation of the health system at times of crisis and despair.

My GP is fantastic. You are scared. You have so many things to think of...so many things to do..... You have to rely on someone else. If you've got someone you trust that's the person you go to. Jane

General practitioners were held in very high regard and thankfully could offer life rafts and mend bridges damaged by colleagues.

Access to ongoing lymphoedema review is welcomed by these women.

Access.....helps my whole life. Yes. I get the right information. To keep everything going. Jess

Regular access is not taken for granted given Sierla's research whereby 1 in 3 rural ladies were unable to access lymphoedema review (32). In this Shoalhaven cohort barriers to access included inadequate and incorrect knowledge of lymphoedema whereby medical staff were unaware of lymphoedema management principles, and also the very existence of services. The local cancer network routinely refers clients with lymphoedema risk for review, however those traveling outside the local area for treatment can be and are often lost to follow-up. The women confirmed their resourcefulness with one lady observing an advertisement in the local paper for a lymphoedema therapist at the hospital and thereby locating the service, and others requesting referrals from general practitioners when specialists dismissed their concerns.

These ladies have access to a publicly funded service where the cost at present is limited to compression garment replacement. Garment expenses were included in family budget without hesitation from the family treasurer. For those on low income this is subsidised by EnableNSW but lengthy delays are often experienced in the first instance. Regular review ensures repeat orders are timely with the women most appreciative.

Distances travelled for lymphoedema review in this cohort is a 140km return trip, however no women described this as a barrier to attendance.

Lymphoedema

Although these ladies were living busy and fulfilling lives they do feel vulnerable when reflecting on their lymphoedema.

Information Dissemination

Initial information regarding lymphoedema risk and minimisation strategies was scarce with most women reporting a definite void of information. There is little recollection of their surgeon discussing the risks associated with lymph node resection prior to or after their surgery. It was acknowledged that "information overload" may have interfered with their ability to absorb information in this initial stressful phase.

You are worrying about everything then - you can't absorb all the fine details. You are worrying about recovery rather than...what might happen down the track. First you have to live. Jane

All reported feeling overwhelmed with the enormous amount of printed general literature received at this time, and felt that perhaps some of the more pertinent details are overlooked.

Inadequate, inconsistent and incorrect advice was a common thread with women reporting confusion around the identification of lymphoedema, lymphoedema risk minimisation and lymphoedema management strategies. Advice in this cohort was sought from the media, advocacy groups, internet sites, chat rooms and message boards, and well-meaning others increasing levels of distress and confusion. The women's frustrations regarding inadequate and inconsistent medical advice about lymphoedema and the risk of lymphoedema are understandable. It is also concerning given research findings of Breast cancer survivors who received information about BCRL appeared to have reduced symptoms and increased knowledge about BCRL, compared with the group that had information on lymphoedema withheld (62). Confusion can arise when transitioning from initial post-operative instructions to later stages of recovery, when recommendations change somewhat. Access to physiotherapy at this point assists with appropriate management and education.

It was evident that health professionals were not always fully informed with updated information, as patients reported incorrect advice and diagnosis, with this being reported previously (27). Information regarding lymphoedema and lymphoedema risk management traditionally emphasised avoidance behaviours, however more balanced advice that is consistent and accurate is required. The sources of incorrect advice were varied with doctors, nurses, massage therapists and allied health practitioners all implicated. Women spoke of occasions when treating surgeons and Professors contradicted the lymphoedema advice of treating lymphoedema therapists, creating unnecessary confusion and suspicion. In these circumstances the women were knowledgeable enough to recognise the inconsistencies but this would not always be the case.

The NSW Breast Cancer Institute updated their patient education material in 2006 to include evidence based guidelines, and Cancer Australia theirs in 2008. Further dissemination of these principles is required. There are no national guidelines for the management of lymphoedema, but therapist training endorsed by the Australasian Lymphology Association is based on an International Consensus document (21). Cancer Australia developed an extensive evidence-based learning package for Health Professionals in 2008 following a grant by the Australasian Government Department of Health and Ageing in June 2007, with accreditation by the Royal Australasian College of General Practitioners for QA and CPD in order to improve knowledge and management of secondary lymphoedema (63). It can be assumed given the findings of this report that health professionals don't access this plethora of information.

Community Reaction and Body Image

Participants reported community responses to their cancer diagnosis and particularly the wearing of compression garments confronting and unwelcome. They didn't feel ready to face the barrage of questions, particularly from strangers. Initially this harassment was completely outside their circle of control.

A lot of people don't know how to handle it still. Yes the cancer thing. A lot of people just don't know what to say next. Jenny

Some women now consider community reactions an opportunity to educate and advocate for others with cancer and lymphoedema, suggesting the health stigma or shame associated with breast cancer and lymphoedema is no longer as evident for them.

The women found it difficult to wear compression garments citing embarrassment, and the lack of privacy irritating. They found them uncomfortable and foreign, “my robot arm” but tolerated them knowing they were helping. Garments also reminded them of healthy lifestyle issues “my special arm”, encouraging them to take care of themselves. Limb size discrepancies and garments also caused clothing dilemmas, with restrictions on trouser style, sleeve length and fabric choices, in an attempt to hide swollen limbs. The practical consideration of needing to purchase two pair of shoes for feet of different size was also irritating and expensive.

Although mentioned the participants didn't linger on symptom distress, despite attempts by the researcher to delve further. It appeared that symptoms or exacerbations motivated them to remain focused on self-care measures and behaviours, promoting positive health behaviour change.

One participant spoke of her lymphoedema experience significantly different to the other ladies. Life and social circumstances were more difficult for her and her experience is one of extreme distress. The lymphoedema in her arm is mild, exacerbated by physical activity, and settles with manual lymphatic massage usually overnight. Her other arm is also at risk of lymphoedema.

“It haunts me you know. This lymphoedema, it rules my life. It does, it does. It is just a thing that doesn't go away. It's always a concern, it never goes away. It's like having dead arms; it's like having useless arms. They will never be 100%. It is so hard.” Jess

Levels of distress in the women did not appear to be related to severity of lymphoedema and this has also been reported elsewhere (33). Thomas-MacLean reported when investigating the relationships between arm morbidity and disability after breast cancer that pain and range of motion limitations correlated with disability rather than lymphoedema severity (70). The connection and possible misdiagnosis deserves further investigation. It is a complex picture including not only limb size but comorbidities, occupational and psychosocial issues along with the natural process of aging.

Research into lymphoedema treatment and management has for the most part focused on objective measures (limb volume, perometry, circumferences, bioimpedence), in keeping with the traditional model of biomedical health care. The “whole person” rather than “the lymphoedematous limb” needs to be front and central in the research question. It is likely that symptom burden is more closely linked to function and quality of life than limb volume and hence further research is required to develop and validate tools to assist clinicians in monitoring symptom burden and treatment outcomes. In this way it may also be possible to identify the more vulnerable or at risk people in this cohort, those requiring closer monitoring and assistance, aligning more consistently with a psychosocial model of healthcare.

Survivorship

On completion of treatment programs women felt relieved although somewhat abandoned.

“That was the end. That was the end of the treatment. That was it. There was no plan for follow-up.”

Joanne speaking of Lymphoedema management at a tertiary hospital

Lymphoedema is a chronic disorder with varied progression, and is not always predictable even with the most conscientious patient. The women remain fearful of lymphoedema, reporting it to be constant. Individual and ongoing review allows for tailoring and clarification of knowledge, giving an opportunity for correction of misinterpretation, enhancing autonomy and encouraging self-efficacy. They feel being connected with the lymphedema service promotes a healthy respect for their lymphoedematous limb and helps ease their discomfort of the unknown.

Ongoing reviews monitoring for the detection of early lymphoedema as suggested by the ALA provide an opportunity to not only identify physical changes in lymphatic flow but assist to further identify the more vulnerable group requiring further support. This regular contact also provides an opportunity to identify and address survivorship issues that are responsive to rehabilitation. Women spoke in hindsight of how grateful they were for encouragement and assistance with return to exercise, chores and work.

Survivorship care plans are now recognised as an integral part of cancer management where cancer is conceptualised as a chronic disease, promoting QoL, healthy lifestyle, and the prevention of other chronic diseases (67-69). Self-management is the cornerstone of chronic disease management but requires surveillance. Surveillance models including multidisciplinary care may help to identify the plethora of symptoms, physical and psychological following cancer and its treatment, which when addressed may lead to improved outcomes for those developing lymphoedema. Rural centres may be able to make use of Telehealth models to access multidisciplinary team members. Stronger ties with rural and regional clinicians would assist in preventing people being lost to follow-up when treatment has occurred in tertiary centres with improved local surveillance and access to local health professionals if required.

Locating lymphoedema services remain problematic as was evident with the women in this study. Presently there is no lymphoedema therapist register in the public health sector in NSW and it is likely that a number of clinicians are trained but not working primarily in this field. For example rural physiotherapists and occupational therapists attend extensive training in metropolitan centres, and return to their primary role where lymphoedema management is not deemed a priority within busy outpatient physiotherapy or occupational therapy departments when specific funding has not been allocated and no budget available for bandages or garments. Secondly lymphoedema management can be complicated, time consuming and challenging for the newly trained therapist, with the availability of supervision limited given no formal network identified. The impact of Activity Based Funding is yet to be felt, even in departments where specific lymphoedema therapist positions were previously funded.

Self-management is a core component in the management of lymphoedema, a chronic disease and perhaps these findings – those people with an extensive personal and professional network assisting with coping skills and surveillance, support the concept of self-management of lymphoedema for this group of cancer survivors as described by Ridner (71).

LIMITATIONS

Achieving generalisation was not the aim of the study. These experiences are most likely not representative of all secondary lymphoedema cancer patients in rural NSW. The participants were women, knowledgeable, and highly motivated. It is plausible they may have experienced difficulties that they wanted to share. These people have access to a free, ongoing individual lymphoedema service, where they are encouraged to seek assistance as required.

The researcher was well known to participants may have had a negative effect with the participants reluctant to share honestly. However a good rapport was already established, and this is reported to be critical when gaining depth of information (50), so may have in fact been a positive influence.

The data was analysed and coded by one researcher however rigorous coding techniques were used, and the findings validated with other therapists. Remaining true to the data was utmost priority.

Primary lymphoedema patients are not included in this study. It is likely this cohort have quite different survivorship issues, and warrants individual attention.

RECOMMENDATIONS

Clearly some people with secondary lymphoedema following cancer are doing well. These women all have access to a public funded local lymphoedema service for ongoing review and treatment if required. Recommendations have been considered from a local, department and academic perspective.

It is recommended that cancer survivors with or at risk of lymphoedema in the Shoalhaven will continue to receive a surveillance model of care providing early intervention for lymphoedema and include general rehabilitative needs. Promotion of the existing reconditioning and maintenance classes to those recovering from cancer treatments will continue. Continuing education opportunities with the local community, medical staff, patients and families will ensure lymphoedema knowledge is evidence based. This may also require assistance to contextualise the information, promoting balance in the management of lymphoedema strategies.

Research into the presence and availability of specialist lymphoedema services in the NSW public sector has not recently been reviewed to the author's knowledge. This is urgently required to determine what the gaps are, where the gaps are, and how we can support both the workforce, and service provision, with improved patient outcomes. It is important to determine where Lymphoedema Management fits into the funding model of NSW Health. In the author's experience Lymphoedema Management is often provided in the acute care sector, ad hoc with little or no funding allocation, resulting in long waiting lists and Occupational or Physiotherapy departments absorbing the costs incurred. Consequently therapists (who have undergone extensive and expensive training) have competing interests with Complex Lymphatic Therapy time consuming for both the therapist and patient, expensive with extremes of

funding models (from full to none where patients are billed for bandages, initial garments and even micropore tape) and often little or no support from their peers and managers. Establishing and maintaining a rural and metropolitan network may also facilitate referral of appropriate clients to services following at risk surgery for risk management, on their return home to the bush.

There is a need to broaden research enquiry to include the social paradigm of holistic medicine as more than a token gesture. Mixed methodology research into lymphoedema not only quantifying but qualifying the variation in physical presentation, comorbidities, and patient levels of distress with its effects on ADL's, psychological and social issues. This is more than including QoL and distress level questionnaires. It's about challenging the traditional biomedical healthcare model of power/responsibility and shifting focus back to the patient and their needs and wants. Investigating patient perspectives around what issues or situations they determine to be problematic, how it affects them from both a personal and community perspective, may assist in the development of tool to assist clinicians ask the right questions. Access to both skills and resources they identify may empower and assist individuals and communities in sustaining good health.

Further dissemination of lymphoedema evidence based practice is required with emphasis on the whole person, not just the limb. Improved education from both the social and biomedical perspective is required not only for risk management and treatment, but also limb morbidity and general disability following cancer treatments. This includes both in the initial stages when signs and symptoms may appear and spontaneously resolve, and later to recognise lymphoedema and other issues amenable to rehabilitation. Education to include basic anatomy of the lymphatic system, pathology and oedema, risk factors including lifestyle and social factors, and strategies to minimise the risk are the building blocks of lymphoedema management and all health professionals involved in cancer patient care are capable of laying the foundations. It is plausible that with improved foundations outcomes for those with lymphoedema can and will improve.

CONCLUSION

This study explored the life experiences of eight rural ladies with and at risk of lymphoedema following cancer treatment, with access to a local free lymphoedema service. They are for the most part getting on with life, acknowledging that at times they do feel vulnerable, however confident to seek assistance from the local lymphoedema service when required. Interactions with medical staff continue to be disappointing with conflicting and inaccurate lymphoedema advice regularly encountered.

Given the chronicity of lymphoedema and cancer survivorship issues it is time to rethink the biomedical model of healthcare and move towards a social model where patient perspectives are central in health decisions. Research including both Quantitative and Qualitative methodology may assist in identifying the skill set required for both individuals and rural communities to further succeed in managing these chronic conditions.

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APPENDIX 1 – Initial information sheet



Health
Illawarra Shoalhaven
Local Health District



HETI
HEALTH EDUCATION &
TRAINING INSTITUTE

Physiotherapy Department Shoalhaven District Memorial Hospital
Information Sheet for Potential Participants
Research Project – Living with Lymphoedema – The rural cancer patient experience

Dear

I am inviting you to consider participating in a Research Project exploring the experience of Lymphoedema or the risk of Lymphoedema, and the management of this risk in Rural Cancer patients in the Shoalhaven. We believe you can help us by sharing your experience, and telling us about what you know, how you came to know about it and how you manage this issue.

The research is being conducted by Clare Eastment, Level 3 Physiotherapist working in Lymphoedema in the Shoalhaven and is supported by the Rural Research and Capacity Building Program 2012.

Participation is voluntary and Clare does not know you have received this request, nor will she know if you chose not to participate. You may withdraw at any point without giving a reason. All services you presently receive through the Physiotherapy Lymphoedema service will continue whether you chose to participate or not.

If you chose to participate, the research will involve you attending an interview to be held at a place convenient to you. It will last approximately 1 hour. Clare will ask you a series of questions regarding your experiences of learning about Lymphoedema. The interview will be recorded and transcribed. The responses of all the participants will be collated and analysed for themes. It will then be written up in a formal report.

The information you share will remain anonymous, in that you will not be referred to by name in the report. You will be given a short summary prior to the completed report being made more widely available.

If you would like further information regarding the project or would like to participate I would ask you to ring either Clare or myself. We will then forward you more information and organise a day, time and place for your interview.

Thanking you for your consideration

Ashley Byrnes
Research Assistant
Ph 44239272
11th September 2013

APPENDIX 2 – Interview Questions



Interview Questions Probes and Prompts

I am interested in hearing about when you were first diagnosed with cancer.

What sort of treatment did you have?

Where did you have this treatment?

What sorts of things were you weighing up when you decided on your treatment?

What aspects of the potential risks and benefits of treatment were important to you?

I am interested in one of those risks in particular, when did you first become aware of the possibility that you might get Lymphoedema?

Tell me more about how you first heard of Lymphoedema.

- Do you remember what you knew about Lymphoedema then?
- Do you know how you came to know about this?
- What ways did you go about trying to understand more about Lymphoedema?
- Are there people you know with Lymphoedema?
- What places would you go to to find out more information about Lymphoedema?

What were the first symptoms you noticed of Lymphoedema?

How did you manage them?

How does it affect you on a day-to-day basis?

What is the most difficult thing to deal with?

Is there anything else you would like to share with me?

APPENDIX 3 – Informed Consent Information & Form



Health
Illawarra Shoalhaven
Local Health District



Informed Consent Form for patients, invited to participate in research project titled “Living with Lymphoedema –The Rural Cancer Patient Experience”

**Researcher: Clare Eastment Lymphoedema Physiotherapist
Illawarra Shoalhaven Local Health District
Rural Research Capacity Building Program 2012
Living with Lymphoedema – The Rural Cancer Patient Experience**

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

I am a Physiotherapist working in Oncology in the Southern Shoalhaven. We are conducting research on the rural patient's experience of living with Lymphoedema or Lymphoedema risk. I am inviting you to be participant in this research. If there is anything you don't understand please stop me and I will explain as we go. You may ask questions at any time.

Purpose of the research

Lymphoedema is a condition commonly associated with surgery and treatment for cancer. We want to learn how we can most effectively help you learn about and manage the risk of Lymphoedema. We believe you can help us by sharing your experience and telling us about what you know and how you came to know about this issue.

Type of Research Intervention

Being a participant in the research involves taking part in an interview with me (Clare), and will take approximately one hour. I would like to make an audio recording of the interview.

Participant Selection

You are being invited to take part in this research because we feel that your experience as a rural cancer survivor can contribute to our understanding and knowledge of local health practices.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. You do not have to decide today whether or not you will participate in the research, and before you decide, you can talk to anyone you feel comfortable with about the research. If you choose not to participate the Lymphoedema services you currently receive will continue and nothing will change. You can withdraw at any time without giving a reason.

Procedures

We are asking you to help us learn more about living with lymphoedema or the risk of lymphoedema. If you accept to take part in this research project, you will be asked to take part in an interview with me (Clare).

During the interview I will sit down with you at the clinic, or if it is more convenient for you the interview can take place at your home or a friend's home. No one else but the interviewer will be present unless you would like someone else to be there.

The questions are focused on your experience of learning about Lymphoedema, on managing the risk of Lymphoedema, and living with Lymphoedema. If you do not wish to answer any of the questions during the interview, you may say so and the interview will move on to the next question.

The interview will be digitally recorded with your permission and then transcribed. The information collected will be analysed and written up as a report. No one will be identified by name.

Duration

The research interview will take approximately one hour and I am expecting these to take place mid- year 2013.

Risks and Benefits

Through this research I am hoping to understand more fully the cancer patient experience in living with Lymphoedema or the risk of Lymphoedema.

You may find participating in this research gives you an opportunity to reflect on your knowledge and journey so far as a cancer survivor. It is possible that this may cause you some distress. If during or after the interview process you become aware that you would like further support this can/will be arranged at the earliest opportunity.

Reimbursements

There is no financial reward for participating in this research.

Confidentiality

The information collected in this research project is anonymous, and no one else except me will have access to the information documented in your interview. The recording will be destroyed as soon as it is transcribed, expected to be within 2 weeks of the interview. The recording and transcription will be stored in a locked cabinet that I only have access to. Information stored on the computer will be in a private file with password protection. All information collected will remain anonymous and you will not be identified in the report.

Sharing the Results

Results from all participants will be combined together so you will be anonymous. I will share a short summary of the study findings with you and all the other participants in early 2014, prior to the findings being made more widely available. I am hoping to publish the results in a medical journal and share with my colleagues around Australia.

Right to Refuse or Withdraw

Your participation in this research is entirely voluntary. You may withdraw at any stage if you wish to without reason.

Who to Contact

If you have any questions regarding this research you can call me, Clare Eastment at Shoalhaven District Memorial Hospital on 44239272 or alternatively leave a message at Milton Ulladulla Hospital Physiotherapy department on 44549123.

This proposal has been reviewed and approved by HREC.....which is a committee whose task it is to make sure that research participants are protected from harm.

You can ask me any more questions about any part of the research study, if you wish to. Do you have any questions?



Health
Illawarra Shoalhaven
Local Health District



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Part II: Certificate of Consent for research project titled “Living with Lymphoedema – The Rural Cancer Patient Experience”

I _____ have been invited to take part in a research project exploring living with Lymphoedema risk following medical intervention for cancer.

I understand it involves taking part in an interview asking me questions regarding my experience and knowledge of Lymphoedema and where I learnt about it. My information will be collated along with others in the form of a report and we will all be anonymous. Any questions I had have been answered to my satisfaction.

I consent voluntarily to be a participant in this study and I know I can withdraw at any stage without reason.

Print Name of Participant _____

Signature of Participant _____

Date _____
Day/month/year

I, Clare Eastment (researcher) have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. Information collection will be via a semi structured interview of likely duration 60 mins
2. All information collected will remain anonymous
3. The participant may withdraw at any stage without reason
4. Information gathered will be used to review and improve Cancer patient outcomes

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____
Day/month/year