

**A qualitative study of supported
self-care in women with
lymphoedema associated with
breast cancer**

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(PhD)**

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Declaration

I declare that this thesis is my own work, and that no material contained in it has been submitted for another academic award.

Anne F. Williams

Dedication

This thesis is dedicated to my parents, Peter and the late Catherine Schwarz,
who always inspired a search for knowledge and wisdom.

Acknowledgements

To Ian and Robert; I owe you a huge thank you for all your support and patience.

I also extend my grateful thanks to the women and lymphoedema practitioners who gave of their time and enthusiasm to provide the rich and valuable stories that helped to form this research project.

Many thanks also to my supervisors, Professor Catriona Kennedy, Professor Diana Woodward and Professor Anne Munro for their ongoing support and advice in developing my thinking within the research thesis.

Abstract

Aim: This study explored the nature of supported self-care for women who had lymphoedema associated with breast cancer treatment, and the work of lymphoedema practitioners.

Background: Health policy indicated a need to examine the potentially evolving roles of individuals with long term conditions who undertake self-care, and health professionals who provide support. Lymphoedema affects around one in five women who undergo treatment for breast cancer. A woman with lymphoedema can experience long term swelling, most commonly of her arm, affecting her life in various ways.

Methods: Three small group discussions were undertaken with women who had lived with lymphoedema for more than two years (n=7). Field observation (n=16) of clinic appointments with women who had lymphoedema, were undertaken alongside interviews (n=15) with eight lymphoedema practitioners. Women who had newly developed lymphoedema (n=10) were interviewed three times over a period of six months. The study was underpinned by social constructionist perspectives, and informed by feminism and relational autonomy theory.

Findings: Various structures of power influenced the capacity for supported self-care in women and practitioners. Lymphoedema influenced women's self-identity, and women experienced substantial distress and frustration relating to the initial development of lymphoedema, the chronic nature of the condition, and in adapting to self-care. Lymphoedema practitioners provided support for women from within a mainly bio-medical framework of care, often based within acute clinical settings. Accessing local, trusted information and advice relating to lymphoedema self-care was challenging for some women.

Conclusion: An anticipatory approach to supported self-care was identified. The development of reflexivity and self-discovery was considered equally relevant to women with lymphoedema and lymphoedema practitioners. Professional approaches to support should recognise this anticipatory perspective and enable timely access for women to individualised and appropriate support at key points in their lymphoedema trajectory.

Glossary of Terms

Allied Health Professional (AHP): a health professional such as a physiotherapist (PT) or occupational therapist (OT) allied to medicine.

British Lymphology Society (BLS): a UK-based professional interest group for lymphoedema practitioners, therapists, associated voluntary sector and industry groups.

Cartesian dualism: as described by the French philosopher René Descartes (1596-1650), a philosophical separation of the human being into two distinct substances: the thinking (mind); and the corporeal (body).

Complex Decongestive Therapy (CDT): intensive therapist-provided lymphoedema treatments that may include manual lymph drainage and bandaging; often provided daily for 2-3 weeks.

Chronic obstructive pulmonary disease (COPD): chronic disease of the lungs due to various causes including chronic bronchitis and emphysema.

Decongestive Lymphoedema Treatment (DLT): as Complex Decongestive Therapy.

Epistemological: relating to theories of knowledge, the origin of our knowledge and its reliability.

Long Term Conditions Alliance Scotland (LTCAS): a collaboration of a range of voluntary sector groups with a focus on people with all types of long term conditions.

Lymphoedema: swelling due to fluid accumulating in the body tissues, resulting from damage or inherent changes in the lymphatic system which fails to drain affected areas of the body.

Lymphoedema Practitioner: a health professionals (often with a nursing or physiotherapy background) defined by their work within the health 'speciality' of lymphoedema.

Lymphoedema Support Network (LSN): a UK-based support and campaigning organisation run by people with lymphoedema.

Manual lymphatic/lymph drainage (MLD): a specific, gentle type of massage originally developed in the 1930s by Dr Emil Vodder; MLD enhances the drainage of fluid from the body tissues into the lymphatic system and blood circulation.

NMAHP: Nurses, Midwives and Allied Health Professionals.

Ontological: relating to the philosophical study of the nature of human being; concerned with the nature of reality; what exists, how things exist and are grouped.

QALYS: Quality Adjusted Life Years; used to measure cost-effectiveness of research interventions in terms of the costs and health gains; often measured using the Euroqol tool.

Simple lymphatic drainage (SLD): a form of MLD designed to be used by a person with lymphoedema.

Self-massage: the same as simple lymphatic drainage.

Supported self-care: originally a politically constructed term, often used synonymously with 'supported self-management'; used in this thesis to capture the notion of a collaborative and equal relationship between the person with a long term condition who undertakes self-care and the health professional who provides support.

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Chapter 1: Introduction and background

1.1 Introduction

In this thesis I am concerned with understanding the nature of supported self-care from the perspectives of women with lymphoedema, and lymphoedema practitioners. Lymphoedema develops in around one in five women who have treatment for breast cancer (Clark, Sitzia & Harlow 2005; Todd *et al.* 2008). A woman affected by lymphoedema may experience long term swelling of her arm, hand, breast, and/or upper body, due to the accumulation of fluid (Figure 1:1). This swelling is usually a visible sign of lymphoedema and can be unpredictable in nature, as reflected by Kim Decker:

Day by Day with Lymphedema (Decker 2007, p.22)

<i>On a Bad Day</i>	<i>On a Good Day</i>
<i>Swollen like sausage</i>	<i>My arm, part of me</i>
<i>Blotchy pain constant vigil</i>	<i>I create and live with joy</i>
<i>For the rest of life</i>	<i>I am here with smile</i>

A woman with lymphoedema may notice that her arm feels stiff and heavy. Her skin may become dry, hard, or thickened at the swollen areas, leaving her vulnerable to developing skin problems and infection. She may experience discomfort or pain, and difficulties with using her arm, affecting many aspects of her life (Fu & Rosedale 2009). There is abundant evidence that, as a long-term legacy of cancer treatment, lymphoedema can have a considerable emotional and psychosocial impact on women (Fu 2008; Hayes *et al.* 2008; McWayne & Heiney 2005; Morgan, Franks & Moffatt 2005). Important to this thesis, lymphoedema is likely to require daily care and attention by the woman herself, as she adjusts to and lives with this long term condition.

Figure 1.1: A woman with lymphoedema of her left arm



Lymphoedema 'self-care', sometimes referred to as 'self-management', or the 'maintenance phase' of lymphoedema treatment (Green 2010), is often described in relation to various physical activities, undertaken on a regular basis, by someone with lymphoedema (Lymphoedema Framework 2006; National Cancer Action Team (NCAT) 2009). These activities may involve a woman in caring for her skin, wearing compression sleeves and gloves to contain the swelling (Figure 1.2), and undertaking specific types of exercise and/or self-massage (Figure 1.3) to encourage movement of fluid away from the swollen areas. Thus, the notion of self-care as a key health care resource in long term conditions policy (Rogers, Hassell & Nicolaas 1999; Scottish Government 2009a) may reflect the experiences of women who face the daily challenges of caring for their lymphoedema.

Figure 1.2: A woman wearing a compression sleeve and glove



Figure 1.3: A woman undertaking self-massage



I will show, however, that a paradox may exist where women make daily decisions about their own self-care, around activities that have been defined from the dominant ideology of a biomedical perspective. In this thesis I explore the development of knowledge for self-care, and identify the processes through which women with lymphoedema may be enabled to reflect and build on their own experiences of self-care, and anticipate their future needs. In particular, I propose a conceptual model of anticipatory self-care, developed from my research findings. I will argue that this model informs an understanding of the concept of 'supported self-care'. It also provides a framework for future development of theory to underpin the work of health professionals such as lymphoedema practitioners, in supporting self-care activities in women with lymphoedema.

In this current chapter I set the scene for the thesis, firstly drawing from my own experiences as a lymphoedema practitioner to position myself in relation to the thesis, identifying certain experiences that provided the impetus for the current research. I then provide a background to the problem of lymphoedema associated with breast cancer, outlining why it develops, how it presents, how it affects women's lives, and the structure of treatment approaches in the UK. Thirdly, I critically examine the long term condition policy context within which the concept of 'supported self-care' has developed, and finally, I explore philosophical assumptions relating to self-care and self-management. Thus, this chapter represents my first steps towards identifying the research questions that have informed the literature review in the next chapter, and generated the themes that underpin the thesis.

I show in this current chapter that the evidence base for professional lymphoedema practice did not readily inform my own work as a lymphoedema practitioner in supporting women with self-care. Furthermore, I describe my experiences of the political nature of lymphoedema treatment and care, which brought me to take the feminist-informed approach to the thesis that I discuss in

Chapter Three. I identify two key considerations for the thesis from the critique of policy relating to the care of people with long term conditions. Firstly, that care and support for people with long term conditions appeared to be driven by notions of empowerment, personal autonomy, choice and self-responsibility. Secondly, that health policy envisages a redefining of the roles of the health professional and the person with a long term condition. The thesis is developed around the concept of 'supported self-care', which is in essence a political construct that I believe reflects how a 'patient' and a health professional may work together, respectively either undertaking self-care or providing support. It is my contention that this concept of supported self-care provides a useful platform for examining the concept of changing roles, as discussed in policy documents, and the power relations inherent in the relationship between a health professional and a woman with lymphoedema.

1.2 Locating myself in the thesis

I first worked with women who developed lymphoedema associated with breast cancer treatment when I was a student nurse in the late 1970s in Scotland. I remember recognising the mutilating nature of these cancer treatments on women. I also look back on our attempts as a hospital nursing team to assemble a contraption with a sheet over an intravenous infusion stand, so a woman with lymphoedema could suspend her swollen arm for many hours. At that time, this rather medieval approach reflected a common lack of knowledge about lymphoedema in the UK. A few years later, as a staff nurse at the Royal Marsden Hospital, a specialist cancer hospital in London, I worked within a breast cancer ward and palliative care unit. In these settings I recognised that the health care team supported women with breast cancer and their families within an environment of open communication and compassion. I found this very different from the rather paternalistic medical perspectives that had dominated my earlier experiences around cancer care.

By the mid-1980s I was a District Nursing Sister in London, at a time when Breast Care Nurses were a rare breed. I took particular responsibility for supporting women who had breast cancer within my community area because of my professional experience. A few had severe lymphoedema, providing me with early experiences of using compression sleeves and bandages to help reduce the woman's swollen arm. These instances again reflected a distinct lack of knowledge of how lymphoedema should be 'managed', and I recognised that my attempts at 'treatment' were often inadequate. Furthermore, working with women in their homes, I saw how they struggled to adapt their lives to accommodate and care for their heavy and bulky arm. An important point to make here is that I learned from these women who were self caring within their own contexts, rather than presenting myself to them as an 'expert' lymphoedema professional. At this early stage, however, these experiences raised fundamental questions for me about how I might best support women as they learned to live with and care for their lymphoedema symptoms.

In the early 1990s, as a cancer nursing teacher in a London College of Nursing, I invited women with lymphoedema to become involved in teaching post-registration nurses. One woman, a nurse herself, had been a founder member of the Lymphoedema Support Network (LSN), and was a key spokeswoman for this new 'patient-led' charity, set up to support people with lymphoedema. I was invited to become a committee member of LSN, providing me with the opportunity to experience the political landscape within which the charity pressed for better awareness and services for people with lymphoedema. At this time, I also worked briefly with a group of women who campaigned as Radiotherapy Action Group Exposure (RAGE), taking legal advice concerning the devastating after-effects of radiotherapy that had left them with a grossly swollen, and sometimes lifeless arm, after breast cancer treatment (Hanley & Staley 2006). Significantly, these women experienced distress and frustration through which they built a determination and a collective spirit that brought them to set up groups such as RAGE, and the LSN. Reflecting back on this I can

see that these women were part of a social movement in which they became a visible presence in the public domain (Klawiter 2004), rather than merely passive recipients of health care, placed within a traditional hierarchical medical model of care.

A few years later, moving from nurse education back to clinical practice, I had the opportunity to set up a hospice and community-based lymphoedema service in west London for people with cancer and non-cancer-related lymphoedema. In the role of 'Lymphoedema Nurse Specialist' I ran a nurse-led service. Few doctors were interested in this mainly practice-based 'speciality', and the UK did not have a designated medical speciality of 'Lymphology'. I also worked for a short time in a hospital-based lymphoedema clinic at the Royal Marsden Hospital. As a 'specialist' my work interfaced with a wide range of other professionals: breast care nurses, physiotherapists, hospital and community nurses, surgeons, oncologists, palliative care professionals, leg ulcer specialists, GPs, vascular surgeons, massage therapists, and a community-based physiotherapist running exercise classes in a health centre. Looking back I recognise the plurality of opinion that existed around approaches to treating and caring for people with lymphoedema. I am also aware of the inter-professional contests for dominance, reflected in the dominant discourses, for example, from cancer surgeons and oncologists (usually men) who could be dismissive of our therapy approaches. Significantly, this opportunity to experience the eclectic nature of lymphoedema care in London was in stark contrast to my later experiences on moving back to Scotland in the new millennium, where resources and services for people with lymphoedema appeared to me to be fragmented and constrained.

Fundamental to the work of lymphoedema practitioners, the mainly nurse and physiotherapy health professionals who work with people with lymphoedema, is the application of a range of physical treatment methods (Williams & Badger 1996). In the UK these physical treatments replaced previous attempts by

surgeons to dissect swollen limbs, and were adapted from the work of lymphology centres in Germany (Földi, Földi & Weissleder 1985). Referred to as Complex Decongestive Therapy (CDT) or Decongestive Lymphoedema Treatment (DLT), the treatment method incorporated four ‘cornerstones’: manual lymph drainage (MLD) massage (Figure 1.4), multi-layer bandaging (Figure 1.5a, Figure 1.5b), skin care and exercise. Since I was already qualified in bodywork and massage, these approaches brought a unique opportunity for me to integrate these skills in my practice. Undertaking courses in the UK, Austria and US, I became one of the first Vodder MLD therapists in the UK and a teacher of the Casley-Smith method of MLD. However, despite this focus on physical treatment, I also recognised that, in reality, most of the ‘work’ was undertaken by the individuals with lymphoedema themselves.

Figure 1.4: A woman having manual lymph drainage massage



Figures 1.5a and 1.5b: Application of layered compression bandaging



As I will show in more detail later in the literature review, there was limited empirical evidence to inform our practice as lymphoedema practitioners, in relation to both therapy approaches and supporting individuals with self-care.

Thus, from a personal and professional perspective, I took the opportunity to become the researcher for an NHS-based randomised controlled trial, providing statistically significant evidence regarding the efficacy of MLD (Williams *et al.* 2002). Subsequently I was involved in other studies, for example, exploring the experiences of individuals with lymphoedema (Williams, Moffatt & Franks 2004) and researching the prevalence of chronic lymphoedema (Moffatt *et al.* 2003). Research developments such as these were part of a growing evidence base within a new speciality. They underpinned the activities of the newly developing International Lymphoedema Framework with which I was involved (Lymphoedema Framework 2006; Morgan & Moffatt 2006). They also formed a basis for my work as an educator involved in the delivery of lymphoedema courses in various settings in the UK.

However, as I settled back in Scotland in the new millennium, I became acutely aware that our developing evidence base would not readily translate into broader outcomes in relation to justifying the development of services for people with lymphoedema. I had the opportunity to work at a national level in Scotland with other practitioners, people with lymphoedema, voluntary sector organisations and politicians, to raise the profile of and seek resources for the treatment and care of people with lymphoedema. During this time I became aware of how evidence could be ignored, and certain knowledge privileged, particularly within an increasingly economically constrained health service. I recognised that the voices of women and men with lymphoedema, and lymphoedema practitioners, were often not heard by those in more powerful positions such as doctors and service planners. For example, our claim of lymphoedema as a significant problem was questioned by various groups (Rampaul *et al.* 2003). I often heard the same story from individuals with lymphoedema, as illustrated in an email I received from 'James' a man with a genitourinary cancer and lymphoedema of the legs:

'I find I am still battling with the fact that the lymph fluid is always mentioned as secondary to my cancer but really my quality of life has been more affected by that than anything else, just can't seem to make it understood' ('James', personal communication, 19th October 2007).

Reflecting back, I am aware of the hierarchies of power that had a constraining influence on the experiences of us as professional lymphoedema practitioners, and individuals with lymphoedema. Certainly, organisations such as the International Lymphoedema Framework, collaborating with 'patient' groups such as the LSN, arguably brought a more powerful global influence. However, in the years prior to and during the time of my PhD fellowship I continued to work as a lymphoedema practitioner, albeit in a small role, running a nurse-led lymphoedema clinic in an NHS hospital. While this provided me with a context for reflection throughout the research process, it also meant I continued to experience the powerlessness that can arise from working within what constitutes, I believe, a relatively marginalised professional group. Thus developing the enquiry from a feminist-informed standpoint, as I will show in Chapter Three, brought my attention to the political context in which I sought to develop new knowledge. Fundamentally, it led me to focus the research on providing an opportunity to hear the voices of both women with lymphoedema and lymphoedema practitioners, the majority of whom are women. However, in locating myself in the thesis, I also recognise that my own experiences of being embedded in the field of lymphoedema treatment and care for many years, as a clinician, writer, researcher and educator, will have influenced the research, my relationship with respondents, how they responded to me, and my own actions and interpretations within the research process. I will reflect on this at various stages in the thesis.

In summary, this section has provided a personal backdrop to the thesis, and points to the insufficient evidence base within my own experiences in supporting women with lymphoedema in their self-care. I will explore this evidence base in more detail in the next chapter. However, these experiences of working with

people with lymphoedema in different hospital and community settings, in their homes, alongside various professional and lay groups, around tables with politicians and government officials, and with voluntary sector organisations did, I believe, introduce me to many different ways of viewing the social world of lymphoedema. Fundamental to the thesis is an awareness of the political context and power structures in which individuals with lymphoedema experienced their healthcare and within which lymphoedema practitioners such as myself were located.

1.3 Lymphoedema associated with breast cancer

Here I provide background to: the causes of lymphoedema associated with breast cancer treatment; the presentation of lymphoedema; the effect of lymphoedema on women; and the organisation of lymphoedema services in the UK. This is background knowledge that broadly underpins the thesis, and informs an understanding of women's experiences with lymphoedema, and the work of lymphoedema practitioners.

1.3.1 The development of lymphoedema after breast cancer

Lymphoedema is often classified as either primary or secondary. Primary lymphoedema results from inherent and sometimes inherited changes in an individual's lymphatic system (Williams & Mortimer 2007), while secondary lymphoedema is associated with acquired changes to the lymphatic system, for example, as a result of cancer treatment. Figures 1.6 and 1.7 illustrate how the lymphatic system is often portrayed in medical terms. This is a complex and often poorly understood system that plays a vital role in ensuring fluid balance and providing a healthy immune system for individuals throughout life.

In women who develop breast cancer, surgical or radiotherapy treatments can compromise the ability of the lymphatic system to effectively return fluid and other products from the body organs and tissues, back to the blood circulation.

Figure 1.6: The lymphatic system

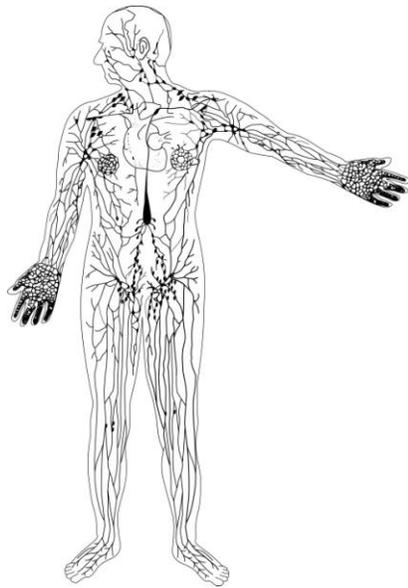
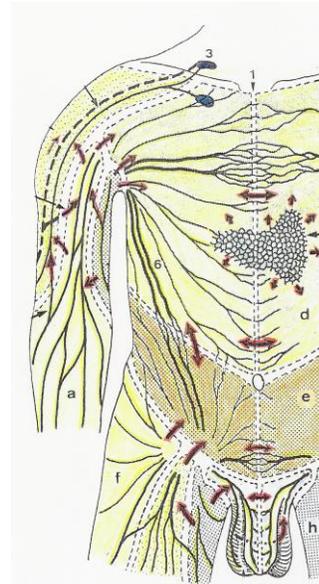


Figure 1.7: Skin lymphatic pathways



However, research into the mechanisms of lymphoedema development indicates that there may be various contributing factors, and that lymphoedema is not merely a result of an interrupted lymph flow. For example, developing evidence indicates that individual features of a woman's blood and lymphatic system may predispose her to lymphoedema (Stanton *et al.* 2009). Whilst it is outside the scope of this thesis to explore in detail the physiological aspects of lymphoedema development, it is important to note that there is currently no infallible way to predict whether or not a woman who has undergone breast cancer treatment will develop lymphoedema.

From the 18th Century onwards, a growing awareness of breast cancer as a problem that initiated in the breast and spread out along lymphatic pathways provided justification for surgical removal of a woman's breast and groups of lymph nodes adjacent to the cancer (Read 1995). This surgery was often extensive and aggressive, resulting in lymphoedema in many women (Veal 1938). Fisher (1992) discussed how evidence that more 'conservative' approaches to surgery were equally effective treatments to removing the whole breast (mastectomy) led to 'lumpectomy', or removal of the 'tumour' or 'lump', becoming more commonly used. Mastectomy or lumpectomy usually

incorporates removal of lymph nodes from a woman's axilla (armpit) (Scottish Intercollegiate Guidelines Network (SIGN) (2005). Complete surgical removal of axillary lymph nodes (often called dissection) has been implicated as a main 'cause' of lymphoedema in women with breast cancer (Mathew *et al.* 2006). A substantial body of literature reflects a preoccupation by breast cancer doctors to find ways of reducing the risk of lymphoedema. Thus, where possible, many women now have 'sampling' of around four lymph nodes, or sentinel lymph node biopsy (SLNB) (Armer *et al.* 2004). SLNB enables surgeons to scrutinise the direction of lymph drainage from the cancer site, assessing potential spread of the cancer, with the aim of avoiding unnecessary removal of large numbers of healthy lymph nodes. It has been shown to reduce the risk of lymphoedema in some groups of women such as those with early stage breast cancer (Fleissig *et al.* 2006; McLaughlin *et al.* 2008; Tsai *et al.* 2009).

Despite changes in breast cancer treatments, lymphoedema remains a problem for women and health professionals and new patterns of symptoms are emerging with women being affected in different ways. For example, women who have a lumpectomy followed by radiotherapy to their breast can develop breast lymphoedema, where their breast becomes swollen and hard (Goffman *et al.* 2004). Cytotoxic chemotherapy (drug) treatment can also result in swelling (Paskett *et al.* 2007) and changes to the tissues of a woman's arm (Vignes & Lebrun-Vignes 2007). The risk of developing lymphoedema may be influenced by factors such as women's high body weight (Helyer *et al.* 2009; Paskett *et al.* 2007). However, there is also evidence to suggest that changing practice, where women limit their arm movement in the week after breast cancer surgery, reduces their risk of developing lymphoedema (Todd *et al.* 2008).

Around 4,000 women learn they have breast cancer every year in Scotland (Information and Statistics Division Scotland 2011). More positively, the number of women recovering from, 'surviving', and living beyond breast cancer is steadily increasing (Information Statistics Division 2011). However, given that

at least 20% of these women are likely to develop lymphoedema (Clark, Sitzia & Harlow 2005; Todd *et al.* 2008), this equates to significant numbers of women currently living with lymphoedema as a long term condition. Furthermore, in a US study Paskett *et al.* (2007) used semi-annual questionnaires to follow up 622 women for three years after breast cancer treatment, reporting that 32% of women had some form of persistent swelling at 36 months. This suggests that the numbers of women affected by lymphoedema, as identified by Clark, Sitzia and Harlow (2005) for example, may be significantly underestimated.

1.3.2 The onset and presentation of lymphoedema after breast cancer

In their prospective study of 631 women, Norman *et al.* (2009) showed that 89% of women with lymphoedema developed it in the first three years after breast cancer treatment, often identified by changes that were visibly obvious to the woman, such as tight jewellery. In a research study, Armer *et al.* (2003) suggested that symptoms of '*heaviness in past year*' and '*swelling now*' were predictive of lymphoedema, and could be used by women to identify and self-report lymphoedema. In other studies of women with lymphoedema, individuals have reported physical symptoms such as numbness, swelling and pain across their chest or back, or in their arm (Bosompra *et al.* 2002a; Thomas-MacLean, Miedema & Tatermichi 2005). In a North American study, Fu & Rosedale (2009) interviewed 34 women with lymphoedema, describing how the women were surprised by the sheer volume of symptoms and the '*perpetual discomfort*' they experienced (p.853). Significantly, these symptoms brought a daily conscious awareness to the women of their lymphoedema, triggered fears about cancer recurrence, and evoked distress and despair when they interfered with women's daily life and work (Fu & Rosedale 2009).

Few studies have considered the temporal nature of symptoms. However, Kärki *et al.* (2005) used a survey method with a cohort of 106 women in Finland and found that the presence of upper limb swelling was fairly constant, with around 25% of women being affected at six and 12 months after breast cancer

treatment. Women also experienced problems with scar tightness, axilla swelling, neck and shoulder pain, with some women limiting their activities and having difficulties with sleeping, as a result (Kärki *et al.* 2005). In a Canadian study, Thomas-Maclean *et al.* (2008) assessed 347 women at an average of eight months after breast cancer surgery and suggested that symptoms such as pain, lymphoedema and restricted range of movement were not necessarily inter-related, but were distinct entities. Pain in particular had potential to impact on women's return to everyday life and recovery from breast cancer treatment, leading the researchers to suggest that health professionals should assess these types of physical problems in women with lymphoedema (Thomas-Maclean *et al.* 2008).

An international staging system for lymphoedema identified a sub-clinical or latent stage where physiological changes may present without swelling being obvious (International Society of Lymphology (ISL) 2003). As such, the pre-clinical Stage 0 has been considered as the point where women themselves may notice initial changes such as heaviness (Fu, Axelrod & Haber 2008), which may not be verifiable by 'clinical' measurement. This suggests that using the subjective accounts of women, through self-report of lymphoedema symptoms, may be valuable in providing an early indicator of lymphoedema (Armer *et al.* 2003). However, given that many studies have reported individuals receiving minimal, no, or conflicting information about lymphoedema from health professionals (Fu, Axelrod & Haber 2008; Lam *et al.* 2006; Langbecker *et al.* 2008; Thomas-Maclean, Miedema & Tatemichi 2005), the scope for self-report and self-identification of lymphoedema symptoms as differentiated from other side effects of treatment, may be open to question.

1.3.3 The psychosocial effects of lymphoedema on women

There is a significant body of research evidence, drawing on qualitative and quantitative approaches, which identifies the various psychosocial impacts of lymphoedema associated with breast cancer treatment on women (McWayne &

Heiney 2005; Morgan, Franks & Moffatt 2005). Various personal accounts also provide rich detail of women's experiences with lymphoedema (Ehrlich & McMahon 2007). A US-based study of 245 women who were 9-16 years after their initial diagnosis of breast cancer, also indicated that, alongside lymphoedema, 'survivors' of breast cancer experienced other long term problems such as menopausal symptoms and osteoporosis (Paskett *et al.* 2008).

Researchers have described women's fears associated with lymphoedema (Fu, Axelrod & Haber 2008; Woods 1993), and reported significant levels of psychological morbidity in women with lymphoedema compared to those without lymphoedema (Woods, Tobin & Mortimer 1995). In the UK, Hare (2000) undertook focus groups with women with lymphoedema, reporting women's feelings of anxiety and helplessness which were made worse by a lack of information, but also tempered by an overwhelming sense of being lucky to be alive after breast cancer (Hare 2000). In Sweden, Johansson *et al.* (2003) interviewed 12 women using a critical incident method set within a phenomenological framework. The authors described how information was controlled by health professionals, and the condition often trivialised by doctors, while the women were disappointed by the limited range of treatments available for lymphoedema (Johansson *et al.* 2003).

Studies have reported women's concerns about job security (Fu 2008), their feelings of a loss of independence and subsequent reliance on others such as family or work colleagues (Fu & Rosedale 2009; Johansson *et al.* 2003), difficulties with getting clothing to fit (Gould *et al.* 2006; Macmillan Cancer Support 2008), restrictions in arm and shoulder movement (Hayes *et al.* 2008; Thomas-Maclean *et al.* 2008) and difficulties with household chores and hobbies (Fu 2005). In one UK survey of 1449 people with all types of lymphoedema (Lam *et al.* 2006), 22% of those responding said they felt resentful or depressed about their compression garment (such as the sleeve),

with women more likely than men to feel this way. Poole & Fallowfield (2002) suggested in their review of the literature that younger women reported more general difficulties with lymphoedema than older women. The authors surmised that older women may incorporate their symptoms into a biography of ageing (Poole & Fallowfield 2002). A validation study of a measurement tool used to quantify changes resulting from lymphoedema suggested that the degree of psychological impact on a woman may relate in part to how she adjusts to and 'manages' her lymphoedema over time (Coster, Poole & Fallowfield 2001). In summary, many similar themes emerge from the literature, identifying the initial distress, followed by the long term psychosocial and potential economic impact of lymphoedema on women and their families.

1.3.4 The provision of lymphoedema treatment in the UK

As I described in Section 1.2, approaches to lymphoedema treatment and care in the UK have developed around a physical treatment model (Földi, Földi & Weissleder 1985). It is not within the remit of this current thesis to fully explicate or evaluate these approaches. However, a brief outline of these approaches provides useful contextual information relevant to the experiences of participants in this current research study. Intensive treatments such as manual lymph drainage and compression bandaging may be used, often daily for several weeks, with the aim of minimising women's symptoms, for example, reducing swelling, improving the shape of her limb, enhancing the skin condition or alleviating her pain or discomfort (Lymphoedema Framework 2006). Surgical treatment such as liposuction, where fat is sucked from a swollen limb, is also used for some individuals with lymphoedema, though relatively infrequently due to its invasive and demanding nature (Damstra *et al.* 2009).

While there is limited empirical evidence to inform the use of many treatment approaches (Preston, Seers & Mortimer 2004), there is a strong body of expert opinion through which standards and guidelines for best practice have developed in the UK (Lymphoedema Framework 2006; National Cancer Action

Team 2009). These frameworks give little detail on long term self-care, but indicate it as an adapted version of the professional 'management' of lymphoedema. As I stated earlier, self-care is often referred to as 'maintenance therapy' (Green 2010; Hamner & Fleming 2007), giving the impression that women who self-care have a role in maintaining the outcome of any work undertaken by the professional; or alternatively, that the body can be likened to an object such as a car. Significantly, standards for practice identify that the '*empowerment of people at risk of or with lymphoedema*' should include the use of individual plans for self-management, developed in partnership with people with lymphoedema, their relatives and carers (Lymphoedema Framework 2006, p.1).

In the UK, professional treatment and care for people with lymphoedema has developed mainly within acute cancer and palliative care settings (Macmillan Cancer Support 2008; Sneddon 2007). Different models of care exist, some based on a specialist centre staffed by specialist lymphoedema practitioners, who may focus on treating people with complex lymphoedema (British Lymphology Society 2004). Others follow a hub and spoke design, co-ordinated by specialist/s who link with various keyworkers, located in a variety of community and other settings. Keyworkers are often community nurses, physiotherapists or other generic professionals who, it is argued, should see individuals with less complex lymphoedema, or those individuals who have been discharged from specialist care (Green 2010). In keeping with health policy, as I will discuss in the next section, the International Lymphoedema Framework, a UK-initiated organisation (Morgan 2006; Morgan & Moffatt 2006), has particularly supported the development of community-based lymphoedema services. Many of the efforts at redesigning service approaches have sought to secure more equitable access to treatment and care for those individuals with all types of lymphoedema. In England, in particular, the growth of a market-driven ideology has supported the work of independent MLD therapists, who may not be registered health professionals, in providing treatment and care for people

with lymphoedema. A review of the literature also reveals an interest in, but minimal evidence relating to approaches such as the Lebed Healthy Steps method, a movement and dance programme (Sandel *et al.* 2005), and team dragon boat racing (Unruh & Elvin 2004). These approaches may be relevant to some individuals with lymphoedema, although they are often not readily accessed, nor always suitable to women with lymphoedema.

1.3.5 Summary

To summarise, lymphoedema arising from treatment that aims to cure breast cancer affects significant numbers of women, resulting in various physical symptoms. As a long term condition, lymphoedema also appears to have a substantial impact on women's lives. The professional treatment of lymphoedema seeks to reduce women's swelling and other symptoms of lymphoedema, but the evidence base is limited. As a variety of health and non-healthcare professionals may be involved in providing services for women with lymphoedema, this suggests that lymphoedema may reflect a potential battleground for contesting the claims of different practitioners. Within such an arena, self-care by the woman with lymphoedema may be a relatively silent and invisible aspect of lymphoedema 'management' that resonates with the policy developments relating to long term conditions, as I will now show.

1.4 The policy context of supported self-care

Here I present a critical overview of UK health policy developments related to people with long term conditions, spanning the 10-15 years prior to the writing of this thesis. Commonly, policy has appeared driven by a perceived demand on health care services resulting from changing demographics and patterns of illness in the western world (Carrier 2009). The growing number of people 'surviving' into old age, and/or living with potentially disabling long term conditions such as diabetes, asthma, arthritis, and neurological conditions, have often been viewed in the policy literature as a 'burden' on the health economy (Department of Health 2005; Department of Health 2006; Scottish Executive

2005a). Such statements appear to reflect significant assumptions about the societal value of specific groups.

Health policy in the 1990s heralded a move towards enhancing primary care-based services, in anticipation that this would reduce the need for more expensive secondary care in hospitals (Department of Health 1996). Partnering or collaborating with 'the patient' developed as an important focus around the same time (NHS Executive 1996). Building on the market-place economy invoked upon the NHS by the previous Conservative government in the 1990s, New Labour policy development, within the context of a new millennium, brought promises of modernising and rebuilding the NHS (Department of Health 1999; Department of Health 2000), formed around a 'patient-centred' approach that placed choice as a guiding principle (Department of Health 2004). Within a devolved NHS Scotland, a national action plan was set out within a spirit of partnership and co-operation (Scottish Executive 2000). By 2005, a review of services had placed 'long term conditions' (the renamed 'chronic disease') high on the agenda (Scottish Executive 2005a). Hospitalisation and crisis management were criticised as the default approach, with increased support for self-care being promised alongside strategic developments aimed at strengthening local primary care services, and improving information and record systems (Scottish Executive 2005a).

The 'new' approach to providing care for people with long term conditions had its roots in the 'Chronic Care Model' (Bodenheimer, Wagner & Grumbach 2002), originally developed in the US, and incorporating four components: self-management support; decision support; delivery system design; and clinical information systems. As I will explain in Chapter Two, much of this work flourished from a body of research relating to arthritis self-management, developed at the University of Stanford in California in conjunction with Kaiser Permanente, a medical insurance company (Lorig, Mazonson & Holman 1993; Lorig *et al.* 2001; Lorig *et al.* 1999). Differing levels of care were assumed to be

necessary for people with long term conditions (Department of Health 2005). As such, '*supported self-care*' was identified as relevant to 70-80% of those with long term conditions, to be undertaken by the individual and family carers, with minimal professional support. It was defined in relation to how health professionals (and others) might:

'...collaboratively help individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively' (Department of Health 2005, p.6).

Supported self-care was differentiated from two other levels of care requirements: individuals who required *disease or care management* from specialist nurses and other health professionals, within a multi-disciplinary team approach; and those who required *case management*, a much smaller group of individuals who were viewed as requiring a more intensive and co-ordinated approach (Department of Health 2005).

In England, a focus on developing an 'Expert Patient Programme' gave rise to a generic group approach, often led by people with long term conditions. This aimed to provide active support to individuals with long term conditions, enabling them to develop various skills necessary for undertaking self-care (Department of Health 2001). In Scotland, a strategy for self-management, appropriately named *Gaun Yersel* (Long Term Conditions Alliance Scotland (LTCAS) 2008), incorporated a significant role for the voluntary sector in representing and articulating the 'patient' view, and providing support. This particular strategy pulled together various themes: the need for a partnership between the 'person' (not 'patient') and the professional/ services; timely access to information and support; recognition of the key stages or trajectory of a long-term condition, such as at the time of diagnosis or during a transition between services, when specific support may be required; the use of personal action plans; the development of self-management courses; and the availability of complementary therapies (LTCAS 2008). Self-management was to be embedded across the country, with support taking various forms, including

information leaflets, self-management courses run by others with the same problem, and one-to-one partnerships between individual and professional (LTCAS 2008).

An important aspect of this policy was a move to viewing the 'patient' as an active partner or 'consumer', with responsibilities for their own health-related and lifestyle choices (Scottish Government 2008). It was argued that an empowered healthcare workforce would lead the changes (Scottish Executive 2005a) and that health professionals must also empower individuals and their families to take control of their own care (Scottish Executive 2005b; Scottish Executive 2006a). Documents talked of a *'paradigm shift'* (National Framework 2005, p.39) from the focus on acute, hospital-centred work, where the 'patient' was passive, and self-care was merely tolerated, towards a new approach geared to long term condition care, which was locally responsive, identified the person as an active co-provider, and encouraged and facilitated self-care (Scottish Executive 2005a). In Scotland, the Long Term Conditions Collaborative aligned these new developments with government health care targets, proposing five areas for development by NHS Boards: the organisation of services; self-management support; delivery systems design; decision support; and information systems (Scottish Government 2009b). Significantly, the Action Plan for Long Term Conditions incorporated language relating to the need to support people with self-healing and recovery (Scottish Government 2009c). The publication *Gaun Yersel'* (LTCAS 2008) reflected similar themes:

'While people are generally unlikely to recover from the condition itself, effective management of symptoms, balanced with increased autonomy and independence can help recover optimum wellbeing.' (LTCAS 2008, p.50).

Thus self-care was promoted for economic reasons, but set within an ideological framework that viewed it as a context for personal growth and empowerment. Policy development incorporated discourses around choice, autonomy, self-fulfilment, and active citizenship, reflecting post-modern, consumerist values

(Giddens 1991). Furthermore, the notion of the changing roles of both the person with a long term condition and the professional was acknowledged as providing new challenges for health professionals (Scottish Executive 2006a). The core nursing skills of assessment, communication, relationship and leadership, and the strengths of the enabling approach currently inherent within many allied health professional (AHP) roles, were seen as central to a new model in which nurses, midwives and allied health professionals (NMAHP) might effectively support people with their own self-care (Scottish Executive 2006a). 'Person-centred' approaches to care were espoused as integral to providing support to individuals (LTCAS 2008; Scottish Government 2007). 'Anticipatory care' was also deemed particularly relevant for community nurses (Scottish Executive 2006a; Scottish Executive 2006b) as a means of preventing unnecessary hospital admissions. However, concepts such as this have not yet been adequately explored, and the limited research evidence available suggests that the term 'anticipatory care' may be perceived in different ways (Kennedy *et al.* 2011).

In summary, here I have provided a critical overview of healthcare policy relating to individuals with long term conditions. This policy reflects an assumption that such individuals pose a burden for the health economy. There is an emerging expectation that people with long term conditions move from a passive to an active role in taking responsibility for self-care of their condition. This makes the assumption that people begin from a situation of passivity, a position which may be open to question. Policy also exhorts a change for health professionals in developing new, enabling, empowering and person-centred approaches to support individuals with long term conditions. However, as I show in the next chapter, the veracity of claims to the cost-effectiveness and efficacy of these supported self-care approaches has not been fully substantiated in the literature. Moreover, the relevance of the notion of empowerment to the relationship between a health professional such as a lymphoedema practitioner, and a woman with lymphoedema requires further exploration, particularly in how

it relates to supported self-care. I have indicated earlier in this chapter that lymphoedema treatment and self-care is a relatively new speciality, characterised by varied competing professional views and assumptions. This thesis therefore uses 'supported self-care' as a framework to examine the power structures that impact on, and the changing roles within, the relationships between women with lymphoedema and lymphoedema practitioners.

1.5 Conceptual issues and ideology in relation to self-care

Self-care has been variously defined as a concept, movement, framework, theory, model, process or phenomenon (Gantz 1990). In their review of self-care in end of life care, Johnston *et al.* (2009) recognised that terms such as 'self-care' and 'self-management' were often used interchangeably, and with varying interpretations. Others have commented on the conceptual complexity of self-care (Dean 1989; Gantz 1990; McCormack 2003; Wilkinson & Whitehead 2009), and the difficulties in defining and measuring concepts such as self-management (Embrey 2006). In this section I overview the ideological considerations that underpin these terms.

Arguably, self-care is the oldest and most widespread of all forms of behaviour affecting individual, family and societal health (Dean 1989). Approaches to self-care intertwine with notions of lay and family care, and self-help; they can be traced back through centuries. Jeanne Achterberg in her book 'Woman as Healer' discussed how women from prehistory onwards have had a central role in supporting the self-care of others, using folk medicine, for example (Achterberg 1991). Dingwall (2003) described how lay approaches to health care were passed through generations in Scotland, influenced through the ages by various cosmologies, localities, secular and religious beliefs, pre-dating the development of a medical orthodoxy born of the Enlightenment period. The popular health movement of 19th Century Britain was characterised by self-care and self-help, and grew from a distrust of the early work of medical doctors (Achterberg 1991). Crawford (1994) described how the attainment of health

through self-motivation and self-discipline was an important feature of Victorian Britain, and linked to emergent forms of scientific knowledge and the Protestant work ethic (Furnham 1990). In a series of public lectures by doctors to the people of Edinburgh, individuals were told of having a '*duty to take care of our bodies*' (Jenkins 1883, p.2). In the 1960s the women's health movement challenged the medicalisation of reproduction and birth (Kickbusch 1989), promoting a new and emancipatory self-care ethic for women's health. Most recently, a consumerist approach to health, where the body is regarded as a project to be worked on with advice from various 'experts', also indicates that self-care may take new forms within a changing socio-economic, historical and political context (Rose 1998).

Self-care has been considered a major determinant of physical and psychological well-being (Dean 1986). It has been described as a process that may change through the different developmental stages of life (Godfrey *et al.* 2010a). In relation to public health and health care policy, self-care has come to be broadly construed as activities undertaken by individuals, family and communities with the aim of preventing disease, and enhancing and restoring health (Department of Health 2005; World Health Organisation 1983). Self-care has also been defined as simply:

'...what each person does on an everyday basis...often compromised for a person living their life with long term conditions' (LTCAS 2008, p.9).

Dorothea Orem, a nurse theorist, described nursing as addressing an individuals' 'health-care deficits', and enabling individuals to move from being dependent on others towards independent self-care (Orem 1991; Orem 2001). Her systems-based model, developed in a US health care setting, explicated nursing within a supportive-educative framework as a means to support people with self-care (Orem 2001). Self-care also underpins rehabilitation approaches undertaken by allied health professionals such as physiotherapists and occupational therapists (Guidetti, Asaba & Tham 2007). However, Wilkinson

and Whitehead (2009) have argued that opposing ideological positions have created diversity and fragmentation around the concept of self-care. Berman and Iris (1998) described how self-care may be grounded in the value systems of representative professional or other groups and dominated by professional hegemony. Without critical exploration of the philosophical beliefs that underpin various terms, it is unsurprising that particular assumptions arise within professional perspectives; for example, that empowerment will be a natural consequence of self-management (Embrey 2006).

Lorig and Holman (2003) considered: *'...it is impossible not to manage ones health. The only question is how one manages it'* (p.1). In contrast to the broader conceptualisations of self-care identified above, the concept of self-management is often associated with the tasks of dealing with an illness condition. For example, Lawn and Schoo (2010) considered that self-management is a process that requires knowledge, the ability to monitor signs and symptoms, and the capacity to deal with the emotional, physical, social and occupational impact of a long term condition. Barlow *et al.* (2002) suggested that self-management may be viewed in terms of tasks that are required to be undertaken on a regular basis by someone with a health problem, in collaboration with or under guidance of a health care professional. Others have defined self-management as:

'...the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real implications of living the rest of their life with one or more long term condition' (LTCAS 2008, p.5).

These contrasting definitions of self-management seem to reflect different ideologies. For example, Barlow *et al.* (2002) appear to imply that self-management involves a level of adherence to medical instruction, with the 'patient' undertaking prescribed self-treatment tasks based on professional values. The LTCAS definition introduces an ideology that recognises a degree of independence for the person to shape their own life (LTCAS 2008). Further

interpretation on what is meant by 'successful' may also be necessary as, for someone with a long-term condition, a decision to do nothing may be seen as an effective personal decision, whereas from a professional perspective, this could be identified as inadequate self-management.

It is my assertion that attention should be given to the philosophies and discourses that underpin these different terms, teasing out their meaning for the different professional and other groups who may have staked a claim on self-care. Terminology such as 'self-management', developed as a component of the chronic care model, may give a flavour of how self-care has become professionalised, or brought into the realm of management and control. Thus as I considered earlier in relation to lymphoedema, the dominant professional perspective on the treatment of a condition may be adapted to a form of self-care. However, conferring professional values onto self-care runs the risk of ignoring unique and personalised approaches to caring for the self. Discourses such as 'maintenance therapy', I would argue, further serve to locate self-care in a reductionist and mechanistic framework, which may be at odds with ideologies of independence and autonomy, identified in the policy overview in Section 1.4.

In relation to the implications for the thesis, I recognised that the term 'supported self-care' was a social construction and a political phenomenon. However, early on in the development of the research ideas, I made a pragmatic decision to develop the research around this concept which I believed served to emphasise the equal significance of the women and lymphoedema practitioner to the enquiry. I defend my decision to avoid the term 'self-management' as the focus for the thesis, as I believed it to be particularly disease or condition-centric. I will show later, in Chapter Seven, why the association with control, that I would argue is implicit within the concept of self-management, may be unhelpful for researching and understanding the context of women with lymphoedema after breast cancer treatment. However, it is important to note that the terminology of self-management will still appear at certain points in the

thesis, particularly in the literature review where I report on particular approaches and studies.

1.6 Chapter summary and plan of the thesis

To summarise, in this chapter I have introduced the two main topics with which the thesis is concerned: lymphoedema in women who have had treatment for breast cancer; and supported self-care. I have shown that lymphoedema may influence many aspects of a woman's life, but in particular, it presents significant assaults on the physical body of women who have treatment for breast cancer. I have indicated that my own clinical experience raised questions regarding how I might, as a health professional, support women with lymphoedema as they undertake self-care. I have explored the political ideologies that have driven healthcare developments relating to individuals with long term conditions. Furthermore, I have also drawn attention to the political, and I believe gendered, context of lymphoedema treatment and care that has driven the feminist-informed approach taken in the thesis, and is discussed in Chapter Three.

In the next chapter, I will identify the various questions that underpinned the literature review, explaining the strategies used for searching and reviewing relevant literature. The literature review will critically explore two key areas: the evidence for supported self-care and self-management in relation to long term conditions, and especially, cancer and lymphoedema; and the theoretical and empirical literature relating to 'the body'. I finish Chapter Two by summarising key questions that informed the research aims. In Chapter Three, I critically discuss the theoretical basis for the research approach and design, the implications of taking a feminist-informed approach within a social constructionist framework, and I identify the research aims. Here I consider the inter-relationships between different theories used in the thesis and discuss, in particular, the concept of relational autonomy, explaining its relevance both to feminism and to an understanding of supported self-care. In Chapter Four I describe the methods used to gather and analyse the research data, giving

attention to the ethical issues that were relevant to the research process, and providing a reflection on the various researcher dilemmas relevant to the process of undertaking this particular enquiry.

In Chapters Five and Six I present my first-level interpretations of the women's and practitioners' perspectives respectively, organised within various themes and sub-themes. In Chapter Seven I provide a synthesis of these interpretations and the relevant literature to discuss the development of the thesis in relation to an anticipatory approach to supported self-care. In Chapter Eight I discuss the recommendations from the thesis, consider the implications of the findings for the developing knowledge base relating to lymphoedema treatment and care, and identify how the findings will be disseminated.

Chapter Two: Literature review

2.1 Introduction

In Chapter One I showed how various questions arose from my own practice experiences. I indicated that the policy approaches to caring for people with long term conditions appeared to raise challenges for professionals who may need to re-formulate their roles, and develop new knowledge and evidence relating to supporting individuals to undertake self-care. I also described the essentially physical nature of lymphoedema associated with breast cancer and how it has the potential to affect the social world of women in many ways.

In this current chapter I provide a critical, integrative review of relevant literature (Whittemore & Knafelz 2005), focussing on two main themes: the empirical evidence relating to the effectiveness of supported self-care and self-management; and the theoretical and empirical literature pertaining to 'the body'. I will show that a significant body of research evidence existed to evaluate the effectiveness of supported self-care and self-management. Much of this was developed from a positivist perspective that privileged professional knowledge, and did not fully inform my research topic. However, different constructions of self-care, drawn from various literature sources, provided a useful platform for the thesis. I will also show that exploring theories and empirical literature relating to 'the body' brought useful perspectives for understanding the supported self-care relationship between a woman with lymphoedema and a lymphoedema practitioner; for example, relating to the presence and shifting distribution of power within a health care relationship. At the end of this chapter I identify how the literature review informed the development of the research aims and direction of the thesis.

2.2 Search strategy

Details of the search strategy, such as the search terms used and the extent of literature identified, will be outlined in each section. In each case I searched a

number of electronic databases: British Nursing Index; CINAHL; EMBASE; Medline; ScienceDirect; and PsycInfo. I also searched the Cochrane Library and Database of Systematic Reviews (CDSR), Database of Abstracts of Reviews of Effects (DARE), Joanna Briggs Institute (JBI), and the publications of the Scottish Intercollegiate Guidelines Network (SIGN), Department of Health and Scottish Government Health Department. I examined a range of key texts identified through Edinburgh Napier University library, SALSER the Scottish Library database, and followed up relevant cited references. Literature searches relevant to the thesis were undertaken and updated annually between 2006 and March 2011.

2.3 Search and review processes

During the search process, citations and abstracts identified in the searches were collated in Endnote software. Abstracts or whole texts were scrutinised for relevance to the thesis and particular aspects of the review. Relevant literature was identified for each section of the review, and sources were obtained and critically evaluated, using a simple data extraction tool that I adapted from that used by SIGN (see Appendix 1). This data extraction tool enabled the assessment of literature sources in terms of: the aim/type of literature; the research process and outcomes used; the methodological quality of the literature; and key findings from the literature source that informed the specific aims of that section of the review. Finally, I developed evidence tables and narrative summaries of categories of literature, to collate the summary evidence from each section of the review.

2.4 Supported self-care

2.4.1 Introduction

The purpose of this section is to: critically review the evidence for the effectiveness of approaches undertaken to support self-care and self-management with individuals who have long term conditions, cancer and

lymphoedema; examine the ways in which the concepts of self-care and supported self-care are construed in the literature; and identify the implications for the research study. Search terms used for this part of the review were: 'supported self-care' or 'supported self-management' or 'self-care support' or 'self-management support' or 'self-care' or 'self-management' combined with 'chronic condition' or 'long term condition' or 'lymph\$' or 'cancer' or 'breast cancer'. Dates for the searches were from 1995-2011.

The initial searches yielded well over 3,000 references and after scrutinising abstracts I categorised nearly 1500 relevant sources of literature into key groups, namely: policy and strategic documents; descriptive papers; systematic reviews; other reviews; and empirical research papers. A final total of 94 literature sources were included in this first section relating to supported self-care. This comprised 12 Cochrane systematic reviews, 16 non-Cochrane literature review papers and 66 empirical research papers. Of these 94 sources, eight pertained to women with breast cancer, and 23 specifically related to lymphoedema.

In recognising the extent of literature, I made a pragmatic decision to focus on relevant reviews of the literature (see Appendix 2 and Appendix 3) and key empirical research studies relevant to the thesis. However, as Elliot *et al.* (2004) have suggested, evaluating the quality of systematic reviews can be difficult, in that reviewers may not follow a consistent approach and often do not provide a critique of methodologies used in the studies they review, or consider issues such as researcher bias. Systematic reviews may also reflect an inevitable delay in reporting findings, so that they quickly become dated, and do not always incorporate the most up-to-date evidence. It is argued that a study may require to be removed from a review if the standard comparator becomes redundant in practice (Coster & Norman 2009).

Cochrane systematic reviews provide an invaluable tool for health researchers. However, the methodology is such that they focus on randomised controlled trials, in which the effect of interventions are usually measured by standardised outcomes, often developed from a health professional perspective. All of the 12 Cochrane systematic reviews listed in Appendix 2 drew on the concept of self-management, although many did incorporate studies concerned with self-care. These systematic reviews also concentrated on conditions such as asthma, diabetes, epilepsy, arthritis and chronic obstructive pulmonary disease (COPD), conditions which may involve a substantial degree of medical 'management', and pharmacological interventions. Thus the extent to which they evaluated aspects of support provided by individuals such as nurses and allied health professionals may be limited.

Therefore I took the decision to draw on a wider range of reviews which incorporated other research approaches (see Appendix 3). These 16 other reviews were of varying quality, each with a specific aim and/or agenda, and many gave limited information on how papers were selected or assessed. Some incorporated both qualitative and quantitative research studies (Chapple & Rogers 2001; Rees & Williams 2009; Spenceley & Williams 2006). One review (Godfrey *et al.* 2010b) followed the methodology of the Joanna Briggs Institute, a collaborative international organisation with a focus on synthesis and utilisation of healthcare research evidence. Two review papers were syntheses of Cochrane reviews (Coster & Norman 2009; Godfrey *et al.* 2010b). These provided clear inclusion and exclusion criteria, and detailed evidence tables in their paper, as did other reviews (Berzins *et al.* 2009; Devos-Comby, Cronan, & Roesch 2006; Johnston *et al.* 2009). However, several reviews (Barlow *et al.* 2002, Newbould, Taylor & Bury 2006) were discursive in nature, and less rigorous in their approach. One paper was a review of economic evaluations of self-care support (Richardson *et al.* 2005), clearly identifying the processes undertaken for selecting and reviewing the literature, and providing a summary table of evidence.

2.4.2 The nature of support with self-care and self-management

Literature reviews and key research papers indicated that support with self-care and self-management took the form of individual and group approaches. Multiple strategies, including individual self-management plans and group educational sessions, were evident in some reviews (Godfrey *et al.* 2010b). Several examined specific approaches such as regular recall to appointments with nurses through computerised tracking (Renders *et al.* 2001), motivational interviewing counselling approaches (Dennis *et al.* 2008), advice on exercising (Markes, Brockow & Resch 2006) and written action plans to support decisions by individuals in responding to disease exacerbations in asthma (Toelle & Ram 2004) and COPD (Walters *et al.* 2010). A systematic review of the effectiveness of the 'patient-practitioner encounter' identified specific elements of support for self-care such as information giving, the use of a guidebook, care plans, treatment structured using checklists, and education and support to enable staff to work in a collaborative way (Rees & Williams 2009). These authors also identified as important the use of self-management plans that discussed lifestyle management with individuals, organisational factors such as the timing and structure of a consultation, and opportunities for seeing the same professional or having early referral to others (Rees & Williams 2009).

The most common group approach reported was educational sessions (Godfrey *et al.* 2010b). Bradley and Lindsay (2009) identified the use of a two day education module delivered in small groups by professionals for adults with epilepsy; this included information about the condition, support with learning to cope, and understanding relevant psychosocial issues. Kate Lorig and her colleagues provided the original format for a generic lay-led education programme which incorporated seven weekly two and a half hour sessions for individuals with a range of chronic conditions (Lorig *et al.* 1999). Content of these courses, designed to enable individuals to develop core skills in self-management, included: cognitive symptom management techniques; information on nutrition; fatigue and sleep management; the use of community

resources; the use of medication; dealing with emotions; communication with others including health professionals; problem-solving; and decision-making (Lorig *et al.* 1999). This was translated into an Arthritis handbook, named the Health Living Programme (Lorig *et al.* 2000), which informed the development of the Expert Patient Programme in the UK (Department of Health 2001). A similar programme has been delivered on-line where participants logged on to weekly sessions and were involved in developing a weekly action plan, keeping exercise logs and undertaking audio-relaxation exercises (Lorig *et al.* 2008).

Whilst there appeared to be a variety of individual and group-based approaches used to provide support with self-care, a review of diabetes support (Deakin *et al.* 2005) identified that educational programmes varied widely in their length, location, and theoretical basis. Another review of self-management education, for individuals with osteoarthritis of the knee, also considered that clear guidelines could not be given regarding the content of education sessions, due to considerable heterogeneity across studies (Smith, Kumar & Pelling 2009).

2.4.3 Evaluating the effectiveness of supported self-care

This sub-section provides a review of the evidence on the effectiveness of support for self-care and self-management, drawn from 18 review papers, and a further 18 empirical research papers that focussed on self-care in individuals with various conditions including COPD, asthma, epilepsy, arthritis, diabetes and breast cancer (see Appendix 2 and Appendix 3).

In relation to individuals with COPD, Effing *et al.* (2007) found a significant reduction in the probability of hospitalisation in individuals, as a result of self-management education, although a meta-analysis of data was not possible due to the heterogeneity of the studies. In a small review, Walters *et al.* (2010) suggested that individualised action plans may enable people with COPD to respond effectively to an exacerbation of the condition, but this approach could not be recommended without a comprehensive self-management programme or

on-going case management. Similarly, Powell and Gibson (2003) indicated that adjustment of medication through a written action plan for individuals with asthma improved control of the condition, but should be used within a wider programme of support. A further review showed that provision of information alone did not reduce hospitalisation or doctor visits, nor improve lung function in people with asthma (Gibson *et al.* 2002). Toelle & Ram (2004) reported inconsistent results between trials, and a lack of evidence to support the use of action plans with individuals who have asthma.

In a review of different interventions, Bradley & Lindsay (2009) found that specialist nurses and self-management training courses provided some improvement in outcomes for people with epilepsy, such as reduced frequency of seizures. Deakin *et al.* (2005) suggested that group based education improved biomedical outcomes such as fasting blood sugar, glycated haemoglobin and systolic blood pressure in diabetics. However, other reviewers surmised that organisational factors enabling more effective follow-up of individuals with long term conditions, meant individuals were more likely to keep taking their medications, potentially indirectly affecting the outcomes in conditions that depended on regular medication (Murray *et al.* 2009; Renders *et al.* 2001). Thus, it has been argued that improvements in physical disease-related outcomes may be linked to enhanced adherence to medication, rather than specific aspects of support (Chodosh, Morton & Mojica 2005; Warsi *et al.* 2004).

A review by van Dam *et al.* (2003) considered group education as having a role in empowering and preparing individuals with diabetes for their encounter with a health professional. As such, Booker, Morris and Johnson (2008) evaluated a user-informed psycho-educational programme for people with Type 1 diabetes, following an empowerment model (Feste & Anderson 1995). In this study, 24 individuals with diabetes were interviewed before and after an eight week programme of three-hour weekly groups facilitated by a diabetes specialist

nurse and a clinical psychologist (Booker, Morris & Johnson 2008). Qualitative evaluation, using interviews and diary data, suggested that being provided with information, sharing experiences with others, and having the opportunity to develop a repertoire of coping skills, increased individuals' sense of control over their condition (Booker, Morris & Johnson 2008), although a control group was not used in the study, nor were physical parameters measured. Lorig *et al.* (2009) undertook a randomised controlled trial in the UK, covering a total of 19 courses taken by 345 adults with Type 2 diabetes, who were randomised between receiving usual care control or a six week community based peer-led diabetes self-management programme (for two and a half hours per week). After 12 months there was evidence of measureable improvement in participants' levels of depression, communication with physician, healthy eating and self-efficacy, compared with baseline (Lorig *et al.* 2009). However, the authors of this study conceded that the inability to 'blind' participants to the intervention, inherent in such a design, could be argued as a particular shortcoming in this type of evaluation. Others have identified the possibility of a Hawthorn effect, where individuals improved as a result of the attention on them from taking part in a study, rather than due to the intervention itself (Richardson *et al.* 2005).

Lorig and colleagues, as I indicated in Chapter One, provided much of the impetus for approaches such as the Expert Patient Programme, producing a significant body of evidence originally developed around supporting individuals with arthritis (Lorig & Holman 1993; Lorig & Holman 2003). However, a review of education interventions for individuals with rheumatoid arthritis (Riemsma *et al.* 2003) indicated relatively poor outcomes as measured by a wide range of physical and psychological measures. Other reviews of self-management education for individuals with osteoarthritis indicated that exercise in particular was useful for individuals in reducing their pain, and improving the functional aspects of the condition and the quality of their life (Devos-Comby, Cronan, & Roesch 2006; Smith, Kumar & Pelling 2009). In an eight-year follow up of an

arthritis self-management programme in the UK, Barlow *et al.* (2009) suggested that short term improvements in self-efficacy, psychological well-being and individuals' use of some aspects of self-management were sustained in the long term, although the researchers were unable to attribute these findings to the group education as a control group was not studied at the eight year stage. However, individuals reported feeling less isolated and the authors considered that social comparison provided through attending group courses appeared to assist participants in accepting their condition (Barlow *et al.* 2009).

Lorig and colleagues have also evaluated the effects of generic courses for those with different types of long term conditions. In one US-based longitudinal study, Lorig *et al.* (2001) followed up a group of 831 individuals representing a variety of chronic conditions, for one and two years. The authors suggested that the group education programme significantly reduced the number of doctor visits undertaken by the participants, reduced their health distress, and improved their self-efficacy (Lorig *et al.* 2001). However, a Cochrane review of 17 trials of lay-led education for people with different chronic conditions reported only modest improvements in the confidence of individuals to manage their condition, with no effect on their quality of life or the number of visits an individual made to their doctor (Foster *et al.* 2007). In the UK, Kennedy and colleagues, based at the University of Manchester, undertook a randomised controlled study with 629 people who had various self-defined chronic conditions, to evaluate the Expert Patient Programme lay-led model, based on 6 weekly group sessions (Kennedy *et al.* 2007). The course followed a manual aimed at improving self-care skills, and incorporated sessions on relaxation, diet, fatigue, 'breaking the symptom cycle', managing pain and medication, and communication (Kennedy *et al.* 2007). The authors reported improvements in individuals' self-efficacy and energy levels, and increased health-related quality of life in those who received the group intervention, suggesting that this group approach was cost effective, despite there being no difference in healthcare utilisation between the intervention and control group (Kennedy *et al.* 2007). In

another paper, the same research team used QALYS, a quality-adjusted life year measure, and surmised that the lay-led group approach did represent a cost effective alternative to usual care in people with a long term condition, but also identified the need for more research to ascertain whether it did provide better value for money than other support approaches (Richardson *et al.* 2008a).

Other approaches, including online self-management programmes, have also been evaluated. In one study of 568 people in the UK, online support appeared to statistically reduce the number of visits individuals made to GPs, and improved their self-efficacy and feelings of satisfaction (Lorig *et al.* 2008). Lorig, Ritter and Plant (2005) have suggested that disease-specific self-management courses may have some advantages over generic courses, with those attending the former having a significantly greater improvement in global health and fatigue than those attending generic courses. Indeed, some authors have criticised the findings from the Lorig studies of generic group courses, arguing that the results were generally disappointing, overstated the evidence, and relied on self-selecting groups, with a relatively higher level of education than the general population (Newbould, Taylor & Bury 2006).

Where there is interest in the use of similar group approaches for people with cancer (Richardson *et al.* 2008b; Wilson 2008), the research is limited and tends to focus on exercise-based interventions. In a Cochrane review, Markes, Brockow and Resch (2006) considered that exercise could be viewed as a supported self-care intervention for women with breast cancer. However, Rogers *et al.* (2004) reported that a group of women with breast cancer had low self-efficacy relating to their confidence to undertake exercise. An experimental research study undertaken in Scotland showed that a 12 week group exercise programme provided for women with early stage breast cancer brought functional and psychological benefit for the women, but did not significantly influence their quality of life as measured by the Functional Assessment of

Cancer Therapy-general instrument scale (FACT-G) (Mutrie *et al.* 2007). An Australian study of 67 women who had received breast cancer treatment compared the effect of a six week community-based individual education programme in rehabilitative exercise by a physiotherapist, with an eight week weekly group session with an exercise physiologist (Gordon *et al.* 2005). The study measured the changes in women using the Functional Assessment of Cancer Therapy–Breast Cancer plus arm morbidity (FACT-B+4) questionnaire and QALYS (Gordon *et al.* 2005). Findings from the study indicated there was a similar increase in quality of life scores over both groups, but suggested that early individualised physiotherapy may be more beneficial in improving women’s upper body function, and more cost effective overall than delayed group exercise programmes (Gordon *et al.* 2005). As I will show later in this chapter, there is some indication, but little firm evidence, that approaches to exercising may be useful in relation to reducing the risk of lymphoedema, or improving lymphoedema swelling in women after breast cancer (Bracha & Jacob 2010; Moseley & Piller 2008).

In the US, a process evaluation of a ‘Taking CHARGE’ programme for women following breast cancer treatment incorporated two small group meetings and two individualised telephone calls for women aged 34-66 years. The programme appeared to enable women to deal with their initial concerns following breast cancer treatment (Cimprich *et al.* 2005). Another study with 48 women undergoing chemotherapy for breast cancer evaluated an intervention of three telephone calls and written self-care measures (Craddock *et al.* 1999), but reported no significant difference in the women’s use of self-care measures between those who did or did not receive the intervention.

In summary, whilst there has been substantial research into a variety of self-care and self-management support approaches for a range of people with different long term conditions, the evidence for the effectiveness of these remains limited. Furthermore, there have been few studies of interventions to

support self-care in women with breast cancer. This is surprising given that there is some evidence that exercise may improve women's shoulder function and mobility after breast cancer (Chan, Lui & So 2010), and that women want information and support to be able to manage their symptoms and deal with the distress of living with cancer and its treatments (Schmid-Büchi *et al.* 2008). There is currently no research evidence on the efficacy of either group or individual approaches for individuals with lymphoedema.

2.4.4 Limitations of the review

This current review has revealed inconsistencies in relation to the quality of evidence for supported self-care. Reviewers have commented on the relatively small subject samples used within studies (Riemsma *et al.* 2003) and the heterogeneity within studies incorporated in reviews, leaving little scope for meta-analysis (Coster & Norman 2009; Smith, Kumar & Pelling 2009). Several authors identified a lack of clarity in what interventions were used in studies, or the comparators such as standard treatments (Berzins *et al.* 2009; Chodosh, Morton & Mojica 2005; Coster & Norman 2009). This made it difficult to identify how resources such as action plans were used, or to recognise the essential features or active ingredients of a self-management programme (Chodosh, Morton & Mojica 2005; Deakin *et al.* 2009). Berzins *et al.* (2009) also argued that a broad range of activities may be subsumed the heading of 'patient education'.

Many papers did not give adequate explanation of the randomisation processes used and, given the nature of the approaches and conditions, individuals were not readily blinded to the interventions within randomised controlled trials, nor were placebo treatments easily given in this type of research design (Coster & Norman 2009; Richardson *et al.* 2005). Indeed, Richardson *et al.* (2005) suggested that randomisation might be undertaken in relation to centres, rather than within centres, to reduce the opportunity for individuals to meet and share ideas, so leading to 'cross-contamination' within the data (Richardson *et al.*

2005). These authors also suggested that as most individuals would be likely to be undertaking some level of self care, consideration could be given to comparing active interventions (Richardson *et al.* 2005).

Furthermore, the literature indicated a variety of instruments used in studies to measure aspects such as physical function, levels of disability, pain, disease-specific variables, illness knowledge, exercise, diet, treatment adherence, aspects of depression and anxiety, self-efficacy, quality of life and health service usage (Berzins *et al.* 2009; Coster & Norman 2009; Devos-Comby, Cronan, & Roesch 2006). It was not always clear how instruments had been validated; some were clinical measures used in a trial setting (Chodosh, Morton & Mojica 2005), while others were openly critiqued. For example, Lorig and Holman (1993) established self-efficacy, a concept developed from social learning theory (Bandura 1982), as a measure of the confidence of an individual in performing or changing a specific behaviour. The researchers included self-efficacy measurements in the evaluation of the arthritis self-care management programmes developed in the US (Lorig *et al.* 2001). However, where Richardson *et al.* (2008a) proposed that self-efficacy may be important to cost evaluation studies, Taylor and Bury (2007) suggested that the theoretical underpinnings of the concept of self-efficacy were questionable, with a lack of clarity in terms of how self-efficacy as an independent variable was related to self-management ability.

In addition, it was argued that a focus on the more immediate and visible changes in symptoms and physical measures might deflect attention away from long term aspects such as psychological and social functioning that could be more difficult to capture (Barlow *et al.* 2002; Coster & Norman 2009; Warsi *et al.* 2004). Commonly, studies included in reviews undertook limited follow up of individuals (Deakin *et al.* 2009; Effing *et al.* 2009), and used varied follow-up periods, leaving reviewers forced to make pragmatic decisions on how to collate the data (Riemsma *et al.* 2003). Riemsma *et al.* (2003) identified a need for

more disease specific rather than generic programmes of support to be conducted. Reviewers also called for more attention to be paid to specific groups such as people over 75 years, who might be more likely to experience conditions such as hypertension, osteo-arthritis or diabetes mellitus (Berzins *et al.* 2009).

A lack of economic evaluation was evident. Richardson *et al.* (2005) suggested that trials were largely pragmatic, taking place in a normal health care setting, thus bringing collateral benefits such as reduced waiting times for others to see a GP, additional outcomes which should be measured. Writers also argued that where the evidence for the cost-effectiveness of approaches such as group support was limited, an emphasis on using these approaches may direct resources from other more equitable ways of providing support (Newbould, Taylor & Bury 2006). Dennis *et al.* (2008) considered that resources should focus on embedding self-management programmes in primary care, and enable access to members of culturally diverse groups, who would not always readily access this type of service.

2.4.5 Summary and implications for the thesis

Approaches such as Cochrane systematic reviews place high value on experimental research, derived from objectively tested hypotheses and 'controlled' trials, providing empirically verifiable claims to knowledge (Tanesini 1999) and answering questions about the efficacy, cost-effectiveness and safety of treatments and drugs. In this current review, these types of systematic reviews, drawing on positivist research approaches, were found to focus mainly on the concept of self-management in evaluating various approaches to supporting individuals with long term conditions. However, methodological difficulties present in the studies suggested that evaluating the cost-effectiveness and efficacy of approaches related to supported self-care may be a more complex issue. Although benefits were indicated, there appeared to be limited research evidence to fully support the policy directions described in

Chapter One. This suggests that within an ideology of evidence-based practice, reliance on 'high-level' objective evidence through methodologies such as Cochrane reviews may be inadequate in fully illuminating supported self-care. Importantly, the contribution of nurses and other allied health professionals was often not well articulated in reviews, and details of which health professionals were involved in providing support was often not made explicit, despite the potential importance of the professional background of the healthcare worker to the interaction (Coster & Norman 2009).

There are implications here for the thesis. It is clear that drawing on positivist approaches reliant on standardised outcomes developed from professional perspectives may ignore important contextual information about the self-care and support experiences of research informants. The literature indicates a developing interest in seeking evidence for self-care support in people with cancer (Wilson 2008), and at the end of life (Johnston *et al.* 2009). However, questions arise regarding how the approaches used for people with other long term conditions might be applied to individuals with lymphoedema. This current review has indicated a need to develop more descriptive evidence regarding the context of self-care, and the relationship between a health professional and individual with a long term condition, before seeking to establish experimental research designs through which interventions to support self-care in women with lymphoedema might be evaluated. It is also not clear to what extent interventions such as individual or group education directly empower women with lymphoedema to undertake self-care, or enable women to address their own personal goals, as described in the policy rhetoric discussed in Chapter One. In order to expand the scope of understanding within the thesis, the present review now considers evidence drawn from qualitative research approaches, to explore how supported self-care was construed and represented within the literature. This has been organised in several themes: self-care as a dynamic process; self care as influenced by social and contextual variables;

self-care as creating control; and self-care in relation to the professional: person relationship.

2.4.6 Self-care as a dynamic process

In their US based study in which they interviewed 50 individuals between 55-91 years, around three quarters of whom were healthy and active, Berman and Iris (1998) showed that many informants used multiple approaches to take care of themselves. As such, the authors identified the need to appreciate the dynamic nature of self-care, as changing over time in relation to any one individual, and as varying between individuals and across different ethnic groups (Berman & Iris 1998).

Several reviews of qualitative research studies have emphasised that individuals undertake self-care of a long term condition as part of an evolving and dynamic process (Chapple & Rogers 2001; Godfrey *et al.* 2010a; Spenceley & Williams 2006). Thus, Chapple and Rogers (2001) suggested that health professionals must recognise how self-care changes within the context of people's lives and explore an individual's beliefs and practices, seeking to reinforce what they are already doing. The authors described how timing may be critical in terms of when people are ready to take on self-care, and considered the importance of family members in being able to influence how self-care activities are used, particularly if individuals experience a stigmatic element to their condition (Chapple & Rogers 2001).

In their review, Godfrey *et al.* (2010a) asserted that self-care behaviours may be influenced both positively and negatively by others. The authors emphasised the importance of support, particularly when individuals may be overwhelmed by their symptoms or disability. This reflects the notion of an illness trajectory (Corbin & Strauss 1988) where particular stages of an illness, such as at the point of 'diagnosis' when an individual may be seriously affected by symptoms (LTCAS 2008), may bring particular challenges for self-care. In an analysis of

their findings from several studies, Thorne and Paterson (2001) described self-care as evolving, with individuals requiring support from health professionals who recognised the relevance of the illness trajectory, enabling individuals to move beyond the more passive and dependent position that may be evident in earlier stages.

In a study of 12 individuals with a chronic condition and their health care professionals such as community nurses, using a grounded theory approach, Baker and Noerager Stern (1994) suggested that an individual's readiness to undertake self-care was a complex and dynamic matter. These authors described the process of 'finding meaning' in the illness as a step towards making sense of self-care messages from professionals, or viewing themselves as a self-care agent (Baker & Noerager Stern 1994). Coates and Boore (1995) also suggested that nurses working from a compliance model of self-care, dominated by a medical model approach, may fail to recognise that the way in which an individual manages their illness will vary according to their changing life context.

2.4.7 Self-care as influenced by social and contextual variables

In their review, Spenceley and Williams (2006) emphasised the need to consider support for self-care in relation to dynamic, contextual elements and social barriers to self-care such as lack of money, social isolation, lack of access to health care and unrealistic health provider goals. Anderson, Blue and Lau (1991) viewed the process of restructuring life in the face of illness as taking place within a complex personal, socio-economic and political nexus. In their feminist-informed case study research with immigrant Chinese and Anglo-Canadian women in Canada, they argued that styles of managing chronic illness and self-care should be understood in terms of class relations and social processes that organised the experience of illness (Anderson, Blue & Lau 1991). As such, the authors surmised that an ideology promoting individualised self-care and self-responsibility could exclude groups such as immigrant women

who did not have ready access to financial and other supportive resources, or were unfamiliar with the dominant professional discourses (Anderson, Blue & Lau 1991). Thus it appears that particular individuals may be rendered relatively powerless by specific approaches taken to providing support. In a later study, the researchers interviewed women with chronic illness, and also health professionals, showing how the social constraints experienced by the women influenced their ability to follow through a regime of prescribed self-care (Anderson, Dyck & Lynam 1997). The authors argued for a critical consciousness on the part of health professionals in recognising that health and illness are social and not just professional practice issues (Anderson, Dyck & Lynam 1997).

In a study in Scotland, 23 individuals in their early 50s who had chronic illness were interviewed twice (Townsend, Wyke & Hunt 2006). Experiencing difficulties with containing symptoms was a common concern amongst individuals, affecting their ability to function in what the researchers defined as culturally-valued ways (Townsend, Wyke & Hunt 2006). Importantly, individuals prioritised maintaining valued social roles at work and at home over controlling their symptoms (Townsend, Wyke & Hunt 2006). In another Scottish study, the experience of an individual woman who was diagnosed with diabetes when she had no symptoms, and her subsequent referral to community rather than hospital services, was identified by the researchers as bringing the individual to underestimate the seriousness of her diabetes and the relative importance of self-care (Lawton *et al.* 2005). This suggested that the way health services are provided, and the nature of the condition and how it presents or is 'detected' can provide important cultural messages that influence individual motivation to undertake self-care.

Taking a realist critical interpretative approach, Vassilev *et al.* (2010) provided a review of literature relating to the family and community social networks that underpinned self-care interactions. The authors recognised that self-care for

long term conditions appeared to operate within a professional and individualistic rather than a community-centred model. They suggested that current literature did not reach beyond more traditional structures for supporting self-care, or consider opportunities for reconfiguring networks to support self-care, particularly in socially and economically deprived communities (Vassilev *et al.* 2010). This suggests that policy views of partnership approaches to support, as identified in Chapter One, are not readily in evidence, and that developing alternative ways for providing support, that look beyond professional visions, may be an important challenge.

2.4.8 Self-care as creating control

Earlier in this review I drew attention to a UK qualitative study of an eight week, community-based educational programme for people with Type 1 diabetes (Booker, Morris & Johnson 2008). This study indicated that having regular contact with others with similar problems enabled individuals to develop an increased sense of control over their lives (Booker, Morris & Johnson 2008). Similarly, in an Australian study, Kralik *et al.* (2004) drew on the autobiographies of nine individuals with arthritis, supplemented by telephone interviews and a group discussion, concluding that self-management was an active process that enabled individuals to create or maintain control in their lives. In a further study, Koch, Jenkin & Kralik (2004) used in-depth interviews and action research groups with 24 adults with asthma, identifying three models for self-management: the medical model; the collaborative model of self-management; and the self-agency model. The latter model was explicated by the researchers as a level of self-determination where individuals with asthma took control and became experts in their condition as part of reclaiming the 'self' (Koch, Jenkin & Kralik 2004). In another interview study with 24 low to middle income adults with asthma, Canadian researchers identified that while some tolerated symptoms, particularly if they found their treatments were unacceptable, the experience of a crisis such as a severe asthma attack,

motivated individuals to use self-care strategies that exerted more control over their condition (Loignon *et al.* 2009).

In a two year qualitative enquiry into self-care decision-making in individuals with Type 1 diabetes, based on grounded theory, Paterson *et al.* (1999) involved 22 adults in undertaking self-recording of their decision-making, also employing interviews and a focus group to gather data. In this Canadian study the researchers described the 'transformation' experiences through which individuals addressed challenges and made a conscious decision to assume control of the self-management of their diabetes, through a type of objectification of the body as differentiated from the self (Paterson *et al.* 1999). In a later study, Thorne, Paterson & Russell (2003) used a similar research design over a period of 12 months with 43 participants with experience of several years of living with a chronic condition (HIV/AIDS, multiple sclerosis or diabetes). The findings showed that all participants shared a common need to exert control over the disease rather than being controlled by it. This was illustrated by the authors in terms of how individuals monitored their bodily symptoms, and established personal self-care goals, relying on personal experience rather than standardised knowledge (Thorne, Paterson & Russell 2003). The notion of objectification is relevant to the thesis and will be discussed in more depth in Chapter Seven.

Researchers in Scotland used semi-structured interviews to explore the experiences of self-care in 11 adults undergoing chemotherapy for colorectal cancer (Kidd, Kearney & O'Carroll 2008). The authors described how some individuals took an active role in self-care in an attempt to preserve their self-identity and normalise what was happening to them (Kidd, Kearney & O'Carroll 2008). Self-care was viewed as involving physical and emotional elements. In a later paper relating to the same study, the researchers described how an individual's perception of control over their symptoms influenced their approaches to self-care (Kidd *et al.* 2009). The researchers suggested that

regular and individual assessment of self-care needs and preferences, and tailored support from nurses, could be used to enhance an individual's perception of being able to control the physical and emotional aspects of their condition and treatment (Kidd *et al.* 2009). To an extent, exerting control over a condition through self-care may be a form of power enacted on the body. I will further discuss the notion of control and the relevance to supported self-care in Chapter Seven.

2.4.9 Self-care in relation to the person: professional relationship

In their literature review (see Appendix 3), Spenceley and Williams (2006) described the importance of a trusting relationship or partnership between the person with a long term condition and a health professional, as a basis for effective self-care. In a further report of their study of 22 individuals with diabetes, as identified in the previous section, Thorne and Paterson (2001) suggested that 'patient' education often assumed a linear relationship between appropriate information imparted by the professional, a reasonably trusting relationship between person and practitioner, and effective self-management decisions. However, the authors also recognised that within this relationship a professional might prescribe or recommend treatments or self-care that were unrealistic, impractical or financially out of the reach of individuals, so rendering the person powerless (Thorne & Paterson 2001). This illustrates how 'support' within a healthcare relationship may be manifested and influenced by a power differential between the 'expert' professional and the passive 'patient'. Indeed, there may be various ways in which this power may be more or less explicit within the relationship.

For example, in another study, Thorne, Ternulf Nyhlin and Paterson (2000) described how professional attitudes about conditions not readily classified within a biomedical framework, such as 'environmental sensitivities', fuelled a distrust within the person: professional relationship, and brought a sense of alienation for unwell individuals who felt their self-knowledge and expertise was

not recognised by health professionals. In a further study using interviews with individuals with a range of chronic conditions, Thorne *et al.* (2004) described how biomarkers and objective indicators influenced the perceived legitimacy of a chronic condition by the professional. The point here is that the acceptance or disregard of an individual's symptoms or problems may represent an enactment of power within the relationship. Furthermore, professionals may take particular approaches to support that enable them to be more or less attentive to an individual's subjective reports of their symptoms.

In a UK study involving 31 people of various ages with varied respiratory conditions, individuals kept illness diaries, and took part in telephone interviews and focus groups (Kielmann *et al.* 2010). Some individuals appeared comfortable to take responsibility for their self-care while others gave the impression to researchers of feeling 'abandoned' by professionals when left to take on the responsibility of self-care. This appeared to suggest that what the professional viewed as support with self-care may have had the potential to be construed by the individual as withdrawal of professional services. Prompt and flexible access to professionals through varied methods of communication, were valued by individuals undertaking self-care, although the authors argued that new policy directions brought a multiplicity of new roles which made the boundaries between professional and self care more difficult for individuals to negotiate (Kielmann *et al.* 2010).

The notion of the 'expert patient' (Department of Health 2001) provides a further basis for exploring the location of power within healthcare relationships. Wilson, Kendall and Brooks (2006) identified the difficulties for generalist nurses in communicating with, and supporting, 'expert' patients with their self-management. Undertaking focus groups, interviews and observation with nurses, doctors and physiotherapists in the UK, the researchers showed that nurses were more anxious, when compared to doctors and physiotherapists, about the concept of working with an 'expert' patient who may know more about

their condition than the professional (Wilson, Kendall & Brooks 2006). Nurses lacked flexibility, were overly concerned about litigation, and although they were observed by the researchers to be the professionals best placed to give emotional support, nurses found it difficult to fully articulate the ways they provided this type of help (Wilson, Kendall & Brooks 2006). Notably, it was specialist nurses who appeared more confident than generalist nurses in being able to enter into therapeutic dialogue with individuals who had long term conditions (Wilson, Kendall & Brooks 2006). This study suggested that where power may be viewed as resting with an 'expert patient', some nurses may perceive this as a difficult concept to embrace, as identified in the policy discussion in Chapter One.

In a grounded theory study in the UK, Macdonald *et al.* (2008) undertook semi-structured interviews with 25 Practice Nurses to explore their views on self-care, and their attitudes towards the Expert Patient Programme. Interviewees appeared most confident in helping individuals who were in the early stages of their condition. The nurses viewed the time of diagnosis as an important stage for establishing a working relationship with individuals, and becoming aware of relevant biographical and social dimensions of the person and their illness. At the intermediate stages, nurses used education approaches to work with individuals, teaching them how to undertake tasks, encouraging them and involving their carers (Macdonald *et al.* 2008). Nurses found it more difficult to articulate their role at later stages, and the researchers reported that nurses often relied on repeated information-giving in the absence of their knowledge of behaviour change strategies (Macdonald *et al.* 2008). However, instances of perceived 'non-compliance' of 'patients' appeared to be a point for renegotiation and continuing dialogue (Macdonald *et al.* 2008). This study suggested that the focus of their role with individuals with long term conditions may be difficult for some nurses to identify, unless it is readily associated with providing particular 'helping' interventions. These findings indicate that there may be potential

challenges for professionals in creating effective relationships with people, in which support is provided over the long term.

The different ways in which forms of support such as anticipatory care may be construed by professionals were identified in a study undertaken by Kennedy *et al.* (2011). In this Scottish study, researchers observed and interviewed Community and Practice Nurses as they worked with individuals who had long term conditions, and also interviewed a number of these 'patients'. The researchers noted the subtle and different ways in which nurses provided anticipatory care, and anticipated the future health needs of individuals (Kennedy *et al.* 2011). Where Practice Nurses were focussed on helping people manage a specific condition, Community Nurses were used to working with people with a number of health problems, and appeared to take a more individualised and life-centred approach (Kennedy *et al.* 2011). Difficulties with taking an individualised approach were also reflected in a literature review that identified nursing consultations about self-care as often medically focussed, and not taking cognisance of an individual's routines and current self-care practices, or modifying advice according to bodily cues (Rees & Williams 2009). The evidence suggests that further work is required to better understand the processes that inspire effective partnership in supporting self-care (Rees & Williams 2009).

Several authors have identified the importance of professionals taking a person-centred approach within the supported self-care relationship (Johnston *et al.* 2009; van Dam *et al.* 2003). McCormack and McCance (2010) have asserted that working in a person-centred way means treating people as individuals, building trust and understanding within a therapeutic relationship. The work of Carl Rogers in relation to the helping relationship suggests this is an approach in which the individual is viewed as an 'expert' who is enabled by the professional to '*be that self which one truly is*' (Rogers 1961, p.173). However, a review of 'patient-centred care' suggested that this concept was often viewed

in the literature in the context of successful adherence to treatment, rather than a more egalitarian view of a therapeutic alliance (Mead & Bower 2002).

The literature suggests that difficulties may arise for professionals in identifying their role within the supported self-care relationship, particularly over the long term support of individuals with chronic conditions. The relationship may evolve over time and the quality of the relationship may influence the success of supported self-care. This is relevant to the thesis as women with lymphoedema often attend lymphoedema clinics over a period of many years. Furthermore, the different terms used, such as 'patient', 'person' and 'expert', may also indicate different perceptions of the individual with a long term condition as a more or less equal or powerful partner within the relationship.

2.4.10 Summary and implications for the thesis

In summarising Sections 2.4.6 to 2.4.9, it is clear that self-care may be conceptualised in different ways; as dynamic; as influenced by context; as a means for creating control; and in terms of the relationship between the person and the professional. There is evidence that self-care and support may be viewed as dynamic forms of power. Indeed, the literature indicates that power may be characterised in different ways within a healthcare relationship, with the potential to shift between the professional and the individual with a long term condition. This suggests that exploring the structures and processes that influence the dynamics of power may be relevant to an understanding of supported self-care and are relevant to the thesis.

2.4.11 Supported self-care in people with lymphoedema

This section draws on research evidence and relevant literature to identify the state of current knowledge relating to lymphoedema self-care and support. In their advice booklet for people with lymphoedema, Todd and Mortimer (2007) recognised a key role for individuals with lymphoedema in undertaking self-care:

'Despite recent advances [in treatment] there is still no treatment that will cure the problem [of lymphoedema] and make it go away for good. But you can learn how to carry out some of the treatment that will help you to control your lymphoedema' (Todd & Mortimer 2007, p.1).

This quote emphasises a point made in Chapter One that the woman who undertakes self-care or self-management is indeed a resource in the health care structure (Rogers, Hassell & Nicolaas 1999). However, a review of treatments for individuals with lymphoedema associated with breast cancer (Devoogt *et al.* 2009) noted that the effectiveness of skin care, exercises, wearing a compression sleeve, and elevating the arm, all examples of self-care, has not been established through robust research. Furthermore, in the UK, an 'empowerment matrix' which appeared to be concerned with supporting self-care in people with lymphoedema was in essence a means for rationalising treatment and care (Todd, Harding & Green 2010). This 'empowerment' approach indicated that an underlying political agenda may dominate professional perspectives on self-care, leading to a focus on discharging individuals from professional lymphoedema services to undertake their own self-care or self-management.

In a US-based phenomenological study where 12 women with lymphoedema associated with breast cancer were interviewed three times, Fu (2005) showed how the women undertook specific self-care activities, motivated by their intentions to minimise the threat or consequence of uncontrollable lymphoedema (Fu 2005). However, where Fu identified that women made conscious decisions to avoid activities that exacerbated their lymphoedema, she also showed that they were also more likely to continue with those actions that were effective and low maintenance, and could be readily incorporated into their daily routine (Fu 2005). This may have particular implications in terms of how support with self-care is provided to women, for example, in relation to timing, content and context.

In a paper reporting on a series of studies concerned with the measurement and prediction of lymphoedema in women after breast cancer, Armer *et al.* (2008) drew on Orem's nursing theory to identify the various 'self-care deficits' relevant to women with lymphoedema. The authors described a supportive-educative role for nurses in enabling women to make judgements and decisions about self-care, by designing a plan to support self-care that took account of how the person viewed and was affected by their condition. In a subsequent paper they reported on a small survey undertaken with 14 women, embedded in a larger prevalence study (Armer *et al.* 2008). In this later paper they identified a range of conditions and situations such as lack of information, fear, lack of interest, family life patterns, and difficulties in controlling body movements that influenced women's motivation and ability to undertake self-care (Armer, Brooks & Stewart 2011). Specifically, the authors suggested that education alone may be inadequate, and considered that other supportive approaches such as cognitive behaviour therapy or motivational interviewing, may provide a means for enabling and empowering individuals towards effective self-care (Armer, Brooks & Stewart 2011). Although these are useful insights, they appear very professional-centric, focussing on behaviour change, and professional goals, as key aspects of self-care.

It has been recognised that the type of self-care activities 'prescribed' for people with lymphoedema may vary across different professional groups of nurses, physiotherapists and massage therapists (Langbecker *et al.* 2008). However, as identified in Chapter One, the role of lymphoedema practitioners in providing support with self-care has not been researched or articulated in any detail. Furthermore, in a review of relevant literature, Moseley, Carati & Piller (2006) described 'self-instigated therapy' as having a limited effect on women's lymphoedema limb volume when compared to therapist-provided treatments. In a small audit, Jeffs (2006) indicated that a 'self-care package' including skin care, exercise and compression sleeves was less likely to reduce limb swelling than therapist-delivered treatments in women with breast cancer-related

lymphoedema. Vignes *et al.* (2007) undertook a non-randomised cohort study of 527 women with arm lymphoedema, and suggested that 'maintenance therapy' including self-bandaging at home, may lead to limited or no reduction in the arm size. The researchers identified that lack of 'compliance' with wearing elastic sleeves during the day, and self bandaging at night, was likely to lead to worsening of the swelling (Vignes *et al.* 2007). Significantly, a study in which 34 women with lymphoedema associated with breast cancer were interviewed three times, Fu & Rosedale (2009) described women's frustrations when their lymphoedema did not improve, even where they did make various attempts at self-care.

The above literature indicates the potentially poor outcomes from self-care and the limited quality of evidence to support the various lymphoedema self-care activities outlined in Chapter One. A few studies have evaluated specific aspects of self-care including self-massage, diet, exercise and preventative care. Studies of self-massage have been incorporated into evaluations of manual lymph drainage, and have been generally inconclusive (Sitzia, Sobrido, Harlow 2000; Williams *et al.* 2002). However, a small randomised controlled trial in the UK reported self-care support in the form of dietary advice from a professional to reduce energy intake, as leading to a significant reduction in body weight and arm volume in women with breast cancer-related lymphoedema (Shaw, Mortimer & Judd 2007).

A number of papers have indicated a possible benefit for women with lymphoedema in undertaking exercises (Ahmed *et al.* 2006; Bicego *et al.* 2006; Chan, Lui & So 2010; Moseley, Piller & Carati 2005). However, Chan, Lui and So (2010) also identified variations in the types of exercise being used in studies, and found little evidence comparing the efficacy of exercise guided by a health professional with 'self-administered' approaches. In an Australian study, 24 women who had lymphoedema associated with breast cancer undertook ten minutes of arm exercises and deep breathing, twice daily for a month (Moseley,

Piller & Carati 2005). The findings showed a reduction in limb volume which was not statistically significant but did indicate significant improvements in subjective symptoms such as arm heaviness (Moseley, Piller & Carati 2005). Small studies have also been undertaken into the use of weight training (Ahmed *et al.* 2006), and dragon boat racing (Lane, Jespersen & McKenzie 2005). These reflect a recurring theme that supports the use of exercise as an important form of self-care for women with lymphoedema or those at risk of lymphoedema. Indeed, in a survey of 175 women who had undergone breast cancer treatment, Lee *et al.* (2009) showed that women who avoided strenuous arm activity were more likely to report upper limb symptoms such as stiffness, swelling and heaviness. This suggests there is some evidence, albeit limited, that health professionals should actively target information and support to encourage women at risk of lymphoedema, or those who have lymphoedema, to undertake exercise (Lee *et al.* 2009). This echoes findings earlier in this current review that women with breast cancer may benefit from undertaking exercise.

Commonly, professional support given to women about what they can do in the form of self-care to prevent or minimise the risk and effects of lymphoedema takes the form of written or oral information and advice. However, a lack of information available to individuals with lymphoedema in terms of self-care and risk reduction activities has been a predominant theme in the literature (Bani *et al.* 2007; Bosompra *et al.* 2002b; Fu, Axelrod & Haber 2008). Furthermore, a survey of centres in the UK showed that information given to women about reducing their risk of lymphoedema varied in quality and content (Todd & Topping 2005). Such risk reduction activities may include protection of the arm from injury, excessive heat, heavy lifting or tight clothing, and monitoring for changes to the skin and infection (Fleysher 2010; Lymphoedema Support Network 2007). However, a study of risk reduction behaviours in 136 women after breast cancer treatment (Fu, Axelrod & Haber 2008) identified that only 57% of the women reported receiving information about lymphoedema.

Significantly, those who had information were more likely to undertake various self-care risk reduction behaviours, while 41% of those who did not receive information had swelling indicative of lymphoedema (Fu, Axelrod & Haber 2008).

2.4.12 Summary and implications for the thesis

There is minimal evidence in the literature to inform an understanding of women's self-care activities and their context in relation to lymphoedema associated with breast cancer. There are, however, indications that specific aspects of self-care such as arm movement and exercise may be highly relevant to women with lymphoedema associated with breast cancer. Evidence earlier in the literature review indicated that self-care may be a dynamic experience, and one that is difficult to evaluate. As lymphoedema is a relatively new and under-resourced area of healthcare, there may be particular challenges in identifying valid and sensitive outcome measures, and addressing the many co-variables existing in the lives of individuals with lymphoedema. The findings from this review indicate that questions remain regarding the nature of self-care and professional support for women with lymphoedema. Importantly, there are gaps in the evidence as no research studies have examined in any depth the ways in which support is represented within the relationship between a woman with lymphoedema and a health professional such as a lymphoedema practitioner. Thus, there are implications for the thesis in seeking to inform the policy notion of changing roles for the person and the professional, as outlined in Chapter One, in the context of lymphoedema self-care.

2.5 The body in health care

2.5.1 Introduction

It is my contention that the body is a central consideration in this study of supported self-care. I showed in Chapter One that women with lymphoedema experience various physical changes to their body, and that the body is the

focus of various self-care activities such as self-massage, which is a type of work on the body. Professional bodywork is also fundamental to the work of health professionals such as lymphoedema practitioners, who not only use physically-based therapies such as manual lymph drainage massage and bandaging, but also enable the woman to learn and undertake her own bodywork. However, Twigg, Wolowitz, Cohen *et al.* (2011) considered that status in health professions tends to be marked by increasing distance from the body; thus bodywork may be relegated to the status of relative unimportance in health care, as those who are more senior often have less contact with the bodies of 'patients'. Significantly, specialists such as lymphoedema practitioners, who may have relatively senior roles, often do have regular contact with the bodies of individuals in their care.

The purpose of this section is to provide an integrative review which examines theoretical perspectives and empirical research relating to the body in healthcare, and to identify the implications for the thesis. The literature search incorporated the Cochrane and JBI databases, CINAHL and PsycINFO from 1995-2010 inclusive. Search terms were: 'body', 'bodywork' combined with 'nursing', 'physiotherapy', 'long term conditions', 'chronic illness', 'breast cancer' and 'lymphoedema'. The Edinburgh Napier University Library was also searched for relevant theoretical and empirical texts with no date restrictions, to enable early theoretical work to be incorporated. Other relevant sources were identified through scrutinising reference lists of papers and books, to ensure particular seminal work was captured. A total of 1009 sources were identified and abstracts scrutinised for relevance to the review. A final 54 literature sources were included in this review, due to their specific focus on theoretical perspectives or relevant empirical research.

The review firstly critically examines five theoretical perspectives relating to the body, and considers their relevance to the thesis. It then provides an overview of the literature relating to the body in breast cancer, and in long term

conditions. Finally, it incorporates a brief overview of the literature relating to the body in healthcare, drawing in particular on nursing literature. The section ends by discussing how the review has enabled the identification of research questions and informed the research design, and particularly, a decision to incorporate field observation in the study.

2.5.2 Theories of the body

The body can be conceptualised in various ways as outlined in Table 2:1. These provide different insights into how the body may be viewed in relation to supported self-care. For example, as an anatomical construction, the body may be known and illustrated as in the diagrams of the lymphatic 'system' (see Figures 1.6 and 1.7), where it is notably one dimensional and often anatomically depicted as male. Arguably, this is a rather reductionist and hence inadequate depiction of a highly complex system, used to teach women with lymphoedema and lymphoedema practitioners. However, that the lymphatic system had eluded anatomists of the past, due to difficulties in visualising the micro vessels in the lymphatic network, may partly explain why Lymphology was not readily recognised as a medical speciality in the UK. The anatomical view of the body reflects the 17th Century thinking of René Descartes, a rather solitary French philosopher (Oakley 2000), who distinguished between the thinking person and the corporeal, arguing that the body may be viewed as independent of the mind/thought. Jewson (1976) described the move in the 18th Century, in part a product of the Scottish Enlightenment, away from a 'Bedside Medicine' that took a person-orientated total view of the body, incorporating aspects of emotional and spiritual life, towards a 'Hospital Medicine' and 'Laboratory Medicine' in which the body was differentiated into specialised anatomical structures.

The naturalistic body predominates in bio-medicine (Shildrick 1997), accounting for the body in biological terms. Seymour (1998) described how the naturalistic opposition of the male and female body represents a type of '*biological bed-rock*' where gender inequalities have been legitimised by medical power (p.3).

Table 2.1: Theoretical perspectives on the body	
Perspective	Theoretical focus
Anatomical body	<p>The body as known in Western medicine, linked to the Cartesian view that the mind/thought is independent of the body.</p> <p>The body is a machine that can be known anatomically and depicted in (usually) one dimensional images.</p>
Naturalistic body	<p>The fleshy, biological body.</p> <p>Assumes individuals are defined by the capabilities and constraints of their body such as genetics; used to account for gender differences in behaviour (Shilling 1993).</p> <p>The body can be a source of pain and pleasure due to physical and biological features.</p>
Social body	<p>The body is a metaphor for society; the social 'body' influences how we perceive and experience the physical body (Douglas 1970). Thus the body is shaped, and constrained by society (Shilling 1993).</p> <p>The body is how the self is presented to the world (Goffman 1959).</p> <p>Institutions subject the body to power through methods of 'surveillance' (Foucault 1989).</p>
Phenomenological body	<p>The body as object can be seen and touched, and as subject, can also see and touch (Merleau-Ponty 1962).</p> <p>The mind is always embodied, and an individual experiences and constructs their world through their body and the inter-subjective relationships with others and their environment.</p>
Post-modern body	<p>Late modernist notions of reflexivity mean the body is known in various changing ways, through narrative for example (Holstein & Gubrium 2000).</p> <p>The body has become a product to be worked on in consumerist terms (Lupton 1997).</p> <p>Developments in post-modern healthcare provide new understandings of the body, so distinctions between the mind and body no longer hold (Rudge 1997).</p>

The naturalistic body is represented by genetic changes that underpin some types of primary lymphoedema, and may in time be found to account for a woman's susceptibility to lymphoedema after breast cancer. Significantly, the anatomical body and naturalistic body are both associated with a positivist medical science that seeks to 'fix' body problems, for example, through surgery or pharmacological means. This view of the body is, however, challenged in long term conditions such as lymphoedema which may render the body unpredictable and unstable (Seymour 1998). Additionally, feminists have sought to challenge this binary thinking in which the body is thought of as a machine, separated from the mind, or bound by gendered or socio-cultural assumptions (Twigg 2006). Martin (1987) considered how women's views may be distorted by scientific metaphors about their naturalistic or anatomical body, and the dominant scripts about the body within society.

Social perspectives view the body as a product of social roles; shaped and constrained by society. Mary Douglas (1970) argued that a concern with maintaining body boundaries may exist at a time of threatened social identities and boundaries. This may be evident in the current focus in health policy on self-care of the body at a time of socio-economic threats when the macro body (and micro bodies) of individuals with long term conditions are viewed as a burden on society. Goffman (1959) recognised the body as the way the self-identity is presented to the world. His theory relating to the management of 'spoiled identity' (Goffman 1963) described the significance of potentially stigmatic visible or non-visible body changes in devaluing the social identity of those affected. This may have particular resonance for lymphoedema, as a potentially visible and stigmatising condition.

Michel Foucault wrote widely about the body as a source and site of power relations, analysing in particular the medical transformations of the 18th and 19th Centuries (Armstrong 1994) and, in particular, the growth of medical schools in Edinburgh and Paris (Foucault 1989). Foucault (1989) recognised how a type

of institutional and disciplinary power was enacted on the body as a result of the 'medical gaze', constituted by medical surveillance of the body, and reflected in medical discourses concerning the labelling and classifying of conditions in relation to specific symptoms. Significantly, he described his observation that the task of a doctor was somewhat political in addressing inequalities and *'dictating standards for physical and moral relations of the individual and of the society in which he lives'* (Foucault 1989, p.40). This indicates that public health and the enforcement of a care of the self and body may be viewed as residing within the power and responsibility of medicine. Equally, it could be argued that a type of self-surveillance is being delegated to women themselves through self-care and the use of self-reported symptoms of lymphoedema (Armer *et al.* 2003). Important to the thesis is the point that power is not necessarily exercised as an obligation, nor merely a source of repression, but may be invested in individuals. It is also transmitted by them, and is not fixed (Foucault 1980). Power may shift between individuals, as I alluded to in the previous section of the review, but is also productive, and used to form new knowledge (Foucault 1980). Bradbury-Jones, Sambrook and Irvine (2008) have argued that within this post-structuralist notion of power, nurses and other professionals must look beneath the discourses of empowerment and become aware of how their own body, and those individuals for whom they care, are subject to the gaze of surveillance and the exercising of power. Examples of these are the rationalising processes and schemata such as standardised care pathways used to organise the 'bodies' of individuals with lymphoedema (NCAT 2009; Todd, Harding & Green 2010). Thus arguably, the body as a site of control and power has social and political significance as a potential 'burden' on the health economy, but also constitutes a source of power that may be exerted through self-care.

In terms of further theories, Merleau-Ponty (1962) rejected the dichotomous split of Cartesian thinking, describing a phenomenological view of the body that recognised the mind as embodied, and humans as social agents who

possessed a body through which they experienced their social world (Merleau-Ponty 1962) (see Table 2.1). Here, the body is viewed as having both an object side which can be seen and touched, and a subject side which sees and touches (Crossley 1996). This perspective has informed work by various nursing researchers, as I will show later in this section of the review. Important to the thesis is that this phenomenological view of the body challenges the dominant frameworks of the body as objectified and stripped of embodied emotion (McDonald & McIntyre 2001).

In post-modern perspectives (see Table 2.1) the body is viewed as belonging to a health 'consumer' (Lupton 1997), or as a project on which to be worked (Rose 1998). In post-modern times, technology also enables the inside and the outside of the body to be known in different ways (Lupton 2003). It is through the changing body that the self may be fashioned and shaped (Giddens 1991). Post-modern feminist writers have called for the traditional boundaries of the body (and self-identity) to be reconceptualised in terms of potentiality and flow, rather than containment, as a basis for understanding personal agency and political action (Battersby 1993). The post-modern body may, therefore, be known in different ways. Examples of this are found in the eloquent and reflexive illness narratives provided by individuals who have experienced illness, some of whom are social scientists (Frank 1995; Horlick-Jones 2011; Murphy 1990; Oakley 2007). A wide range of personal narrative accounts from women with breast cancer also show how the body has been perceived in many different ways: for example as one that is disintegrating and facing death (Picardie 1998); as one that can be altered by lifestyle changes (Plant 2003); and as one that bridges the personal and professional perspectives of breast cancer (Kaelin 2005).

It is also argued that post-modern fabrications and narrations of the body, for example within a social model of disability, may provide inadequate recognition of the '*impaired body*' (Williams 2003, p.101). The post-modern body is also

viewed as subject to collapsing hierarchies, pluralities of choice (Parker 1997) and risk (Giddens 1991). Relevant to the thesis, therefore, is the shift of 'patient' and professional roles described in Chapter One, as an apparent attempt to collapse power hierarchies. I have also indicated in Chapter One that post-modern healthcare may provide a battleground for different professional views, representing a plurality of choices. This context may be particularly bewildering for a woman who undertakes self-care of her body in relation to a condition such as lymphoedema.

In summary, this theoretical review has brought attention to different views of the body and indicated some areas of relevance for the thesis. Arguably, lymphoedema practitioners may be entrenched in the anatomical and naturalistic perspectives of the biomedical body, but they may be required to work in a phenomenological way as they enable women with lymphoedema to develop their self-care approaches and acknowledge the subjective experiences of lymphoedema. Furthermore, views of the social body draw attention to the body as a site and source of power within the supported self-care context. These insights inform discussions of my research interpretations in Chapter Seven.

2.5.3 The body in breast cancer

This section summarises the views of the body in relation to breast cancer. Although there is a vast array of literature in this area, a full critique is beyond the scope of this thesis. However, it is significant to note that much of this literature is framed around features of 'late morbidity' (Rietman *et al.* 2002), 'quality of life' (Gordon *et al.* 2005; Paskett *et al.* 2008), 'psychosocial needs' (Schmid-Büchi *et al.* 2008), 'sexual functioning' (Marshall & Kiemle 2005) and 'body image' (Helms, O'Hea & Corso 2008). Body function and quality of life are often measured using various scales such as the Functional Assessment of Cancer Therapy-Breast Cancer (FACT-B) (Gordon *et al.* 2005). A range of body changes such as weight changes, hair loss, and women's 'satisfaction'

with surgery, may be subsumed under the heading of 'body image' (Helms, O'Hea & Corso 2008). A loss of sexual self has also been associated with adjustment to life after having a surgically reconstructed breast (Marshall & Kiemle 2005). The point to make here is that 'the body with breast cancer' is talked of and measured in somewhat selective ways in academia, medicine and related disciplines.

Qualitative approaches to research do, however, provide a substantial literature reflecting how women talked of their bodies before, during, and after breast cancer, and a number of examples will be identified here. In an Australian longitudinal study undertaking a series of interviews with women after breast cancer treatment, Cromptvoets (2006) suggested that restoring health and wellbeing after breast surgery was commonly associated with regaining pre-surgical appearance, with the dominant 'message' from medicine, media, corporate and advocacy groups being that anything else was 'ugly'. Thus evidence of breast cancer might be concealed by restoring the breast shape through prosthetics or reconstruction, enabling, at least, a 'work-in-progress' restoration to some level of self, albeit a false one (Cromptvoets 2006). Cromptvoets (2006) argued that this dominant script did not provide room for individual exploration and that, consequently, the body was a site for many women of ambiguity and anxiety (Cromptvoets 2006). This has important implications for the thesis, as lymphoedema may be assumed to compound this ambiguity for some women. Even where shape might be restored to the breast, the swollen arm now provides a visible representation of having had breast cancer that cannot be so readily hidden.

Langellier and Sullivan (1998), in a US-based study, suggested that breast cancer disrupts a woman's life, her physical and emotional integrity, marks her body and changes her sense of personal and social identity (Langellier & Sullivan 1998). In their study using narrative data from interviews with women, the researchers considered that the ways women talked of their breast after

treatment did not suggest a narrow or primary preoccupation with femininity and sexuality, as presumed by the literature. Rather, the women's experiences were constructed more in terms of personal agency, and their stories were representative of the changing relations between body, self and others (Langellier & Sullivan 1998).

In a Canadian study of women's experience of embodiment after breast cancer, Thomas-MacLean (2005) drew on a blend of feminist and phenomenological approaches, gathering narrative data through an open-ended focus group with five women, and a series of two individual interviews with 12 women. She identified how some women experienced the medicalisation of breast cancer, where their body had become a site of manipulation, with little attention paid by medicine to the intersection between self and body (Thomas-Maclean 2004). In a later paper based on the same study, Thomas-MacLean (2004) suggested that descriptions such as 'numbness' were inadequate, and that the complexity of sensations that remained following mastectomy were not fully acknowledged in the medical literature (Thomas-Maclean 2005). This suggests that the physicality of the body is an important feature in women's experience of breast cancer, certainly within the western world, which may not necessarily be captured adequately within biomedical measures and discourses.

2.5.4 The body in long term conditions

This section will identify several points relating to the body in physical long term conditions: that illness has the potential to fracture the relationship between body and self, as it takes away the silence of the body; that self-identity may be influenced by the trajectory and stigmatising aspects of a condition; that illness can be an opportunity for reconstruction of the self in the context of body changes; and that an uncontrolled body can influence the adjustment that an individual makes to their long term condition.

Leder (1992) has argued that the body is often taken for granted and remains invisible until physical bodily changes render it entirely visible, if not to others, at least to the experiencing person. In her interview study with 57 people with a variety of chronic conditions, Charmaz (1983) employed a grounded theory approach, identifying how physical body changes structured individuals' worlds, leading them to become isolated and experience challenges to their self-identity. Particularly, a discrediting encounter with someone, such as an outsider commenting on a visible bodily aspect of an individual's condition, could adversely influence their self-concept (Charmaz 1983). In a later study of 55 individuals with chronic illness, Charmaz (1995) suggested that people adapted to impairments and integrated new information about their body with chronic illness into their self concept, enabling the self to be redeemed. Murphy (1990), in his personal story of living with a paralysing illness, considered how self-concept, a reflection of the way one is treated by others, could lead to a diminution of the self as a result of others' reactions to visible body changes.

Seymour (1998) suggested that the body can become a site for anarchy, betraying the years of attention we give it. In her study of 24 men and women who sustained body paralysis as a result of a spinal cord injury, she showed that rebuilding the embodied self was challenging for individuals. Self-image had been developed over a lifetime according to social norms, and some aspects of self-identity had to be relinquished in reconstructing the new self (Seymour 1998). However, in challenging a personal tragedy view of the 'damaged body' Seymour (1998) argued for a more positive view of re-embodiment as reflecting the processes of remaking the body in which we all engage, as we reconstruct our embodied selves on a daily basis.

In a theoretical paper, Kelly and Field (1996) discussed the physical and biological changes associated with the chronic illness that impinge on the social self. As I have shown above, it is these physical changes, for example those experienced by a woman with lymphoedema associated with breast cancer, that

may influence how she reconstructs her identity after illness. Recognising the central importance of the physical body, Kelly and Field (1996) considered:

'A central prerequisite for the development of the human (ie social) being is the control of the physical body and capacities. Such control and the knowledge it brings provide a sense of constancy of the embodied self and the ability to plan and predict future actions' (Kelly and Field 1996, p.244.)

This suggests that conditions which remove this sense of constancy and the ability to predict future actions may have a significant impact on the re-embodiment process. This is an important point, which will be considered in relation to my own research interpretations in Chapter Seven.

In an Australian study, a researcher undertook interviews with 18 individuals with advanced cancer during massage treatments, while they were being cared for in a palliative care unit (Waskul & van der Riet 2002). These individuals reported feelings of powerlessness and alienation, as a result of their medical treatments for cancer and the uncontrolled nature of their leaky, smelly and terminally ill bodies. However, adopting the language of medicine enabled them to experience their abject body in an objective form, and assume control over parts of the treatment and care of their body, while relinquishing the rest to nurses and others (Waskul & van der Riet 2002). The abject body was a source of humiliation and made it difficult for them to control and conceal their stigma; instead the primary tactic for managing this was to embrace the abjection, either as an object of fascination, in the context of or as a subject of humour (Waskul & van der Riet 2002). The notion of objectification appears to reflect the processes of transformation that were described by Paterson *et al.* (1999), as noted earlier in this chapter. Importantly it also links to the work of stoma care nurses as described in Section 2.5.5.

A transition to viewing the self as 'body-object' was also described by Lawton (2000) in her ethnography of a hospice in the UK. Observation of individuals who gradually became more physically dependent as they were dying, drew

attention to physical bodily ability, or '*bodily autonomy*' (Lawton 2000, p.113), as fundamental to selfhood in both the dying person, and in some cases, the family carer who was the agent of another's bodily actions. Significantly, the erosion of the physical boundaries of the body, and loss of bodily capability to 'act', led to dying individuals experiencing considerable difficulties in maintaining a sense of self (Lawton 2000). These findings indicated the dynamic relationship between self and body in illness, and pointed to the potentially inter-subjective and inter-corporeal nature of selfhood (Lawton 2000).

A further point relating to the body in long term conditions is the relevance of the concept of an illness trajectory, as developed from a study of couples in the U.S. who were managing and adjusting to chronic illness at home (Corbin & Strauss 1988). The shape of a trajectory illustrates the phases of an illness through, for example, an acute phase, periods of crises and instability, or the dying phase (Corbin 1998; Corbin & Strauss 1988). This notion of trajectory underpins the identification in the self-management strategy (LTCAS 2008) of the key stages of a long term condition: *diagnosis*; *'live for today'*; *progression*; *transitions*; and *end of life*. In relation to the body, stages such as *diagnosis* or the '*trajectory onset*' phase (Corbin & Strauss 1988), or the advent of particular *crises* may represent times when physical body symptoms become particularly obvious and uncontrolled (Kelly & Field 1996). Corbin (2003) has suggested that for the experiencing individual, new physical bodily changes or sensations may be '*anchored in meaning*' (p.258). How individuals embody, or 'manage' these changes, predicting their future implications and reconstructing the 'self' in the context of these physical changes within their social world, is of particular relevance to this thesis.

Cancer is increasingly being conceptualised as a long term condition, and researchers undertaking a study in Scotland at around the same time as the research for this current thesis interviewed 66 people diagnosed with a variety of cancers, their close family members, and relevant health professionals

(Forbat, Hubbard & Kearney 2009). Individuals were interviewed around 6-10 weeks after the initial diagnosis of cancer, again after 4-6 months, and then a subsequent 10-14 months later. Particularly relevant to this current thesis was the finding that cancer had a direct impact on the individuals' sense of self-identity which shifted, not necessarily between different phases of the illness trajectory but '*moment by moment... as it entered and then left people's conscious awareness*' (Forbat, Hubbard & Kearney 2009, p.96). The study focussed particularly on periods when individuals were undergoing cancer treatments such as chemotherapy. At these points, physical changes such as loss of weight and potentially discrediting encounters in their social contexts relating to incontinence, or loss of hair, brought some individuals to differentiate the cancer as a separate entity to the self. Physical changes were varied, and the symptoms were not always severe, although particular examples were given of how physical appearance affected intimate sexual relationships (Forbat, Hubbard & Kearney 2009). The research findings relating to health professionals did not appear to focus in depth on the professional role in supporting individuals with self-care and dealing with physical bodily changes (Forbat, Hubbard & Kearney 2009).

2.5.5 The body in nursing and allied health professional practice

As I have shown earlier, women with breast cancer and those with lymphoedema may experience a sense of dis-embodiment. At the same time, the support of women with self-bodywork may involve processes that have potential for re-embodiment. Twigg *et al.* (2011) have argued that bodywork represents the micro-political power relations between a 'patient' and a professional. This resonates with the writings of Foucault (1989) described earlier in this current section. There is a small but significant literature around the work of health professionals in relation to the body, and some specific aspects of which will be summarised here.

McDonald and McIntyre (2001) have argued that the body and embodied experiences have been marginalised in nursing, influenced by the dualistic thinking of bio-medicine. An emphasis on embodiment, however, may create vulnerability for the professional (and ill person) and may be circumvented by a focus on objective measurement and documentation, for example, which creates a 'safe' distance from the messy and uncontrolled nature of many areas of health care (McDonald & McIntyre 2001). Benner (2000) has argued that reading the body, and emotional states of the 'patients' in their care, is highly relevant to the reflective practice of health professionals who must be perceptive and check out their interpretations, in order to learn from experiences. In an interpretative study of 130 nurses in hospital, Benner, Tanner & Chesla (1996) undertook observation and individual narrative interviews with nurses. The researchers described how the nurses developed an 'embodied knowledge', based on their experiences of the patterns of illness, and the unique narratives of the individuals with whom they worked (Benner, Tanner & Chesla 1996).

Undertaking participant observation and interviews with 34 nurses in Australia, Jocalyn Lawler (1991) developed a nursing-related theory of 'somology'. Influenced by Merleau-Ponty and Foucault, Lawler (1991) argued that to work somologically required nurses to recognise the embodied existence of individuals and take account of the physical body while integrating this understanding with the lived (and felt) body. In a narrative-based study focusing on the work of 'stoma' nurses, Parker & Wiltshire (1999) used psychoanalytic perspectives to guide their data analysis. They suggested that the emotional aspects of dealing with the 'wounded' bodies of people who had 'stomas', and the powerful emotions this aroused in the nurse and the individual with a stoma, could be viewed in terms of containment. As such, specialist nurses working with individuals who had a stoma were seen by researchers as using used a form of '*aphoristic containment*' (Parker & Wiltshire 1999, p.109). Here the expert nurse simultaneously verbally acknowledged the stoma as something 'terrible' but also used discourse (and humour) to '*introduce it into the order of*

the everyday and thinkable' (Parker & Wiltshire 1999, p.109). This appears to reflect the findings of Waskul and van der Riet (2002), and may echo the phenomenological nursing approach to bodywork espoused by Lawler (1991), that simultaneously incorporates the body as both subject and object.

There is limited evidence of research undertaken to explore the phenomenological approach to bodywork in other disciplines. Indeed, a Danish study undertaking observation and interviews with physiotherapists and individuals who had undergone hip replacement suggested that much of the work of physiotherapists focussed on physical aspects of care and did not draw on socio-cultural or 'patient's' narrative of their experiences (Jorgensen 2000). In a Swedish study, 12 Occupational Therapists (OTs) were interviewed once regarding their experiences of working with people with stroke or spinal injury (Guidetti & Tham 2002). These professionals emphasised the importance of establishing a trusting health care relationship and identified how they took a relatively passive role at first, observing individuals and their bodies, and listening to their narrative experiences, to enable clients to confront their bodily limitations and to set realistic self-care goals. The OTs also used their own bodies to demonstrate self-care practices, positioning their body to ensure safety for the client as the latter learned to regain control of their own body (Guidetti & Tham 2002). Savage (1997), in an ethnography of a UK hospital ward, also noted how nurses positioned their bodies and used their bodily senses to negotiate the boundaries between them and the 'patients'. Although little researched, this aspect of the use of the professional body may be a significant element to supportive practice.

Rudge (1997), in her observation of wound care with individuals who had experienced severe burns, also considered the discourses that nurses used to talk about the body with the individuals concerned. She argued that the 'patient' may readily be drawn into the frame of self-care that is defined by the professional view of the body (Rudge 1997). Important to this thesis, she

recognised that a health professional such as a nurse may be located between the dominant medical perspective, technology and the ill person, thus becoming a type of interpreter of the body, whose work may often appear contradictory and ambiguous (Rudge 1997).

In summarising this section, it may be suggested that lymphoedema may represent, at least for some individuals, a type of abject embodiment, similar to the experience of living with a stoma. Thus viewing self-care within the context of the embodied and physical experience of lymphoedema may provide an important dimension to a study of supported self-care. The issue of embodiment is important to the thesis and will be further explored in Chapters Five, Six and Seven.

2.5.6 Summary and relevance to the thesis

This section of the review has focussed on 'the body' and has indicated that varied ways of conceptualising the body may have specific implications for understanding the experiences of women with lymphoedema and lymphoedema practitioners. It appears that individuals with long term conditions including cancer may experience many challenges to the physical body and selfhood that may be equally relevant to women with lymphoedema. A particular point has been raised about the sense of a lack of constancy of the uncontrolled physical body. The review has also suggested that the everyday work of health professionals may incorporate specific aspects of care of the body that may have potential to facilitate a process of re-embodiment. This may be highly relevant to the support of women who live with and undertake self-care, a form of bodywork, for the potentially stigmatising and dis-embodimenting condition of lymphoedema. Research methods such as field observation and narrative accounts of the experiences of 'patients' and 'professionals' appear to have provided important research insights into embodied and embodying 'practices' relevant to self-care and support in these varied areas of health care.

2.6 Chapter summary and implications for the thesis

Foucault (1980) argued, in his work on knowledge and power, that what constitutes legitimate or worthwhile knowledge at any one time is dependent on the dominant 'regime of truth', and may not always imply scientific progress. This literature review has incorporated a range of empirical research evidence relevant to the topic of supported self-care, and also examined theories and empirical research relating to the body, to inform the development of the thesis.

In the context of policy initiatives relevant to individuals with long term conditions, there appears to be very little existing evidence to provide a comprehensive understanding of women's experiences with self-care and of the work of lymphoedema practitioners who provide support to women. Indeed, questions remain as to the relevance of research evidence relating to other long term conditions to an understanding of supported self-care in women with lymphoedema. There appears to be a need to focus on articulating and making visible the specific experiences of women with lymphoedema and lymphoedema practitioners in order to inform this understanding of supported self-care.

As I have shown in Chapter One, health policy also has a particular interest in the empowerment of individuals with long term conditions, through changing their roles and those of health professionals who work with them. This review has suggested that questions arise regarding the nature of these roles, the power relations between these two parties within the context of the person: professional relationship, and the structures of power within which this relationship is enacted. Research approaches such as field observation and narrative accounts have illuminated many features and contextual elements of these relationships within other areas of health care, and thus appear to provide particular directions for this current thesis. In the next chapter I will discuss the theoretical perspectives that further informed the research questions, gave direction to my thinking, and underpinned the identification of the specific research aims.

Chapter Three: Theoretical perspectives

3.1 Introduction

This chapter provides a theoretical underpinning to the thesis. I critically discuss the rationale for, and implications of, taking a feminist-informed approach to the research, and explore the relevance of relational autonomy theory to the thesis, drawing on feminist critiques. Further discussion of the ontological and epistemological beliefs underpinning the development of new knowledge within the thesis, is followed by identification of the research aims. I end the chapter with a critical overview of the inter-relationships between the different theories used within the thesis, and discuss the implications.

3.2 Feminist-informed approaches to research

In Chapter One I discussed the political and gendered context of lymphoedema care and treatment, exploring my own experiences of feeling relatively marginalised and powerless as a lymphoedema practitioner. I also described how individuals with lymphoedema could have their condition ignored, misunderstood or given a lower status than other medical problems, within the context of healthcare. Thus, lymphoedema, as a problem associated with 'cancer survivorship' is often, I believe, given minimal funding relative to the substantial resources given to cancer treatment. Taking a feminist-informed approach therefore provided me with an important lens for viewing the research process, drawing my attention to the nature of the wider political and social structures that impacted on women with lymphoedema and lymphoedema practitioners. It also provided more clarity for viewing women as agents of knowledge in the study, and brought me, as I will show in the next section, to explore the relevance of relational autonomy to an understanding of supported self-care.

In seeking a theoretical underpinning for my research I recognised, as I have shown in Chapter Two, that within the broad field of breast cancer care,

women's bodies are sites for discourses about risk and surveillance, and are subject to multiple interventions. Oakley (2005a) has argued that '*a significant aspect of women's health is its over-determination by medical ideologies and technologies*' (p.46); medicalisation is a salient part of the experiences of women who develop breast cancer. The point here is that care of individuals with problems such as lymphoedema, may require new forms of knowledge that recognise the long term needs of women (and men) within the emerging arena of 'cancer survivorship' (Department of Health 2010). These may well differ from the structures that are constituted as knowledge for acute biomedical treatment and care. I also indicated in Chapter One that policy assumptions appeared to view people with long term conditions as a burden on health care resources. It is my contention that this invokes significant messages about the value of different individual groups whose problems may rest outside the positivist dominance of medical science. Important to the thesis is the observation that aspects of health care such as supported self-care may be rendered invisible or relatively silent, as they take place in predominantly non-technical environments such as women's homes.

Brunskell (1998) suggested that to take a feminist standpoint is to be committed in a broadly political sense to identifying and transforming the social conditions of women. Maguire (1996) has argued that feminism brings a commitment to identify those forces that cause and sustain oppression, and encourage women to create new structures or reshape existing forces. Many authors have agreed that research informed by feminism is likely to involve a political element, and should produce new knowledge that enables social or individual change (Letherby 2003; Ramazanoğlu & Holland 2002; Roberts 1981; Stanley & Wise 1983). Kralik (2005) has argued that a woman-centred approach is fundamental to feminist scholarship but that feminist researchers must examine the assumptions that underpin their thinking and actions. Webb (1993) has called for creative interpretation of feminist principles in research as there is no one kind of feminist research method. However, Morris, Woodward and Peters

(1998) considered that all feminist research must embrace a set of principles: to make the formerly invisible, visible; to be committed to developing research *for* women rather than *on* women; that the researcher makes a commitment to reflexivity, openness and intellectual honesty; and rejects hierarchical relationships in the research process. I will briefly consider each in turn.

In seeking to make visible the invisible spheres of women's lives (Harding 1987), my task was to find ways to allow the voices and accounts of the women with whom my research was concerned to be heard and interpreted. I was aware that early feminist researchers had sought to counterbalance positivist perspectives from within social science research, by using qualitative methods to produce authentic accounts of women's experience (Morris, Woodward & Peters 1998). Authors such as Oakley (2000) had also argued for a deconstruction of the quantitative: qualitative divide, calling for feminist researchers to embrace a range of research approaches relevant to their research questions and topic of enquiry. As I have shown in Chapter Two, supported self-care in women with lymphoedema had a limited evidence base. Thus I recognised the potential for qualitative research approaches to explore the embedded processes in individual lives (Barbour 2008), and examine the constraints and experiences within the social worlds (Denzin & Lincoln 2003) of women and practitioners. I considered that inductive approaches, enabling the development of theory from data, as opposed to deductive, or theory testing approaches, would prove most useful for a study of this under-researched aspect of lymphoedema care. However, Letherby (2003) identified that some feminists have rejected inductive approaches such as grounded theory, believing that no study can be completely inductive and free of politics. Others have argued that all research, and not only grounded theory approaches, must be theoretically grounded (Maynard 1994). My study therefore is essentially a robust enquiry that is informed by feminism, and based, as I show later in this chapter, on the precepts of social constructivism, combining various research

methods to gather qualitative data in order to explore the phenomenon of supported self-care.

Where I recognised the explication of women's experiences as integral to my work, I was also mindful of the potentially emotional context of these experiences. Indeed, Hartman (2004) has identified a silence around breast cancer, as a relatively taboo subject even in feminist literature, suggesting that the breast's complex associations with women's femininity and maternal identities made it less likely for feminists to view it in terms of issues of empowerment. Thus in seeking to make visible the experiences of women through their accounts, I also was aware of the potential vulnerability of women with whom I would work and the importance of not adding to their disempowerment through my conduct of the research process (Munro *et al.* 2004).

In planning to undertake research *for* women, not *on* women, I believe I faced several considerations. Ostensibly, this study was part of my work towards a PhD thesis, and therefore a fairly solitary and isolated project, for example, not feeding directly into NHS or voluntary sector developments, although using these settings as a basis for study. Cannon (1989) suggested that researchers may feel guilty that they have nothing to give back to women who have helped them with a research study. Certainly, during the whole period of study and writing, I often reflected on how any knowledge developed from the study may be used to benefit women with lymphoedema, and health professionals. I address this point in Chapter Eight. Furthermore, I was also aware that to take a feminist-informed perspective might appear to argue that the experience of men was unimportant. As I have shown in Chapter One, men have similar problems with their lymphoedema being ignored so this was certainly not my intention. However, I believe that engaging with feminist theory led me to a specific awareness of the power relations relevant to supported self-care that

may be equally important to the experiences of women and men with cancer, and with other long term conditions.

Reflexivity in feminist-informed research implies a need to make explicit the power relations and exercise of power in the research process (Ramazanoğlu & Holland 2002). The fact that the research was undertaken within the scrutiny of a PhD thesis meant that the research process and any knowledge claims I made were opened up to the possibility of negotiation and challenge (Bola *et al.* 1998). In a practical sense in relation to reflexivity, I recognised the importance to the current study of my writing in the first person and locating myself in the thesis early on in the research process (Stanley & Wise 1993). Being already embedded in the cultural and social environment around lymphoedema, I was aware that I might make assumptions and privileged certain viewpoints. Indeed, Denzin and Lincoln (2003) have argued that post-modern researchers must recognise that the age of value-free inquiry is over. Thus, the biographically situated researcher becomes an important feature of interpretative, qualitative research. By including a biographical account in Chapter One and detailing the research process in Chapter Four, I believe I have provided a degree of openness in terms of how I researched and constructed new knowledge (Letherby 2003). In the next chapter, I will explore in more depth the various dilemmas for me as a feminist-informed researcher in relation to how I conducted the study and applied the various methods.

The importance of creating an egalitarian relationship between researcher and those participating in the research is a central tenet to feminist-informed research approaches. However, Hammersley (1995) has argued that it is not possible to remove completely all forms of hierarchy and power from within the researcher: researched relationship, as some control over the research process is necessary, and does not imply that the research participant is subordinated. Clearly, a researcher may often possess the objective balance of power, for example, deciding on the order in which questions are asked in an interview,

and shaping the analysis and interpretation of information in the final research report (Letherby 2003). However, it has been argued that the research relationship is fluid and always jointly constructed (Luff 1999). As Crompton (2006) described in her study of women with breast cancer, the interview space, far from being controlling, could also provide a place for women to open up, in apparent contrast to the constraints of peer support groups which she reported were dominated by discourses about the importance of a reconstructed body after breast cancer.

Another feature of power within the research relationship relates to the political implications of the '*webs of meaning*' (Hughes 2002, p.196) that are inherent in the language created around research and academic endeavours. In a community-based participative project, VanderPlaat (1999) recognised that as a professional and academic, she readily slipped into using language that constructed the research population as passive. I would argue that drawing on a feminist-informed approach enabled me as a researcher to become sensitive to the values that were reflected in disciplinary language. As such, I made the decision early in the research process to refer to the research participants as 'women with lymphoedema' rather than 'patients'. This attempt to locate my thinking outside the biomedical domain, felt comfortable to me as a feminist-informed researcher and, I believe, reflected principles of equity and partnership. It is notable that the strap-line '*people not patients*' is used by the Long Term Conditions Alliance Scotland (LTCAS 2011).

There is an obvious point here that the researcher: researched relationship echoes the relationship between the women with lymphoedema and the lymphoedema practitioner, insofar that both researcher and lymphoedema practitioner might seek to reject the hierarchies of power that are inherent in traditional roles, and to re-establish a more equal basis for creating new knowledge. As I will show in Chapter Seven, it is my contention that it is through an anticipatory approach to practice, that new knowledge relevant to

individual self-care may be jointly constructed by the woman and practitioner. As I will now show, the focus on a relational view of autonomy also provided a broader perspective which illuminated the various sources of power that influenced the women and the lymphoedema practitioners within the context of supported self-care.

3.3 Feminist critiques of autonomy- a relational approach

As I have shown in Chapter One, health policy documents talked of moving beyond the context of a passive patient and paternalistic environment, to one in which people make autonomous choices. Biomedical ethics in health care has tended to be dominated by liberal and individualistic conceptualisations of autonomy based on the Kantian belief of rational adults as morally equal and free to decide how they should live and self-determine their individual goals and values (Atkins 2006; Beauchamp & Childress 2009; Mill 1975). These notions have underpinned informed consent processes and the argument that individuals must be enabled to become actively involved in decision-making relating to their health care needs (Coulter 2002). Autonomy has also been described as being equated with dignity, and identified with qualities of self-assertion and critical reflection (Dworkin 1989).

However, feminists have argued that this liberal view of autonomy is inadequate and instead support the notion of a more socially grounded theoretical perspective, referred to as relational autonomy (Mackenzie & Stoljar 2000; Sherwin 1998). Arguments for a 'relational autonomy' centre on a reconfiguring of traditional views of autonomy, which are seen as bound up with masculine ideals, individualistic, rationalistic, and hostile to women's interests and freedom (Mackenzie & Stoljar 2000). As such autonomy is viewed in terms of relational theory that:

'...allows us to appreciate how each relationship a person participates in plays a role in fostering or inhibiting that individual's capacity for autonomous action by encouraging or restricting her opportunities to

understand herself as an autonomous agent and to practice exercising the requisite skills' (Sherwin 1998, p.36).

Mackenzie and Stoljar (2000) considered this relational approach as providing a richer account of the autonomous agent, recognising that the 'self' cannot be adequately understood as distinct from the complex social and historical context in which the person is embedded. This view of autonomy recognises the emotional, embodied, desiring and creating nature of agents, and incorporates a phenomenological view of the body. It also considers that oppressive socialisation, cultural practices and social relationships can impede autonomous agency, and shape desires, attitudes and beliefs, restricting an individual's opportunities to make meaningful choices (McLeod & Sherwin 2000).

Meyers (1989) has suggested that the socialization of women towards altruism and putting others before themselves, along with women's concerns about how their actions may be received, may further compromise the scope of women's autonomy. She described a theory of *autonomy competence* as requiring skills in self-reading, self-direction and self-actualisation; to some extent, a journey of self-discovery yielding opportunities to make choices that are in harmony with the authentic self (Meyers 1989, p.76). This is viewed by Meyers as being enabled by identifying what she referred to as a 'life plan', developed around the self-actualisation of personal interests and goals.

Nursing has tended to uphold an individualistic view of autonomy (Ballou 1998; Keenan 1999), despite the potential shortcomings of an approach that relies on individuals who are unwell, and often in unfamiliar surroundings such as a hospital, to make rational choices and decisions. However, some nurse researchers have argued for a contextual and socially embedded view of autonomy, suggesting that autonomous agency might be preserved and enhanced by taking account of the relationship between the health professional and 'patient' (Goldberg 2003; Moser, Houtepen & Widdershoven 2007) or others

such as family members (Ho 2008). In his work with older people in long term care settings, Agich (1993) has suggested that autonomy is developmental, socially determined and dynamic, and likely to be formed by experiences and habits. In a study of autonomy in the relationships between nurses and older people, McCormack (2001) analysed recorded hospital-based conversations between these two groups, showing that professional-based information-giving and decision-making was the dominant mode. Nurses were viewed as being at an advantage as they could identify salient features, for example, as they assessed individuals within an already established professional framework, in which paternalistic decision-making prevailed (McCormack 2001). Thus, McCormack (2001) argued, the autonomous choices and preferences of the older people were not held central, while the complexities of decision-making and the restraints of the care environment also impacted on any authentic choice they might make. McCormack (2001) identified an alternative view of autonomy based on 'interconnectedness', which, similar to relational autonomy, takes the view of a person as social, and existing in relation to others, in a particular context. A further point made in the relational autonomy literature is that respecting autonomy may also involve taking social action, ensuring access to services and promoting enabling relationships, and focussing, as a professional, on what choices are not available to people, rather than merely on the choices that are made (Ells 2001).

In summary, liberal views of autonomy are dominant in healthcare, and professionals may freely accept the assumptions on which they are based, believing them to be a natural route towards avoiding paternalism. However, a view of relational autonomy appears to suggest that, in relation to supported self-care, both the women with lymphoedema and the lymphoedema practitioner may enter into a relationship in which they both affect each other's actions and choices (Barnes 2000). From a feminist perspective, autonomy is therefore seen as socially embedded and dependent on the nature of the partnership between the person and the health professional. As such, autonomy may be

dynamic and grow out of the relationship, but this process requires health professionals to be skilled communicators and able to reflect on their own practice (Moser, Houtepen & Widdershoven 2007), as well as being provided themselves with adequate support and resources within their practice environment (MacDonald 2002). In Chapter One I described the policy assumptions that have been made in relation to supported self-care, and imply that an empowering relationship exists between women and practitioners. It is my contention, therefore, that the relational view of autonomy provides an additional depth of understanding which is highly relevant to the thesis.

3.4 Ontological and epistemological considerations

I will show here that an essential focus in the thesis is on the meaningfulness and humanness of social life (Lazar 1998). Ontologically, I take a critical realist standpoint, believing that an external reality exists independently of our beliefs and understanding, but that we come to know our reality through the human mind and socially constructed meanings within our social worlds (Snape & Spencer 2003). In taking this stance I draw firstly on symbolic interactionism, and secondly, on the work of John Dewey.

Symbolic interactionism, based on the work of George Herbert Mead and Herbert Blumer, is concerned with human behaviour, how people perceive and empathise with others, and the nature of individual actions in the context of their social world (Blumer 1969; Mead 1934). Central to symbolic interactionism is a belief that what an individual says, and how she acts, is a consequence of her learned social world, which may be communicated through common systems of symbols such as language and gestures which have particular significance or meaning (Blumer 1969). Thus meanings arise out of social interactions, while individuals understand each other through structures and processes which are socially constituted. Additionally, Berger and Luckmann (1966), drawing on the work of Mead, saw knowledge encountered within everyday life as socially distributed, recognising that a *'bewildering array of medical specialists'* (p.60)

might claim jurisdiction over knowledge, such as that relevant to self-care for women with lymphoedema, as suggested in Chapter One of the thesis.

I believe that symbolic interactionism is particularly relevant to the thesis as it recognises that the social interaction between a woman with lymphoedema and a lymphoedema practitioner has the potential to involve language and actions that bring meaning and understanding relating to supported self-care. Importantly, women or practitioners may act on the basis of the meanings that events or institutions have for them, and, as a researcher, I have sought to interpret these. I recognise that while there may be a potential for a shared 'culture', unique and individual biographies will also exist.

Theoretically, I also draw on the work of John Dewey (Dewey 1933), a philosopher with an interest in educational theory, who was influential in establishing 'pragmatism' as a school of thought towards the end of the 19th Century. As a pragmatist, Dewey rejected Cartesian dualism and views of knowledge and fact as existing separate from the lived world, as might be reflected in the objective and rational approaches to evidence development within a positivist paradigm. Instead, Dewey recognised the value of something in terms of its practical application to life. He believed that an individual gave meaning to an object, event, or a situation in terms of how it related to other things, its relevance, and its consequences within everyday life (Dewey 1933). Thus, our ontology develops through this inter-relationship we have with the world, and the practical relevance of an experience in achieving or working towards human goals and a sense of self. As shown earlier in this chapter, far from being an independent source of decision-making, we exist and make choices within an interconnected web of social experiences (Agich 1993).

Dewey (1933) based his educational work on a belief in the interconnectedness of experience, interaction and reflection. For example, he proposed that education of children should build on the experiences of the individual in their

context, recognising the scope for change in meaning and knowledge as a result of reflection on the diverse experiences within our lives. He considered:

'...the distinction between information and wisdom is old, and yet requires constantly to be redrawn. Information is knowledge that is merely acquired and stored up; wisdom is knowledge operating in the direction of powers to the better living of life' (Dewey 1933, p.63).

This philosophy for education reflects a social constructionist perspective which is, I would argue, very relevant to the concept of 'supported self-care'. In particular, it recognises that individual experiences of self-care, used within everyday life, may draw on an essential wisdom that is not, for example, necessarily a direct product of being given information or being exposed to 'patient education'. I will show in the next chapter that, as a researcher, I recognised the value of using this philosophy to inform the qualitative research design. It enabled me to explore the nature of supported self-care, drawing attention to people's interpretation of meaning, or '*verstehen*', in the context of social actions and environments.

Thus epistemologically, I have set out my own beliefs about the origin of knowledge as, in part, socially constructed, and accessed through the meanings that different individuals such as women with lymphoedema and lymphoedema practitioners ascribed to their social experiences, and how I interpreted them. The reliability of this approach as a basis for the development of new knowledge (Snape & Spencer 2003) lies in the rigour of my work as a researcher, as clearly, findings influenced by my perspectives and values cannot be objective or value-free. Significantly, the epistemological perspectives taken in this thesis recognise the potential for contrasting, dynamic, and socially constructed realities, and acknowledge the temporal nature of experiences that may be captured within the diverse accounts of different women and practitioners, at different time points.

The background discussions in Chapter One and the evidence from the literature review in Chapter Two have indicated the need to understand more fully the phenomenon of supported self-care and its relevance to women with lymphoedema and lymphoedema practitioners. Recognising these gaps in the evidence, and drawing on the feminist-informed approach, social constructionist theory and the work of John Dewey, as explicated in this present chapter, I therefore present the aims for the research study.

3.5 Research aims

- To analyse the nature and construction of supported self-care for women who have lymphoedema as a result of breast cancer treatment, in order to inform developments in lymphoedema practice
- To explore and contrast the experiences of self-care in relation to women who have newly developed lymphoedema, and those who have lived with lymphoedema for more than two years
- To observe and describe how lymphoedema practitioners work with women who have lymphoedema after breast cancer.

3.6 Theoretical considerations and implications for the thesis

I believe that the distinctiveness of this thesis lies partly in how I incorporated various theoretical perspectives and also, as I will show in the next chapter, different research methods, to explore a relatively new and under-researched area of healthcare. At this point, however, it is useful to acknowledge the ways in which the various theories inter-relate, considering their points of convergence and potential tensions, within the boundaries of the thesis. In this current chapter I have discussed how my own experiences inspired the feminist-informed approach that drew my attention to a particular view of autonomy. This was congruent with the relational context of supported self-care and, as I will show later, illuminated by my research findings. Thus, in Chapter Seven I will emphasise the relational context of the professional practitioner and a

woman with lymphoedema, and the structures of power that impinged on both individuals' autonomous agency.

Furthermore, I have argued in this current chapter that social constructionism, and a sense of the importance of interconnectedness, interaction and reflection as emphasised by Dewey (1933) also underpin the thesis. These perspectives appear to sit comfortably with relational autonomy theory, and also indicate that divergent understandings may be potential sources of tension. For example, health policy constructions of long term conditions as a burden on the economy and overly determined by medical ideology, may be at odds with feminist, relational and emancipatory perspectives that emphasise social change and personal agency. That individuals and organisations working within an emancipatory framework must recognise and seek to interface with existing structures of power has implications for the application of findings from this current research.

Arguably, an extreme feminist view may be somewhat narrow, failing to acknowledge the oppressive nature of healthcare structures on men. This indicates why I chose to take a feminist-informed rather than purist-feminist approach to the thesis. It is also clear from my critique in Chapter Two, that theoretical constructions of the body may be more or less congruent with a feminist-informed approach. For example, social theories of the body provide insights into how the body is constructed as a site and source of power, reflecting post-modern feminist thinking of the body in terms of potentiality and flow (Battersby 1993), and also as a basis for understanding personal agency. Contrastingly, the naturalistic body, where capabilities may be defined in gendered and genetic terms, appears at odds with feminist views. The phenomenological perspective of the body complements relational autonomy and feminist theory, emphasising a relational sense of the body and embodiment, and informs the approaches taken within the research analysis, later in the thesis.

Foucault (1989) argued that care and surveillance of the self is an extension of the medical gaze, and an enactment of power on the body. He considered that medicine seeks to understand the individual through forms of bio-power that objectify the body. This raises the possibility of tensions existing between this apparently individualistic view and relational theory. However, it has been argued that Foucault and feminism do converge to an extent as they both recognise the body as a site of power at a local and intimate level, and pay attention to the crucial role of relationships and discourses in potentially sustaining hegemonic power (Diamond & Quinby 1988). Thus it is clear that Foucauldian theory has potential to complement feminist approaches to research. I would also argue that, in the context of a relational and whole systems approach to cancer care, (Illingworth *et al.* 2010), further exploration of these theoretical ideals, and their relevance to contemporary healthcare, is required.

Thus the theoretical landscape upon which the thesis draws is necessarily complex, but also inter-related. While there is not scope to explore each theory in depth, I believe I have indicated where various theoretical strands are interwoven and how they have informed my thinking. Examples are found in the recognition of particular themes within the research findings, illustrating sources of power on the body, such as discourses, and the identification of the structures of knowledge that informed lay and professional practice in terms of the research participants. Arguably, while health policy appears to embrace a fairly one-dimensional view of supported self-care, drawing on these various theories brings attention to the complexities and inter-relationships between different sources of knowledge, and enhances an understanding of this relatively widely used concept.

3.7 Chapter summary

In this current chapter I have explicated the rationale and implications of taking a feminist-informed approach. I have discussed the ontological and

epistemological perspectives that drove my work, arguing that I viewed meaning as socially constructed and potentially accessible through the accounts of women and practitioners. I also considered meaning as dynamic in nature, and a product of reflection, interaction and an interconnectedness of experience. I have also recognised that the thesis is informed by a complex range of theoretical concepts that are complementary but also potential sources of tension and ambiguity. As I come now to show how I developed research methods to gather research data and identify ways of knowing that were meaningful to women with lymphoedema and lymphoedema practitioner, I also acknowledge the responsibility of my role in interpreting their individual accounts of their social world.

Chapter Four: Research design and methods

4.1 Introduction

In the previous chapter I summarised the theoretical perspectives that underpinned the research design and identified the research aims. In this current chapter I will outline the research design, provide a rationale for the choice of methods, and I will identify the ethical dimensions of the study, describing how I acquired approval from the Multi-centre Research Ethics Committee (MREC), and the relevant Research & Development (R&D) departments. I then report how I negotiated access to research participants, providing a critical discussion of the processes of recruiting participants for the study, data gathering and analysis. I finish by examining the various dilemmas that I addressed as a researcher.

In Chapters One and Two I showed that relatively little is known about how self-care is used by women with lymphoedema, with minimal evidence to guide the work of lymphoedema practitioners in supporting women with self-care. In Chapter Three I described how I took a feminist-informed approach, seeking to illuminate the life context of women, rooted in their experiences and frames of reference (Kralik 2005). I also discussed the social constructionist principles that underpinned my beliefs, and brought me to an understanding that generating credible evidence around a phenomenon such as supported self-care might be achieved through interpreting the individual and subjective accounts of women with lymphoedema and lymphoedema practitioners (Avis 2005). The research aims outlined at the end of Chapter Three emphasised the exploratory nature of the study. Thus I drew on the philosophies of qualitative research, with its focus on understanding social realities (Holloway & Wheeler 2002), developing the research methods within a broadly qualitative, social constructivist and feminist-informed framework, in order to meet the research aims.

4.2 Outline of research design and timings

Table 4.1 outlines the various stages of the study, its research methods and participants.

Table 4.1: Data gathering phases, methods, participants and data sets.			
	Method	Participants	Data obtained
Phase One			
Data set 1	Small group discussions (n=3)	Women who had lymphoedema for over 2 years Group 1 (n=3) Group 2 (n=2) Group 3 (n=2)	3 transcripts
Phase Two			
Data set 2	Periods of field observation (n=16) at lymphoedema clinics in NHS Board areas (n=6)	Lymphoedema practitioners (n=8) [Nurse background (n=4) Physiotherapy background (n=4)]	16 sets of field notes
Data set 3	Interviews (n=15) with lymphoedema practitioners during field observation	Lymphoedema practitioners (n=8)	15 interview transcripts
Phase Three			
Data set 4	Series of 3 interviews with women Int. 1: within 2 weeks of observation Int. 2: at 3 months Int. 3: at 6 months	Women who had newly developed lymphoedema (n=10)	30 interview transcripts 30 sets of field notes
Researcher reflexive diary throughout the period of data gathering			

The development of the study and the generation of research data took place in Scotland during my Research Fellowship that ran from June 2006 to July 2009. I recruited participants for the small group discussions (Phase One) through a third sector cancer-related organisation based near a cancer centre in a large city hospital in central Scotland. These group discussions took place over September and October 2007. I recruited the lymphoedema practitioners and

women who had newly developed lymphoedema via the lymphoedema clinics within six NHS health board areas, across central Scotland. The lymphoedema clinics were based in a health care setting in a city or town, and included NHS hospital, community and palliative care settings. I had to draw participants from different NHS board areas as there were relatively few lymphoedema clinics in Scotland. However, this had the advantage of providing me with a relatively broad array of clinic settings. The field observations and interviews with practitioners and women who had newly developed lymphoedema ran concurrently between December 2007 and December 2008 (Phases Two and Three).

4.3 Rationale for the choice of research methods

As I showed in the previous chapter, the main considerations that underpinned the research design were a need to make visible aspects of the lives of women studied, and to give women with lymphoedema, and lymphoedema practitioners, an opportunity to articulate their experiences. I believed that this could be achieved by gathering group and individual narrative accounts and undertaking non-participant observation in a naturalistic environment. In my research diary I reflected on the discussions with my supervisors in the early part of the research process. I recognised, for example, that existing knowledge in this specific area of health care was too fragmentary and poorly developed to establish quantifiable methods or an experimental research design to evaluate aspects of supported self-care. I also made the decision that a questionnaire survey design was not a suitable approach for studying the topic area as it would rely on my own assumptions in establishing the survey questions, and would not provide enough scope for exploring individuals' experiences. Importantly, the research aims drew attention to identifying methods that enabled women's voices to be discernible (Morris, Woodward & Peters 1998). I also sought to incorporate a longitudinal component to capture aspects of change and transition, while providing some, albeit limited, opportunity for

comparison within and between different groups of women with lymphoedema and practitioners.

4.3.1 Rationale for small group discussions

I believed that group discussions with women who had lymphoedema for more than two years would provide an open forum where ideas about self-care might be exchanged, and that these accounts from 'experienced' women could have the potential to inform further data gathering (Cote-Arsenault & Morrison-Beedy 1999). As such, the early analysis of the small group data was used to inform subsequent field observations, and provided for comparison with the narrative accounts of women who had newly developed lymphoedema and the practitioners.

Focus groups and small group discussions, which are widely used in social science and healthcare research (Finch & Lewis 2003), are relevant to a wide range of research paradigms (Barbour 2008). They provide an opportunity for participants to share and shape ideas, and can generate rich narrative data (Webb & Kevern 2001) as participants interact, discuss and debate different views or experiences. Barbour (2008) emphasised that focus groups can be used to study how views are created and modified through group interaction. As such they may thrive on the 'synergy' between different groups members. Wilkinson (1999) suggested that focus groups are useful within feminist-informed studies as they provide a social context for meaning-making and are relatively naturalistic, tapping into social processes of communication. It is considered that focus groups may help women overcome a sense of isolation (Wilkinson 1999), and are relevant to the study of underrepresented or oppressed groups (Madriz 2003).

Wilkinson (1999) has argued that focus groups inevitably reduce the balance of researcher power, by virtue of the larger number of participants as compared to researchers, and leave the control of the interaction more in the hands of

research participants (Wilkinson 1999). Inevitably, however, group discussions are led to some extent by the researcher who guides the discussion by posing questions, probing topics that arise, and creating opportunities for everyone to contribute to any emerging issues (Finch & Lewis 2003). In this current study, I considered that using this method to generate data could potentially transfer some degree of control from me as a researcher to the women who jointly developed the group narrative (Halcomb *et al.* 2007), enabling the women to share their experiences.

My original intention was to run focus groups consisting of around 8-12 participants (Barbour 2008). However, as I will show later in the chapter, due to recruitment difficulties, these became smaller group discussions. MacDougall and Fudge (2001) suggested that smaller numbers of group members may be useful if the topic area is sensitive. However, caution is emphasised in using groups that arise from pre-existing networks as the discussion can impact on future relationships among participants (Barbour 2008). I reflect later on how recruiting women to the groups through their contact with another third sector organisation may have influenced the quality of the data in various ways. This forms part of the critical discussions of the various dilemmas that I faced as a researcher in this study.

4.3.2 Rationale for non-participant observation and practitioner interview

Observation as a research method was new to me, and therefore it was also an opportunity for personal research training. Where it has been suggested that all social research involves some degree of observation (Hammersley & Atkinson 1995), participant observation is a fundamental tenet of ethnography, used to account for the world, and to explore and describe cultural patterns (Barbour 2008; Hammersley & Atkinson 1995; Spradley 1980; Van Maanen 1988). Observation enables a researcher to explore phenomena in their natural setting and, in its purist sense, requires the researcher to integrate into the lives of the research participants in order to understand their view of the world. However,

this approach of 'fully integrating' in a context, to develop a full ethnography, was not practical for the study, as the lymphoedema clinics generally functioned within small and relatively contained structures, incorporating successive one-to-one appointments with individual women. This type of setting, I contended, did not lend itself to a traditional ethnography developed through extended periods of observation in one field (Barbour 2008). I recognised that observing in one clinic over a significant period of time could be intimidating both for professionals and the women who attended appointments. However, choosing to observe specific encounters such as an appointment, within different environments, I believed would bring scope for wider insight into supported self-care, particularly if combined with practitioner interviews. Indeed, I recognised that observation may enable access to events which may not be illuminated in interviews where practitioners might merely share their professional assumptions relating to supported self-care.

The study therefore drew on observation and field note data to complement and support individual and group narrative interview data. This approach enabled me to contextualise the questions I put to the lymphoedema practitioners and the women with lymphoedema in subsequent interviews, and it provided, I believe, an important lens on the structures and processes within the 'partnership' between the two individuals, as I will reflect on in Chapter Seven. It also enabled data to be generated from three perspectives: the women; the practitioner; and myself, in the form of my field notes. These notes generated from my observations provided important details about the environment and the processes observed in the appointment, and were useful in informing the analysis and synthesis of the data.

4.3.3 Rationale for interviews with women

I made the decision to undertake individual, semi-structured interviews with women who had newly developed lymphoedema, whom I had observed in their clinic appointment with the lymphoedema practitioner. I believed that following

up a group of women after their initial contact with the lymphoedema practitioner, and interviewing them three times over a period of six months, would provide an opportunity to explore the transitional and dynamic nature of lymphoedema self-care. I recognised that one-to-one interviews with women away from the clinic environment could provide insight into personal aspects of self-care and support.

Interviews can be used in a structured or non-structured way to generate data, although it is argued that no interview is ever completely unstructured (Mason 2002). They are usually informal, conversational and may be used to access the participants' understanding of their own world (Taylor 2005). Thus they were relevant to my exploratory approach. Mischler (1986) suggested that the discourse of an interview is jointly constructed by the researcher and participant. I was therefore aware that data generated through this method would represent socially constructed meanings, which may be subject to change.

I believed that where, as a nurse, I already had skills in interviewing, I also recognised this as an important opportunity for developing my social science research skills. I therefore made the decision to use a semi-structured approach, using an interview topic guide for each interview but also drawing on individualised questioning to explore specific details relevant to each woman, as the series of three interviews progressed. Fu (2005) used a series of three interviews to study how women 'managed' lymphoedema, employing multiple interviewing over a 1-3 week period to establish 'data reliability'. However, in this current study, I used the three interviews to look for the changing and developing constructions within women's narratives, rather than to establish the reliability of their accounts.

4.4 Access to research participants

Negotiating access to the research field and to research participants is not confined to the early stages of a research study, but rather is an ongoing

process of re-negotiation (Barbour 2008; Munro *et al.* 2004). Access to participants for the small groups was negotiated via a Maggie's Centre, a charitable organisation that provided open access and support to individuals with cancer and their families. The Maggie's Centres, of which there are several in Scotland, are situated close to NHS cancer centres. Access to the lymphoedema practitioners was via their line managers, but negotiated informally beforehand with the practitioners themselves. The lymphoedema practitioners were also the 'gatekeepers', enabling access to the women who took part in the observations and subsequent interviews.

4.5 Ethics and Research & Development approval processes

Obtaining ethical and local NHS Board approval to undertake the research was an early step in the research process, and so an account of the process is therefore included at this point in the thesis. I applied for approval for the study from a Multi-Centre Ethics Committee (MREC) and the R&D units in each NHS Board in which the research took place. The responsibility of the MREC is to ensure safety for research participants, and the process of approval focuses on confidentiality and anonymity for participants, procedures for seeking non-coerced informed consent from individuals participating in the research, and the secure storage of research data (Royal College of Nursing (RCN) 2009). The language used in research forms, for example, must be easy for individuals to understand and participants must be clear on their right to withdraw from a study at any time (RCN 2009). My application to the MREC was completed and submitted online through the National NHS Ethics approval systems and the study was granted ethical approval in March 2007.

Prior to this I had preliminary and informal discussions about the project with lymphoedema practitioners, emphasising that this did not assume their participation. However, this early stage of negotiation enabled me to ascertain their level of interest in taking part in the study and also to obtain their views on the research design. I was also cognisant of the potentially lengthy processes

for ethical approval, and the time-span of my Fellowship. As most of the lymphoedema practitioners were known to me, I also believed it would be more appropriate for them to hear about the study initially from myself, rather than through their manager to whom I had also written.

Once I was granted approval from the MREC, I then applied via the Multi-centre Research and Development (MRAD) Consortium to the Research and Development (R&D) Departments at the six NHS Boards with lymphoedema clinics identified as suitable for study. The approval through MRAD was a relatively smooth process, and once I had established the necessary honorary contracts for working with 'patients' and employees of the various different NHS Boards I made contact with relevant staff members at Maggie's Centre, the lymphoedema practitioners, and their relevant managers.

4.6 Recruitment of participants to the study

I will now explain in more detail how I recruited participants to the study, providing a critical discussion of this process.

4.6.1 Recruitment to the small group discussions

As identified earlier, I recruited women to the small group discussions through a lymphoedema support group that I knew was currently running on a regular basis at a local Maggie's Centre. I felt this was a useful way to access women who were likely to have some interest in their self-care, by virtue of attending this group. Early on in planning the project, I talked to the staff at Maggie's Centre about my research protocol and found them very supportive and keen to be involved with the study, as it reflected the philosophy of the centre. One of the Cancer Information Specialists at the centre also agreed to co-facilitate the groups.

Once we had approval to proceed with the study, I provided the relevant Maggie's Centre staff with the Research Information Form 1 (Appendix 4) and a

letter to be sent to prospective participants. The Maggie's staff members were 'gatekeepers' to participants, sending my letters on to their group members, and I did not have direct access to the women themselves. However, due to staff sickness at Maggie's Centre, there was a delay in the letters being distributed. As such, by the time of the first group meeting, only five women had returned the reply form agreeing to take part, or had emailed me to express an interest. Another three women returned the reply form saying they were not interested in taking part. One woman contacted me to say she had stopped attending the support group at Maggie's Centre as she felt it was aimed at either those newly diagnosed with cancer or those who were terminally ill. She described her perception of the prevailing view at support groups of lymphoedema as a '*debilitating condition*', and considered that an alternative, more positive, approach that focussed on general wellbeing might be required for women with lymphoedema after breast cancer. In total, nine women expressed an interest in taking part in the group discussion, and seven were able to attend at least one of the three group discussions, providing their written consent for this (Appendix 5). As such, the groups were much smaller than the originally intended focus groups.

I believe that this approach of recruiting women who had lived with lymphoedema for more than two years through Maggie's Centre alone had limitations and benefits. Firstly, I had to rely on the staff at Maggie's Centre to identify and recruit potential participants on my behalf. Secondly, women might have erroneously viewed my research as being formally affiliated with Maggie's Centre, or as an evaluation of its lymphoedema support group. Involving the staff member who ran the support group may have emphasised this link, potentially influencing the women to be more or less open in their contributions. Thirdly, I was also aware that those attending Maggie's Centre were already a self-selecting group who were probably motivated to seek out support, and possibly more proactive than other women, and accordingly, may well be

unrepresentative of the wider population of women with lymphoedema. I will discuss the process of this first phase of data gathering later in this chapter.

4.6.2 Recruitment to the non-participant observations and interviews

The recruitment of participants to the observation and interview stages of the study was an integrated process. I invited lymphoedema practitioners from various NHS Boards to take part, while they themselves were also the 'gatekeepers' to women who attended appointments at their lymphoedema clinic. Thus, the lymphoedema practitioners were invited to identify women eligible to take part in the study and were the first point of contact for these women. On the day of the observations, I then invited women whom I had observed at their appointment, and who had recently developed lymphoedema, to take part in the series of three interviews over six months.

I approached 13 practitioners from six NHS Boards, sending them each an invitation letter and the Research Information Form 2 (Appendix 6) by post or email. Practitioners who had undertaken an education course in lymphoedema to specialist or keyworker level were eligible to participate in the research (British Lymphology Society 2004). They also had to be working in a lymphoedema clinic in an NHS Board or associated area during the period of study, and undertaking appointments with women who had lymphoedema after breast cancer. Of the 13 practitioners approached over the period of the study, five did not return the necessary forms or were unable to recruit appropriate women to the study, leaving a total of eight who completed and returned a signed consent form. Once I had the written agreement of their managers, I then sent each practitioner the information to be sent to the women deemed eligible for taking part in the study. This included the Research Information Form 3 (Appendix 7), copied on to peach coloured paper, for those eligible to take part in the observations. I also sent them the Research Information Form 4 (Appendix 8), copied on green coloured paper, relevant to the women who had recently developed lymphoedema, and were eligible for taking part in the series

of three interviews. Munro *et al.* (2004) identified the importance of renegotiating access at various stages during their research process in which they undertook observation in health care environments, to inform a study of learning in low paid public sector workers. Similarly, despite having Ethical and R&D approval, I maintained momentum for recruitment by keeping contact with practitioners, often via email. Where required, I also clarified with the practitioners women's eligibility criteria at periods during the study, to ensure I recruited sufficient women within the necessary timeframe.

As already indicated, women were recruited to the observations by the practitioners, who contacted women prior to their appointment at the lymphoedema clinic, and provided them with the Research Information Form 3 (Appendix 7). Eligibility criteria for women taking part in the observations were: aged over 18 years; a diagnosis of lymphoedema after breast cancer treatment; and English speaking, as I had no access to translation services. At the end of the observations, the women eligible for interview were invited by me to take part in the series of three interviews. I talked to them briefly about the interview stage of the research and gave them a copy of the Research Information Form 4 (Appendix 8) to take away. Eligibility criteria for the women to take part in the series of interviews were the same as for the observations, with the additional requirement of the women attending the clinic for the first time, having developed lymphoedema in the previous six months. Reflecting on these processes, I recognised that where practitioners were gatekeepers to the women, they may have intentionally identified particular women for the observation. Arguably, women who had more complex problems may not have been viewed by practitioners as suitable for inclusion in the study, while as research participants, these women may have provided specific insights that were not evident in the other accounts. However, given that the women were attending the clinic for the first time, it is unlikely that practitioners made any particular differentiation.

Ten of the twelve eligible women agreed to take part in the study, and two women declined. I did not pursue their reasons for declining, but I was encouraged that they felt able to refuse and had not felt obliged to take part. Where a woman expressed an interest in taking part, I took her contact number and rang her back a few days later. That way I felt she had adequate time to read the information and to make an informed decision about whether she wanted to take part. Although the information sheet included a reply form, which a small number of women returned to me, most agreed to be contacted by telephone. On ringing them a few days after their initial appointment at the clinic, I then arranged with the women a date for the first interview. I also telephoned or emailed them the day prior to the interview to ensure they were still available and willing to participate. Written consent was established from the ten women who wished to take part, prior to their first interview. As required by the MREC, I wrote to the general practitioners of all the women who took part in the study (Appendix 9).

4.7 Data gathering processes

In this section I give details of how I used the small groups, observation and interviews with women and practitioners in the study, providing a critical reflection on these processes.

4.7.1 Group discussions

I held the small group discussions in a private room in Maggie's Centre, in late afternoon or early evening. I provided finger food, and hot and cold drinks, at each group meeting. The atmosphere was very informal, with us all sitting on comfortable chairs in a circle. The co-facilitator from Maggie's Centre took part in Group One. We had agreed that she would observe and make notes, and contribute to the discussion if she felt it was indicated. The three group discussions were audio-recorded, with the participants' consent.

At the start of each group I introduced myself and gave background information about the study (Appendix 10). I had also developed an outline topic guide for the discussions (Appendix 11), based on a template incorporating a series of topics and possible prompts or questions informed by my literature review (Halcomb *et al.* 2007). I had refined this topic guide to identify key areas and potential prompts, with the help of an experienced researcher colleague. As an experienced nurse and teacher myself, I felt comfortable facilitating the group discussion, and used using the topic guide in a flexible way. However, I was keen that the group meetings should provide women with adequate opportunity to interact freely, and to develop the narrative as much as possible themselves, rather than having it unduly structured by my own questions and frames of reference.

I invited the members of the first group to undertake an activity, where each woman shared her self-care activities while I listed them on flip chart paper on the wall. I felt this may be an '*aide-memoir*', that would ensure that none of the activities they mentioned would be ignored or lost. However, on reflection I felt it placed me in a potentially dominant 'teacher' role, when I stood to write on the flip chart, so I did not use this in subsequent discussions. Prior to the third group I had prepared a sheet with a summary of topic areas, which I gave to each woman at the start. Despite the small numbers of participants, the discussions, often between the women themselves and with limited prompting from me, were spontaneous and insightful. I was encouraged by the women's enthusiasm to take part in the research, and welcomed the depth of the stories they shared.

Each group discussion lasted just over one hour. I transcribed the tapes myself, verbatim, into word documents to generate almost 80 pages of transcripts. I also made additional field notes in which I recorded details of how I felt after the group, and particular observations that I had made in relation to the group interactions or individual members. On reflection, I acknowledge that having a

larger number of women in the groups, as I had initially planned, might have elicited a wider range of experiences. In Group One, I was aware of some degree of 'group think' with participants appearing to agree on 'being lucky', and I recognised that having a larger number of women might have given opportunities for others to speak out with alternative views. Alternatively, women may have found a larger group more intimidating. As such, the research transcripts showed that all the women actively contributed to the discussions.

4.7.2 Observations and interviews with practitioners

In all but one NHS Board, ethical and R&D approval had allowed me to obtain verbal consent from the women who took part in the observations, as this was a routine clinic appointment and I was not an active participant in the appointment. In the other NHS Board, written consent for observation was requested from the women. Each field observation took place over a period of between one and two hours, incorporating one or more lymphoedema appointments. I did not spend much extra time in the clinic, although on several occasions I sat and waited in an area near the clinic. As I was aware that these opportunities for observation provided useful insights into the context, I recorded them in my field notes.

In preparing for field observation, I did substantial reading around the method and considered various ways of recording the data (Barbour 2008; Emerson, Fretz & Shaw 1995; Spradley 1980). As the research progressed, I developed my skills in 'switching on' to focus on specific aspects of the encounter. Initially I drew on the observation guide (Appendix 12), developed from the early analysis of the small group discussion data, as I will discuss later in this chapter. In relation to the field notes, I sometimes discreetly jotted down bullet points or notes during the appointment. However, most were written as soon as possible after each observation, always within the same day (Berg 2007) and they incorporated fairly extensive descriptions. This process was helped by using a digital voice recorder, usually in the car before leaving the setting, or writing

field-notes in various cafes based on hospital sites. I generally found it most useful to include a chronology of events in the observation, and descriptions of the activities I viewed and the people involved. I resisted taking the notes to an overly reflective and analytic level at this stage, and sought to record the factual detail of the experience. However, it has been argued that field notes do represent a form of initial level analysis and as such, they are not raw data themselves (Spencer, Ritchie & O'Connor 2003). I paid particular attention to observing from the stance of a researcher and felt this was particularly important given that, as a clinician with existing 'expert' knowledge and professional attitudes, I believed I might be socialized into certain expectations of the woman or the practitioner, leading me to inadvertently filter out significant aspects of the interaction. In particular, I recognised that since the quality of my field notes of the observations depended on my memory of the event, they should be recorded as soon as possible.

My plan was to undertake at least two field work episodes with each practitioner. However, due to the unavailability of practitioners in specific areas towards the end of the data gathering period, two practitioners were observed once only. In one of these field observations, the woman did not attend for her booked appointment and thus I undertook a practitioner interview without observing an appointment. Informal discussions with practitioners were also often undertaken in the period of time before the appointment, either in the clinic or in the office of the lymphoedema practitioner. These were usually not taped, although I did record the details soon afterwards in my field notes.

Morris, Woodward and Peters (1998) suggested that feminist researchers must consider how they present themselves to the study participants. As such, I attended the observations in casual but smart clothes, although intentionally I did not wear a suit, as I felt this would give the appearance of me being in an authoritative position. I also wore a name badge. I was conscious of trying to wear fairly neutral colours and no bright colours or sparkling accessories that

might cause a distraction. During the observations I was usually sitting in a corner, but sometimes within 'eyeshot' of either the woman or practitioner. I therefore tried to be as quiet and unobtrusive as possible during the encounter. On reflection, I am aware that having worked in various lymphoedema clinics myself, I did not feel particularly out of place during the observations, and probably settled quickly into the rhythm of the appointment, knowing where to place myself to be discreet. I did not participate at all in the majority of the appointments, apart from talking to the woman at the start and end, although on a few occasions I did write down numbers as requested by the practitioners who were measuring a woman's arm.

The practitioner interviews usually took place immediately after, but occasionally before, the observed clinic appointment. Generally they were in a private place, either in the clinic or in a nearby room. I explored specific topics with the practitioners (Appendix 13), drawing cues from the appointment setting and the interaction between the woman and practitioner. Often I had many different considerations in my head, so that at times I found the central focus on supported self-care challenging, as it seemed an elusive and difficult concept to tease out from what had happened in the routine of an appointment. The topic guide (Appendix 13) helped me to maintain some focus in the interviews, and I continued to refine this as the study progressed. However, I am aware that the time I spent in the clinic was minimal and covered only one small part of the work of the practitioner. As such, different features of supported self-care may have taken place in other ways that I did not observe or capture in the data.

I felt that I was able to establish a rapport with practitioners over the time of the study, possibly made easier by already knowing most of them through my professional work. The interviews were constructed in a fairly conversational manner (Borbasi, Jackson & Wilkes 2005). However, I took care to ensure that my questioning was sufficiently open, with adequate opportunity given for practitioners to share their stories. The process of undertaking repeated

observations and interviews with some practitioners on different days also enabled us both to build on thoughts and ideas raised in previous interviews. For example, several practitioners told me that they reflected on their work as a result of our discussions, and I saw evidence that some were changing aspects of their practice as a consequence. None appeared to be overly threatened by the observations and I do not believe my presence distracted them greatly during the appointments with the women. All of the practitioners who took part invited me back for subsequent observations, although this was not possible in all cases due to time restrictions.

When I specifically asked the practitioners about how my presence might have influenced the conduct of the appointment, they all responded that it had made little difference to what they did. However, as I had previously known some in a lecturer/student relationship and was their professional colleague, I was aware that they might have held '*a priori*' assumptions about my own expectations of their work. For example, they might have perceived me as an 'expert', and felt intimidated by my presence. These are important considerations and I cannot know fully how I influenced the actions of the practitioner and the research data. In my defence, I also believe that my approach as a person is relatively gentle and supportive, and all the practitioners seemed happy to discuss their experiences and ideas with me. On two occasions, even where their colleagues were leaving at the end of the day, the practitioners were keen to stay to continue sharing their thoughts with me.

A specific consideration for my role as a researcher concerned the extent to which I remained a passive observer or took an active role in the field (Barbour 2008). Borbasi, Jackson and Wilkes (2005) considered that nurses may find it relatively easy to slot into a social setting, but need to decide how much to participate, particularly if it is a setting familiar to their own clinical practice. In the event, spending short periods in clinics meant I was looked upon as a visitor and my role was essentially non-participative. However, ethnographic

researchers have argued that collaborating with research participants for a period of time, then withdrawing from the field, and eventually developing and owning the research product themselves, raises the potential risk of them betraying the trust of research participants with whom they have been working (Stacey 1988). In my own case, the contact with participants was relatively brief, although I still recognised the importance of being aware that methods such as observation or interview could leave research participants subject to risk of exploitation. For example, I was aware that the women with lymphoedema associated with breast cancer may already be distressed and vulnerable, and that as an observer I should seek to minimise the impact of the research on them. Thus I planned to observe women at one point only, during their first assessment or follow up appointment, and not during treatments such as manual lymph drainage.

4.7.3 Interviews with women who had newly developed lymphoedema

I undertook the first of the three interviews with the women around two to three weeks after their first appointment at the lymphoedema clinic, and I saw them again at three and six months later. I believe a longer follow up period would have enhanced the data, although this was not possible given the time restrictions of my Research Fellowship. The interviews took place in the homes of the women, apart from one woman who was interviewed at work, and another two who were interviewed for the third time over the telephone due to bad weather conditions preventing my travel. For safety reasons, a research colleague always knew where and when I was out visiting, and I always contacted them to report my safe return.

I was aware that talking with each woman outside the healthcare setting, and over a series of interviews, enabled me to build a relationship with her in which I hoped she felt comfortable to share her stories. I felt it was particularly useful to have met each woman firstly at their lymphoedema appointment, as there was some level of recognition and familiarity, including a shared experience of the

appointment, which formed a useful basis for our initial discussions. I was keen to encourage a relatively flexible, unstructured conversation with the women, using open questions and prompting her to discuss her particular story. I did draw on a topic guide (Appendix 14) to guide my questioning, but having been present at the lymphoedema appointment I also had a contextual perspective that provided an important individualised focus. Later, as the interviews progressed, and we got to know each other better, I drew on previous discussions, and followed up cues from the earlier interviews, taking time to prepare for each by rereading the previous transcripts. I believe I established a good rapport with the women, and each appeared comfortable about talking with me, with none refusing to continue with the series of interviews.

In undertaking interviews with women over a period of time, I considered that while I was creating an intrusion in their lives, I should ensure this was undertaken sensitively and in a non-exploitative way. I recognised that my skills, sensitivity and awareness as an interviewer were crucial to my seeking to establish a safe environment for these research participants. I was aware that they seemed comfortable to talk with me and I believe that in some instances, some level of therapeutic encounter took place. However, I recognised fully that I was not there in a counselling or clinician role and this was not the aim of the interviews.

In providing an open environment for them to talk about sensitive and personal details, it was perhaps inevitable that some women became emotional and tearful in the interviews. I dealt with this in several ways: asking if they felt comfortable to continue; providing a supportive, non-judgemental and empathic environment; and giving information on relevant points of contact or support for the women, including their lymphoedema practitioner. All stated they wished to continue with the interview at that time. While in my clinical practice, I have often worked with women who are similarly distressed, when this arose in the research interview it did raise issues for me, particularly when women were

upset or frustrated as a result of a lack of services or inefficient care. As a researcher, later working with the transcripts over a period of time and listening to the tapes, I found some of the data emotionally draining (Cannon 1989), and sought support with some of the issues this raised for me. As a gesture of appreciation, but perhaps also to bring some symbolic sense of closure on our relationships, I brought each woman some flowers to their third interview.

In reflecting on my approach to interviewing the women, I recognised that I relied on their memory about past experiences and emotions, and the way they chose to present their retrospective accounts to me. However, undertaking a series of interviews provided the opportunity to follow up and clarify any points raised previously. Furthermore, I was aware that although extending the time between interviews may have provided further longitudinal data, this was not possible due to the time frame of the study.

4.8 Data organisation

I had accumulated considerable data in the form of transcripts and field notes by the end of the fieldwork phases, and careful organisation was required to enable me to easily refer to various aspects of the data and cross reference different parts of the data set. The three taped small group interviews, 15 taped interviews with the lymphoedema practitioners and the total of 30 interviews with the women, were all transcribed verbatim. Initially I transcribed some of the tapes myself, sometimes using voice recognition software, but later due to time restraints, I used a professional transcription service, always checking each transcript against the audio-tape. In each case I formatted the transcripts with page numbers and identification footers. I also used a red font to highlight the researcher comments and questions, differentiating these from the words of the participants, which I left in black text. For reasons of anonymity, I gave pseudonyms to all the participants and to other individuals and places mentioned in the text (apart from Maggie's Centre). In each case I listened to each taped conversation several times to check the transcriptions for accuracy,

to note particular emphases, and generally re-familiarise myself with the data. I also typed out the field notes of the observations, with similar attention to anonymity, and set them out with double line spacing for ease of reading and annotating.

I assigned each transcript, whether of the small group discussions, interviews or field observations, a code that corresponded to its origin, for example from a woman with lymphoedema or a practitioner; the series of three interviews were numbered accordingly. I kept each dataset in hard copy in a locked cabinet. The data were also easily accessible to me, through a password protect system, on my personal computer, and stored in labelled folders. I also stored the data in QSR NVivo software on the same personal computer, for analysis purposes. I kept a tabled list of recruitment information with coding symbols used for each participant. I therefore had a clear filing system for the data and a cumulative record of the data, enabling me to easily cross-reference and compare data from the different sources.

Ritchie, Lewis, & Elam (2003) discussed the importance of organising and managing a large, potentially unwieldy and intertwined data set. I recognised that effective data management was important to ensure the integrity of the subsequent stages and the research findings themselves (Ritchie, Lewis, & Elam 2003). It enabled me to move more readily back and forth between the raw data and analytic processes (Miles & Huberman 1994).

4.9 Data analysis

Having such a combination of data sources raised various challenges with integrating the data, in order to come up with meaningful and authentic findings. In analysing the data I undertook a thematic analysis, combining coding and constant comparative techniques borrowed from grounded theory research methods (Strauss & Cobin 1998). Taking this approach provided analytic diversity (Sparkes 2005) and enabled me to gain a broader and deeper

understanding of the data (Coffey & Aitkinson 1996) within a fairly rigorous framework. It is argued that data gathering and analysis is a simultaneous and iterative process (Barbour 2008; Bluff 2005). Indeed, the processes of analysis and synthesis extended over the period of data gathering and throughout the time I was writing the thesis. Denzin and Lincoln (2003) have argued that qualitative inquiry is a creative endeavour, with interpretations being constructed and text re-created as the researcher makes sense of what is learned.

Thematic analysis refers to a range of techniques used to identify themes from the data through the processes of coding and categorising the data (Strauss & Corbin 1998). Thus I began with 'open coding' (Strauss & Corbin 1998), identifying codes within the data, and undertaking constant comparison between data in terms of words or phrases used within the individual stories, and between different narratives and field notes (Strauss & Corbin 1998). I then focussed on linking selective 'codes', seeking to explore patterns and relationships across and within the datasets. Analysis of the small group discussion data enabled me to identify a number of early conceptual ideas, some based on 'in vivo' codes: *the medicalised world around women with breast cancer; options and expectations*; and *'how much of a story do you want to give anybody?'*. I generated a coding framework from these small group findings (Appendix 15) that I used to underpin the earlier stages of the observation and individual interviews.

Later on I refined and developed the conceptual framework to form several themes and sub-themes, to identify the women's perspectives (see Chapter Five), and the perspectives of the lymphoedema practitioners (see Chapter Six). Initially I used QSR NVivo software to organise data and code the transcripts of the small group discussions. I felt that becoming familiar with this software would be an important research training exercise. However, I found it difficult to visualise data within their context while it was fragmented by excessive coding within the programme; at this point I had identified around 48 codes from three

small group discussion transcripts. Consequently, therefore, I returned to the hard copies of transcripts to code them manually, annotating the transcripts in pencil, and using coloured pens to focus my attention to certain groups of patterns of codes and categories in the data (Miles & Huberman 1994). I also produced matrices to facilitate cross-checking of the themes and sub-themes, and identify the similarities and differences between the different data sources (Miles & Huberman 1994). I repeated this process of hand coding, annotating, and cross-checking themes with the observation field notes, and the transcripts from the interviews with the women and practitioners.

Seale (2007) suggested that use of a 'code and retrieve' data management package such as QSR NVivo may encourage short cuts and is unlikely to be useful for narrative data. However, I did find it practically useful for collating quotes in relation to different themes and sub-theme. I exported these into word documents to which I could refer while writing up the findings. Early coding identified 62 codes from the women's interview transcripts, field notes and practitioner interviews. Importantly, I found that writing memos for each transcript, particularly for the woman and practitioner interviews, was extremely useful. I believe these illuminated my decision trail as I moved on from the initial codes to create broader themes and sub-themes. It is suggested that memo-writing enables the researcher to engage with the data, initiating new ideas and helping to extract meaning from the data (Birks, Chapman & Francis 2008).

Following a mainly inductive approach, and recognising the iterative process of data analysis (Barbour 2008), I frequently moved between memos, themes and the original data, looking for recurring assumptions and ideas, and checking across and amongst different datasets. I strove to remain open to new ideas (Barbour 2008). Strauss and Corbin (1998) suggested that the researcher has to choose between salient phenomena as they relate to a core theme. I also recognised that various themes and stories may arise from data analysis (Keddy, Sims and Stern 1996). I report my interpretations of the themes and

sub-themes for the women and the practitioners in Chapters Five and Six respectively, and then synthesise these with the relevant literature in Chapter Seven.

I recognised the epistemological challenges of integrating findings from different sources (Moran-Ellis *et al.* 2006). As such, I also found it useful to draw on techniques of narrative analysis to support and develop the thematic analysis in the later stages (Holloway & Freshwater 2007). Thomas (2008) described the use of narrative analysis techniques in a secondary analysis of interview data which had previously been subjected to a cross-sectional thematic analysis. She considered how this second approach led her to look at the narrative form and the broader social contexts of the stories (Thomas 2008). Similarly, Simons, Lathlean and Squire (2008) considered the potential for greater complexity and depth of understanding achieved with a combined approach to data analysis. Using the three-dimensional approach described by Clandinin and Connelly (2000), I reread the transcripts, examining them for salient themes, and interrogating the data by asking specific questions such as: *'what particular differences and similarities are there between individual narrative accounts?'*; *'when and where/under what conditions does this happen/not happen?'*; *'what social forces shape these actions?'*; *'what does the narrative suggest about the implications of a particular course of action?'*; and *'how does this relate to the concept of relational autonomy?'*. I believe this additional narrative focus enabled me to gain a sense of context, sequence, timing, continuity and interaction. Importantly, this process drew attention in particular to the social structures which appeared to influence the various participants. It is my contention that the combined processes of thematic and narrative analysis were important in establishing an authentic account that addressed the aims of the research.

4.10 Researcher dilemmas and considerations

There were several dilemmas that faced me as a researcher. Kralik (2005) considered that a feminist-informed research relationship helps to ensure equality and collaboration between researcher and research participants in the generation of research data. However, as I have identified earlier, this can never be entirely equal, as the researcher is inevitably the person who drives the data generation, interprets the accounts and constructs the research outcomes. I aimed to achieve where possible a non-hierarchical relationship with research participants (Morris, Woodward & Peters 1998), for example, by asking questions that enabled interactive dialogue in the interviews. In her much cited study of women making the transition into motherhood, Oakley (2005b) argued that researchers are at risk of exploiting research participants if they take on a detached, objective interviewing role, for example, working from a structured interview guide and not answering questions asked of them by the research participants. There were instances in the current study where participants, both women and practitioners, asked my advice, and I believed it appropriate to answer them as fully as possible, although in the case of the women, I also encouraged them to refer back to their lymphoedema practitioner or doctor.

A further dilemma concerned how to present myself to the women, for example, as a lymphoedema practitioner, or as a researcher. I felt that to be honest and authentic, I had to be clear with them that I was a practitioner undertaking research, particularly as the women were likely to hear this from staff at Maggie's Centres or the lymphoedema practitioners. However, I was also aware that this might mean the women would make specific assumptions about me as a professional, bringing them to be more or less open about their experiences. I was, therefore, honest about my background, but also clear about my agenda and the purpose of the research, which was open and exploratory.

I suspect that as a qualitative study there could be an assumption by an ethics committee that this would be a relatively 'harmless' study, but I was prepared for some women to become emotional during the interviews, as indeed happened. Having respect for the research participants and providing an environment where participants could make an informed choice about taking part in the research were fundamental principles that underpinned my approach at all stages of the study. As such, I was aware that the practitioners and the women required time to read the research information, to ask about the study, to decide if they wish to take part, and also to withdraw if they wished. Notably, while two women refused to take part, all of the ten women who did agree to be interviewed took part for the whole of the six month period, and all seemed very committed to working with me and sharing their accounts. Similarly, I respected the wishes of the practitioners who did not reply to me, or who felt unable to help me by recruiting women to the study.

Over the course of the study, I constantly reflected on my potential influence on the research process. It would be impossible to remove this personal influence from an interpretative study such as this, and it is inevitable that the choice of methods and participants, and also the processes of data analysis and interpretation, were influenced by my own values and agenda. Indeed, Barbour (2003) argued that, within a rigorous research process, the agency of a researcher and her influence in creating and interpreting the data in the context of their personal and professional experience are potential strengths of qualitative study. As I showed in Chapter One, I did not come to the research as a neutral and naive observer. I had been immersed in the field for some years prior to the research. I found that maintaining a reflexive stance throughout the research period, through the use of a reflective research diary, and being questioned and challenged during my research supervisions, were particularly important steps in disentangling my professional and researcher roles. Undertaking this research within a PhD Fellowship meant that, within the boundaries of research supervision, I essentially worked on my own as a

researcher, generating and analysing the data. I therefore also recognised the need to be transparent about the assumptions that guided my work, and I continued to reflect on these in my research diary as the thesis developed.

Criteria of reliability and validity, as applied to quantitative research methodology, are much debated in the literature by qualitative researchers (Holloway & Wheeler 2002; Rolfe 2006). However, it has been suggested that it is difficult to establish one set of criteria for judging qualitative approaches, given their varied paradigmatic roots (Rolfe 2006). Sandelowski (1993) has argued for the use of trustworthiness as a basis for assessing whether the study was carried out as described by the researcher. She called for a clear decision or audit trail to enable others to substantiate the research process in any given study (Sandelowski 1993). I believe I have provided this in the thesis.

In this study I did not draw on member, expert or peer checking of the data or my inferences from it to any extent, although some aspects of this were built in to the design. In the next section I discuss the process of feeding back the early findings to a small group of practitioners who took part in the study. In relation to the women who had newly developed lymphoedema, interviewing these women on three occasions meant I was able to check out earlier discussions with them, to seek clarification or to identify changes. This process of checking information with the women was in the spirit of feminist-informed research; a type of collaboration between equal 'expert' parties. I found it particularly useful nearer the end of the study, when I wished to develop various conceptual ideas that I developed from the data. However, while I invited five of the women to look at the transcripts of their previous interview, they all declined. In retrospect I could have provided a short summary which might have been easier for them to digest and could have formed a useful starting point for the next interview. Forbat and Henderson (2005) discussed the sharing of transcripts with research participants, recognising that this process can have the unhelpful effect of

'freezing' in time or reifying constructs from which people have moved on by the time the data are shared.

Another dilemma concerned how I maintained confidentiality and anonymity, particularly for the lymphoedema practitioners who worked within a relatively small field and knew each other. I have omitted locality details and used pseudonyms in the text for women and practitioners. However, now the thesis is written, I continue to be aware that practitioners in particular may recognise themselves in the findings, and this has implications for how I present the research findings at conferences or in print, where I would wish to respect and protect their anonymity. During the course of the research itself, I was emphatic about ensuring confidentiality for the women and practitioners. Although I sometimes met practitioners who took part in the research at other meetings over the course of the study, I always avoided discussing any aspects of the research at these occasions.

A final point to consider was how I balanced different and potentially competing roles during the study. I continued to work as a lymphoedema practitioner myself, albeit for only four hours per week. Thus I was attending meetings of the Scottish Lymphoedema Practitioner Network with practitioners who were both colleagues and participants in the research. For some of that time I was Chair of this group and had established what I believed was a good relationship with these individual practitioners. However, I was aware that the practitioners may have had expectations of me and the research, and this may have influenced their decisions to take part or the ways in which they did or did not contribute to the research. I consider this 'insider' role and the fact that I knew most of the practitioners quite well to be a positive feature of the research. It meant that I had insight into their work, helping me focus my questions and awareness in certain ways that I feel has enhanced the data.

4.11 Feedback discussion with practitioners

Around six months after the end of the data gathering process, during the analysis stage, I arranged a meeting for lymphoedema practitioners who took part in the research. The main aim was to give them feedback about the research process, to identify the emergent study findings, and to clarify with them my understanding and interpretations of the data. For example, I was keen to explore the linkages within data, to explore whether my assumptions and findings felt relevant to them as practitioners.

The meeting took place mid-morning in a hotel and was followed by lunch paid for by the university. I presented my findings from the women and practitioner data, outlining and describing the various themes, and asking for comments and ideas. Four practitioners were able to attend, and all contributed constructively and openly to the discussion, which I taped. Listening back through the tape, I was able to summarise the main points from the meeting and became aware of how the issues they raised built on my findings. However, at the meeting, the practitioners also provided additional perspectives on the uniqueness, and demanding nature of the work of a lymphoedema practitioner. In particular, the meeting raised issues of caseload management that I had recognised but had not fully explored in the previous observations and interviews. I was able to incorporate these into the practitioner themes in Chapter Six. Not all practitioners were able to attend, but it was encouraging to hear that those who did attend had found the previous observation and interview processes to be useful and productive. In particular they commented that the experiences of taking part in the research, and talking with me when I came to observe them, had given them time for reflection and discussion, opportunities they often did not have within their relatively isolated roles.

4.12 Chapter summary

I was aware that the phenomenon of 'supported self care' would not take place in one setting alone, and not even necessarily in a health care setting. My approach was, therefore, to generate data in a variety of settings to inform an understanding of this politically driven concept. In this chapter I have attempted to provide a clear and thorough account of how I have designed the research, and applied the methods in generating and analysing the data towards meeting the research aims (Avis 2005). While some of this has involved making pragmatic and practical decisions, within the timeframe of the study, I believe I have articulated the methods and provided a clear audit trail of the steps taken through the identification of research questions, aims and methods, and the processes of data analysis.

In Chapter Five and Six I will now present the themes and categories developed from the analysis of the women's and practitioner's account respectively. In Chapter Seven I then synthesise these themes in relation to relevant literature to develop the main arguments for the thesis.

Chapter Five: Women's perspectives

5.1 Introduction

In this chapter I present my first-level interpretations from the accounts of the women with lymphoedema. Seven women who had lymphoedema for more than two years (Table 5.1) took part in the small group discussions in Phase One of the study (Table 4.1). Ten women who had newly developed lymphoedema (Table 5.2) were observed at their appointments and interviewed on three occasions in Phases Two and Three. As I have described in Chapter Four, Phase One preceded Phases Two and Three, which ran concurrently. The analysis of the Phase One small group discussion transcripts was, therefore, useful in informing the early stages of the observations and interviews. For example, as shown in the early coding framework in Appendix 15, this early analysis drew my attention to the discourses they used to refer to 'the arm', the stories that women told about the medical context of their lymphoedema experience, and the notion of 'good' or 'bad' choices around self-care. As the data gathering and analysis progressed, the early analysis of the small group discussions enabled comparisons with the experiences of women for whom lymphoedema was a more recent experience. This chapter incorporates my interpretations developed from a synthesis of the data from the two groups of women.

In every case, to ensure anonymity, I used pseudonyms for the women. The women taking part in the small group discussions (Table 5.1) were all more than 50 years old and had lymphoedema for more than six years; two of the women had lymphoedema for around 20 years. In comparison, several of the women who had newly developed lymphoedema (Table 5.2) were between the ages of 35-50 years, reflecting a younger age group of women who may be affected by breast cancer; one was 87 years old. They had all developed lymphoedema in the previous six months. Several women were carers of family members. Nine of the seventeen women were in paid employment. Detailed information about

the women's breast cancer treatments were not recorded, as these were not the focus of this naturalistic enquiry. Notably, the views of younger women were missing from the small group discussions and it is possible that they may be less likely to attend this type of event due to childcare or employment commitments. All the women who did take part were white Europeans, with no ethnic minority women represented.

Group	Facilitator/s	Details of women	Duration of lymphoedema
One	Researcher (AW) and co-facilitator from Maggie's Centre	'Audrey' aged 51-60 years, working part-time, married 'Betty' aged 61-70 years, retired, married 'Chris' aged 80+ years, retired, widowed	6-10 years 6-10 years 6-10 years
Two	Researcher (AW)	'Dora' aged 61-70 years, retired, divorced 'Elaine' aged 61-70, retired, married	6-10 years 16-20 years
Three	Researcher (AW)	'Fiona' aged 51-60 years, working part-time, married 'Grace' aged 61-70 years, working part-time, married	21-25 years 6-10 years

Name	Age group	Details	Approx. time since breast cancer diagnosis	Duration of lymphoedema
'Heather'	51-60 years	Lived with/carer for father; divorced; recently returned to part-time work	1 year	6 months
'Irene'	61-70 years	Lived with husband; carer for husband and grand children	5 years	6 months
'Joanne'	41-50 years	Lived with husband and teenage daughter; worked fulltime	3 years	6 months
'Kate'	35-40 years	Lived with partner and two year old daughter; due to return to work	<1 year	2-6 months

'Linda'	41-50 years	Lived with husband and two adult children; worked full time	4 years	2-6 months
'Mary'	51-60 years	Single; carer for older relative in her own home towards end of the study	4 years	2-6 months
'Nina'	41-50 years	Lived on own, had partner; no children, returned to work during study period	1 year	1-2 months
'Olive'	85-90 years	Widowed, lived alone; daughter in England	3 years	2-6 months
'Petra'	51-60 years	Lived alone, daughters nearby, returned to fulltime work during study period	1 year	6 months
'Rona'	61-70 years	Lived with husband; carer for grandchildren	4 years (and >10 years previously)	2-6 months

In total, I generated three and a half hours of audiotapes from the small group discussions, and 19 hours of tapes from the series of three interviews with the ten women who newly developed lymphoedema. All the tapes were transcribed verbatim. In the previous chapter I described the processes of data organisation and analysis. In Table 5.3 I present a summary of the first-level interpretations, identifying three themes, each comprising several sub-themes which I will describe below.

Table 5.3: Themes and sub-themes relating to the women's accounts
<p>Knowing lymphoedema in the context of breast cancer</p> <ul style="list-style-type: none"> • Being aware of and interpreting the signs of lymphoedema • Moving through and beyond breast cancer treatment • Negotiating the medical world
<p>What can one do?</p> <ul style="list-style-type: none"> • Expectations and disappointments • The good, the bad and the ugly • Developing knowledge about lymphoedema • Looking for other options
<p>Life with lymphoedema</p> <ul style="list-style-type: none"> • Getting a life back • Seeking perspective • 'How much of a story do you want to give?'

5.2 Knowing lymphoedema in the context of breast cancer

The accounts of the women indicated that coming to know and making sense of the signs of lymphoedema could be a significant physical and emotional experience for them, particularly in the early stages of lymphoedema development, and where the lymphoedema was unpredictable and uncontrolled. The accounts described in this theme show that the physical changes and sensations of lymphoedema could have an oppressive and threatening quality, evoking anxiety and fear about cancer recurrence, and making it difficult for women to judge the significance of any symptoms. Some women also experienced difficulties with the medical world relating to breast cancer, in not having their lymphoedema taken seriously by doctors, or not being able to access well-timed and trusted information about lymphoedema. These findings provide an important context for understanding the nature of supported self-care, and in Chapter Seven I draw on these interpretations when, in particular, I examine the social construction of lymphoedema.

5.2.1 Being aware of and interpreting the signs of lymphoedema

Many of the women provided quite detailed descriptions of the physical bodily sensations associated with having lymphoedema. Audrey and Joanne talked of experiencing a nagging pain in their arm, and Joanne considered:

'Everything is really tight; when my fingers and my hand get swollen it is difficult to type...then I do stop using it [her hand]...but I wouldn't say it was painful, it's like a dull pain; it's always there, and you're always really conscious of it in the back of your mind' (Joanne, Interview 1, p.2/3).

This conscious awareness is an important point, reflected in other lymphoedema research studies, and forms a basis for understanding how women may be supported to anticipate changes in their lymphoedema, and undertake self-care activities, as I will show in Chapter Seven. For example, Betty, who had lived with lymphoedema for many years, described her arm as throbbing and spoke of feeling a sense of pressure in her arm if she did not wear her compression sleeve. In contrast, Nina had newly developed

lymphoedema and experienced her arm as feeling tight and swollen. She was concerned to see indentations in her skin where she had been lying on her arm, but was unsure of their significance. Mary also noticed her lymphoedema visually, and in a practical sense:

'I think just wearing clothes, I could see a difference that, you know, things were getting tighter on that arm, and I always wear that bracelet, and that was getting tight...I mean, it was nothing too uncomfortable, nothing that was painful, or anything. I was just gradually aware of it' (Mary, Interview 1, p.4).

This sense of a gradual change was identified by Fiona, who also drew attention to the dynamic nature of her swelling over her many years of living with lymphoedema:

'Initially I didn't have it very badly...but then it gradually started to become a problem and sometimes it was huge and sometime less so.' (Fiona, Small Group (SG), p.3).

In apparent contrast, Irene talked of her surprise at how quickly her lymphoedema developed over a weekend:

'I noticed I said to John "Look at my arm... I never noticed that as bad as that", he said "No, you haven't got an elbow". It was all swollen and I said, "When did that happen?" It just suddenly crept up on us' (Irene Interview 1, p.5).

These excerpts suggested that women could have varied experiences relating to how their lymphoedema developed, and how it changed over the course of a day, or between different days:

'I felt the other day, my hand was quite swollen and down to my wrist; you can really see it some days... especially at night... my watch was tighter than on other days' (Petra, Interview 1, p.2).

Petra appeared very aware of her body, constantly noticing specific details of the swelling and how it changed. She described other sensations such as numbness, which made her *'panic'* until her physiotherapist reassured her it was quite normal. Heather also talked vividly of how, alongside the symptoms of swelling and feelings of tightness in her arm, she had a sense of numbness in her armpit which she repeatedly rubbed to try and restore some feeling to the area. This appeared to be a heightened awareness that prompted particular

action but also anxiety. In contrast, Irene and Olive talked of almost forgetting about their arm during the daytime, until bedtime when it prevented them from sleeping due to the discomfort. However, like Petra and Nina, Kate talked in her first interview of paying constant attention to her arm and how it changed, noticing marks in her skin and generally feeling uncertain as to what was happening to her body. By Interview Three she appeared more confident:

'My arm's been fine, but occasionally I have a dull ache, like when I had a cold...but I don't get too alarmed when it does get sore now as I kind of know it is going to go away' (Kate, Interview 3, p.1).

It is possible that as Kate recovered from her cancer treatment, the swelling had reduced, although measurement and recording of limb size was not a facet of this particular study, so no link can be made. Another possibility is that Kate's perception of the swelling, and her concern over the significance of the swelling, and her ability to deal with it, had also altered. Notably, by Interview Three, Linda, Olive and Rona also talked of their lymphoedema having almost completely reduced, and I was aware that their sense of anxiety had also greatly diminished. The accounts of women who had lived with lymphoedema over several years indicated that these changes in women's perceptions and awareness of lymphoedema could often occur:

'I think that very awareness that you have to begin with when you are looking at it all the time, and thinking, is it any bigger today? Obviously you can't go on living like that so you just take it for granted' (Betty, SG1, p.9).

Here, Betty was living with an obviously swollen arm which she said did not interfere with her life, despite her having to wear a sleeve most days. Fiona also considered her arm to be no longer a problem, while Elaine related her lack of problems to the observation that:

'In 12, or maybe 16 years, it [the arm] has gone down tremendously' (Elaine, SG2, p.7).

Where it is likely that women became less anxious once the lymphoedema swelling was reduced or appeared to be controlled, accounts from both the

small group discussions and the individual interviews emphasised the unpredictable nature of lymphoedema. For example, Elaine reflected:

'I think that's the most difficult part to cope with. If for no reason, all of a sudden, it will go [gestures shape of a swollen arm]' (Elaine, SG2, p.2).

Thus it appeared that this unpredictability could present challenges. There were specific examples of crisis or sudden changes that brought particular difficulties and distress for women. Heather and Grace talked of how their arm became bright red and sore when they had an infection; this had clearly frightened and distressed them at the time. Dora shared similar experiences of having an infection; she was notably despondent in the group discussion as she reflected on the ongoing nature of her lymphoedema, her frequent experience of infections and the unpredictability of her swelling.

Nina and Heather, who had newly developed lymphoedema, recognised the visibly obvious worsening of their swelling over the series of three interviews. In Interview One Nina referred to her swollen hand:

Nina: *'That's where it feels most noticeable... it probably does go up and down, but it's just because it is swollen all the time; but she [the lymphoedema practitioner] said it's mild so obviously there's people who have got a lot worse'*.

Researcher: *'Do you feel it's mild?'*

Nina: *'I would have thought it was maybe a bit more than mild...but she's seen so many different people that she can compare it to them'* (Nina, Interview 1, p.3).

This comment suggested that getting a realistic perspective on the lymphoedema, and assessing its relative severity, could be difficult for Nina. By Interview Three Nina was hopeful, but uncertain that the forthcoming end to her Herceptin (drug) treatment would bring a reduction in the swelling:

'I'm pinning my hopes on that because it's [the lymphoedema] just horrible, I hate it, it's so unsightly' (Nina, Interview 3, p.7).

Thus, while some women experienced a reduction in their swelling, the ongoing difficulties for women such as Nina and Heather appeared to cause them significant distress. Heather summed up her feelings:

'You've nae [no] choice, nae choice at all, you've got it, it's there and you have no control over it, not like you can get up and say I'm going to have a good day with it because you've always got it and you don't know what's going to happen, it never goes down, the fingers go down and my hand goes down a wee bit but nae [no] choice at all' (Heather, Interview 3, p.6).

This excerpt emphasised the limited control that Heather perceived she had over her lymphoedema, recognised by her as a distinct lack of choice. The lack of constancy and her frustration, particularly where her attempts at self-care were in vain, suggested a real sense of dis-empowerment for Heather. This is a significant finding in relation to supported self-care which will be explored in more detail in Chapter Seven.

The accounts also indicated that lymphoedema was only one of a number of bodily changes experienced by women after breast cancer treatment. I interviewed Kate for the third time as we sat at her kitchen table. Looking back on her experiences of surgery, chemotherapy and radiotherapy over the last months she talked articulately and honestly:

'The thing I have suffered the most with is poor self-image and that's come from what's happened to my body and that's not because I think I have a lopsided breast, it was that I put on weight and I was bloated, I didn't have any hair, my eyelashes thinned. That was the biggest damage for me.... you just felt you had this body that wasn't yours' (Kate, Interview 3, p.3).

This suggested that Kate, aside from lymphoedema, felt like she was living in a body that she did not fully recognise. I found that through undertaking a series of three interviews with the ten women who had recently developed lymphoedema, I became aware of them gradually getting to know their changed body and, for example, coming to understand how their arm might respond to changes in the weather, or certain activities. Discussions in the small groups indicated that women who lived with lymphoedema over a longer period of time had learned to recognise and adapt to various body changes, but also constantly reassessed their arm in quite a routine way:

'It's usually only in the mirror in the morning, isn't it (all laugh), especially if you're brushing your hair or something and you think "Oh, that one's looking big today"' (Betty, SG1, p.8).

This use of the term *'that one'* appeared similar to other instances where a woman referred to her arm as *'it'*, or *'the arm'*. In SG3, Grace took off her compression sleeve and held her arm up for us to see, gently slapping it and proclaiming:

'Look, there's the infamous arm!' (Grace, SG3, p.5).

This appeared to be a type of objectification of her arm as an external entity and suggested a degree of alienation from her lived body. Significantly, this rather detached view of *'the arm'* as an object to view appeared to sit alongside women's strongly subjective and embodied experience of lymphoedema. As such, it seemed like *'the body'* affected by lymphoedema might be both object and subject; capable of being viewed in a detached way, but also lived and known in an intensely physical, emotional and dynamic sense.

A further aspect of this category related to how women sought to make sense of or interpret their experience of lymphoedema from seeing others with the same problem. This was evident even in the small group discussions where Fiona compared herself with Grace:

'I can see that you have got a bigger problem than I have.' (Fiona, SG3, p.9).

However, as a type of visual backdrop to their own experiences, this provided opportunity for comparison, but also for misunderstanding and concern. Petra, Rona and Joanne all talked of seeing other women with lymphoedema who were wearing their sleeves. Nina had seen one woman with what Nina thought was particularly severe lymphoedema at a breast cancer support group:

'There was a woman there who seemed to be quite badly affected by it, and she carried a pillow with her and her arm seemed to be... she was always resting it...it frightened me because I thought I really didn't [did not] want that...obviously her case is quite a bad one compared to maybe what I've got' (Nina, Interview 1, p.3).

Betty described her experiences of other women at a Maggie's centre group, suggesting this could motivate her self-care activities:

'Well, two of the ladies coming to the group have stopped wearing their sleeves and I think it is quite noticeable how their arms have got bigger, and well, I don't want mine to get like that; that sort of reminded me about the sleeve.' (Betty, SG1, p.6).

For Kate, seeing others with lymphoedema while at the chemotherapy room was frightening, and she described having 'visions' of how bad lymphoedema could become.

To summarise, these accounts showed that lymphoedema in the context of breast cancer was associated for many of the women with a conscious awareness of bodily changes; what might be viewed as physical 'signs' that something is not right. These could evoke anxiety, particularly in the early stages of lymphoedema, when women could not readily make sense of these changes. Some women who had lived with lymphoedema for longer appeared to have incorporated the physicality of lymphoedema into their lives. Rather than being preoccupied with physical changes, they appeared to have developed a routine approach to self-monitoring. However, unpredictable or uncontrolled lymphoedema led to particular distress and frustration. These accounts paradoxically suggested that women could experience lymphoedema both in an objective and almost detached sense, but also in a strongly subjective and embodied way.

5.2.2 Moving through and beyond breast cancer treatment

For all the women who took part in the research, lymphoedema was an unwanted legacy of their breast cancer treatment. Unsurprisingly, the women who took part in the small group discussions appeared to have put breast cancer more firmly in their past, while many of the women who had newly developed lymphoedema were still living through the realities of medical treatments as a continued presence in their lives. There was a sense of rawness in their experiences as they reflected back on their diagnosis and

subsequent treatment of breast cancer, and several of the women were tearful during at least one of their interviews. Nina reflected:

'I mean, I have never been ill... seriously ill, in all my life before; so it's been a major thing for me' (Nina, Interview 1, p.10).

All the women I interviewed had surgery at some point, either removal of a breast lump, or the whole of their breast (mastectomy), and many had also had radiotherapy. I have given brief information on how these approaches may lead to lymphoedema in Chapter One of the thesis. Although specific details of their treatments were not the focus of the interviews, the women did discuss some aspects of these as part of their stories, providing an important context for their experience of lymphoedema. Heather talked about her experiences:

'To be honest, I did have a problem with the mastectomy... I was a bit frightened to touch it' (Heather, Interview 1, p.17).

Thus adjusting to the experience of lymphoedema in this context may provide additional challenges for women who also sought to reconcile their post-surgery body. The new experience of lymphoedema could therefore be a particularly unwelcome interruption to their 'journey' through breast cancer treatment. Petra talked through the stages of treatment she had undergone over the previous year since being told she had breast cancer, getting through many of them with few problems until the lymphoedema developed:

'Then after the mastectomy I took all this [arm swelling and shoulder pain]...I did all the exercises like they told me to do at the hospital because I knew lymphoedema can set in...I did everything. I got a wee bit depressed about that, because you sail through everything...you think, right, I've been two stages...I'm at stage three... just before my radiotherapy and then you get told your radiotherapy is delayed because of all these funny feelings' (Petra, Interview 1, p.5).

Only a few months after her breast cancer diagnosis, Kate talked in Interview One1 of being at a '*processing stage*', still undergoing radiotherapy treatments and trying to come to terms with the changes that had happened to her over

recent months. When she recognised she might have lymphoedema Kate described this as:

'...the icing on the cake, it's the thing that tips you over. You cope with the other stuff but that is just kind of like getting to la la land over that because I really didn't know what to do and if I will get help with it' (Kate, Interview 1, p.6).

Similarly, Nina, nearly a year since learning she had breast cancer, described when she developed lymphoedema at a stage where she was already feeling very unwell as a result of the side effects of chemotherapy:

'I got it [lymphoedema] probably at my lowest point I would say' (Nina, Interview 1, p.10).

The women's accounts emphasised that developing lymphoedema could be a badly timed and significant setback. For some women it appeared more challenging or upsetting than their initial diagnosis of breast cancer:

'I would say this [the lymphoedema] has held me back mair [more] than my mastectomy' (Heather, Interview 1, p.2).

Later in Interview Three, Heather's daughter agreed:

'I think lymphoedema has caused you mair [more] pain than anything, you still suffer wi' [with] it even though the other treatment is finished' (Susie, Interview 3, p.2).

Thus, lymphoedema was for some women a significant legacy of cancer treatment, leaving women to 'suffer' with a constant and visible reminder of their breast cancer. There was also evidence that the development of lymphoedema had particular significance in the context of a life threatening illness such as breast cancer.

'I believed at first when I had the diagnosis of breast cancer it was a case of, well, one in three people have got cancer; this is me got it. I've got the best kind possible, and that's it, scored off the list. Move on. But now, because I think all the symptoms are still hanging about, you're still thinking, well maybe that's not it; something else could happen; it could come back' (Joanne, Interview 3, p.9).

Here Joanne appeared to express existential fears associated with the experience of continued physical symptoms. Rona also considered:

'If you have had cancer, it is always at the back of your mind...could it be cancer again?' (Rona, Interview 2, p.9).

For Mary, the onset of her lymphoedema had been an initial sign that she had recurrent breast cancer; as such, she viewed the lymphoedema as a type of barometer, an indicator of the success of her chemotherapy:

'If it [the lymphoedema] clears up then in my mind it's [the chemotherapy] shrinking the tumour' (Mary, Interview 1, p.12).

This suggested that prevailing sensations and symptoms in the context of lymphoedema and breast cancer may be indicative of something serious, and thus women may be justified for being concerned. However, while most women did not have lymphoedema as a result of cancer recurrence, some women continued to worry about this:

'In some ways the further you get from it [breast cancer] the more it is OK; in other ways, the further you get, the more I think it could catch up' (Linda, Interview 1, p.13).

In this situation, Linda had unexpectedly developed lymphoedema four years on from having breast cancer treatment, provoking particular concerns for her. In contrast, Irene and Olive considered it easier to deal with their lymphoedema several years on from their original breast cancer treatment, rather than immediately after or at the time of initial cancer treatment.

A key point from these interpretations is that for some women, developing lymphoedema was a significant setback to their attempts to recover from and move beyond breast cancer. The continued physical 'symptoms' of lymphoedema could raise existential fears for women and represented a real but amorphous threat around cancer recurrence.

5.2.3 Negotiating the medical world

This section reflects women's accounts of their experiences with health care professionals in the context of their breast cancer treatment. Several accounts showed difficulties for women in accessing appropriate and timely information

about lymphoedema. Some experienced problems when trying to discuss lymphoedema with their doctor or were surprised that their doctor did not know about lymphoedema. Other women talked of having to be assertive when dealing with health professionals regarding the care of their arm. Betty considered:

'..very few professionals know about not taking blood from that arm...or even taking your blood pressure, I won't have it done on that side, I think they think I am a bit of a fusspot' (Betty, SG1, p.16).

However, Rona considered that health professionals such as doctors worked within a defined area of expertise, and was unsurprised that they did not take an interest in lymphoedema.

Irene, who had a good relationship with her GP, as he regularly visited her husband at home, talked of noticing her arm was swollen and eventually going to the GP:

'He said "Oh I know what is wrong, you have golfers elbow here and tennis elbow here".... [Irene laughs] so I just said "Alright what do I get for that?"... ' (Irene, Interview 1, p.4).

Uncertain about the eventual diagnosis of osteoarthritis from her doctor, and continuing to worry about the swelling, Irene looked out the number of a Breast Care Nurse (BCN) and telephoned her for advice.

Several women recounted their experiences of BCNs. Kate reflected on the different levels of support and information available to her, depending on which BCN she consulted. Nina and Petra talked of having good relationships with their individual BCNs but recognising that these nurses often had limited expertise in lymphoedema. Linda had found her BCN helpful but spoke of relying particularly on the expertise of her consultant surgeon, finding him easy to talk to, helpful and reassuring, in that he allayed her fears about the pain she was experiencing after surgery. However, she found him lacking knowledge about lymphoedema. Olive talked of her difficulties in getting information from the doctors given her age:

'They immediately take for granted if you're old that you're an imbecile'
(Olive, Interview 1, p.18).

Heather found her hospital consultant very willing to talk about lymphoedema, but several women described difficulties on returning to the breast cancer clinics:

'I felt when I was there they were not interested in my arm, they were only interested in the surgery I had had done' (Grace, SG3, p.23).

Audrey relayed her particular experience of talking to her surgeon when her lymphoedema first started:

Audrey: 'I said to my surgeon in a check up appointment, I said, "I have lymphoedema", and he said, "Well I am so surprised because he said we were so anatomically correct and we all did our best"'

Co-facilitator: 'So do you think he almost thought you were blaming him?'

Audrey: 'Well, yes, I think so, that I was suggesting the surgery was to blame; but, you know, that he'd felt that he done his bit really well [Audrey laughs]. But I was just giving him the information'

Researcher: 'Do you think that was a sort of defensive reaction?'

Audrey: 'I think his pride was dented somewhat there'
(SG1, p.17).

This excerpt suggested that Audrey perceived her surgeon as believing he had done his work, and was now trying to absolve himself of some degree of blame for causing her lymphoedema. The women in Small Group One also emphasised their exasperation at the general lack of knowledge and interest around lymphoedema amongst the doctors they had met over the years. In contrast, Heather's GP had set out to find out about the condition when Heather had first developed lymphoedema.

Several women reflected on the possible reasons for them developing lymphoedema. Heather and Nina both recognised that having a cannula [plastic tube] inserted into their arm, to give chemotherapy for example, seemed to have been associated with the start of the lymphoedema. Having had breast cancer treatment many years previously, Fiona considered that in the past, surgery had been *'over-zealous'* in removing all the lymph nodes, thereby putting women

more at risk of lymphoedema. Grace who was operated on more recently, considered her own situation with lymphoedema to be due to having chemotherapy and radiotherapy. These discussions indicated that women may have sought to identify a clear cause for their lymphoedema within their own frame of reference, as part of integrating it in their lives, and finding meaning in their experiences.

Their experience of the lack of adequate information about lymphoedema being available to them prior to surgery, and at the time of other treatments, such as radiotherapy, was raised by many of the women. Heather believed she was not adequately warned about the possibility of developing lymphoedema:

'I was terrified, it was out like a balloon and the breast clinic said "You've got lymphoedema" and I looked at them "What's that?" and they said "You must have been told about lymphoedema?", and I said "No". I phoned my daughter in tears; she said "No, they never mentioned it" ' (Heather, Interview 3, p.3).

Susie, her daughter, agreed:

'I think we were all quite ignorant about it, I don't think it was highlighted enough in the hospital; they never really said what could happen or what the after-effects could be, nothing, we didnae [did not] have a clue about lymphoedema' (Susie, Interview 3, p.3).

Nina reflected on how her treatment progressed in blocks, with information provision being '*phased*' by the hospital according to the stage of her treatment. This, Nina felt, had left her unaware of what was coming next, and lacking the complete picture, including her risk of lymphoedema. She appeared to be very self-directed, taking books out of the Maggie's Centre library and searching on the Internet, but also considered that too much information could be equally unhelpful, as women might then imagine symptoms. Importantly, Nina recognised that no-one had ever really asked her how much information she would like. Petra also relied on reading leaflets and books, rather than talking to others, until she was referred to the lymphoedema practitioner, whom she

found very informative and easy to talk to. In her final interview she talked of being warned about lymphoedema at the time of breast cancer surgery:

'I also thought it was a bit scaremongering, you know the way it was put; and your hormones are all over the place and they say "This lymphoedema gathering of fluid can appear at any time"; and to get in touch with your doctor at once' (Petra, Interview 3, p.4).

These accounts suggested that the health care structures did not sufficiently anticipate or reconcile the information needs of the women. Kate in her first interview talked of experiencing the *'fear of God'* when a health professional came to the ward the day after her surgery to tell her about the risk of lymphoedema. Later, once she was at home, she suspected she had lymphoedema, but did not know who to ask and, like Joanne, was passed between various different professionals for several weeks until eventually being given the contact details of the lymphoedema practitioner, whom she phoned to leave a message:

'By the time [the lymphoedema practitioner] phoned me I was kind of like [takes deep breath in] I'd had quite a lot of anxiety about it. The first week I couldn't sleep; I couldn't get anyone to give me a straight answer' (Kate, Interview 1, p.6).

This excerpt showed vividly the anxiety that Kate experienced where she could not get easy access to information and advice about her symptoms of swelling. However, Kate also spoke of her problem of *'information overload'* where she found it difficult to identify salient information. In Interview 3, she reflected back on her anxiety and vulnerability at this earlier time. Rona also considered that women might be given too much information when they already had so much on their minds. Similarly, Joanne commented on the extensive, but often conflicting and confusing, information made available to her after surgery. Mary, however, felt she was given a suitable amount of information, enabling her to easily recognise lymphoedema when it occurred, and to know where and when to seek help.

The accounts indicated that some women may have experienced a paradox where they relied on the medical world to treat their breast cancer, but then found that health professionals did not always take seriously their problem of lymphoedema. Women appeared to have contrasting experiences with health professionals. Several women experienced difficulties accessing services and appeared anxious as a result. Only a minority of the women appeared to be adequately informed and satisfied with the level and timing of information they had received about lymphoedema prior to being referred to the lymphoedema clinic.

5.2.4 Summary

In conclusion, this theme has provided important insights, particularly relating to the social construction of lymphoedema, which is explored in more depth in Chapter Seven. For many women, developing lymphoedema was a dynamic, traumatic and distressing experience. There was evidence that women could experience a sense of alienation or detachment from their arm and the changes in their body. The physicality of these changes in the context of a life-threatening illness such as breast cancer provoked particular existential fears. This first-level analysis of the accounts suggested that women ascribed various meanings to lymphoedema in this context; for example, as something to be fearful and suspicious of, or as I will show later in this chapter, as a trade-off for cancer 'survival'.

The women's accounts provided evidence of a health care environment which focused on the medical treatment of breast cancer, and did not take seriously women's concerns around lymphoedema. This was reflected in a lack of access for women to the requisite volume of well-timed information and support, and in some cases, a relative disinterest in lymphoedema from health professionals. Significantly, the experience of lymphoedema in this context appeared to take on an oppressive and threatening quality for women. There was a sense of some women feeling powerless in understanding the salience of

specific symptoms or physical changes, particularly in the initial stages. Those for whom lymphoedema was new, unpredictable or uncontrolled appeared to experience significant distress and frustration, and a sense of having little choice in dealing with the effects of a condition that had resulted from medical treatment. This is further reflected in the next theme.

5.3 'What can one do?'

The title of this theme was an original 'in-vivo' code identified early on in the analysis of the research data. It reflected a rhetorical question posed by Fiona in Small Group (SG) Three, in response to my giving them a brief list of questions to consider at the start of the discussion. She said:

'I must admit, just reading it makes me feel... it brings back all the frustration I've had over the years that there's so little that seems to be able to be done...when you say, how do you care for it? I mean what, what can one do to care for it? I mean I just put, slap the cream on, put the sleeve on, end of story' (Fiona, SG3, p.2).

Previously in Small Group One and Two, I had perhaps somewhat naively, asked the women to list the various activities they undertook that might be seen as self care. Most of the women talked of activities such as moisturising their skin, wearing their lymphoedema sleeves, exercising their arm or doing Tai Chi. Contrastingly, Dora suggested there was nothing she could do to help her arm as it was too swollen and uncomfortable. Elaine, who had lived with lymphoedema for over 15 years, appeared to be rather ambivalent about her lymphoedema:

'I don't do anything...I have enough other things to think about which have more priority' (Elaine, SG2, p.5).

Integral with many of the women's accounts was a strong sense of frustration that little could be done to improve their lymphoedema; this was particularly evident in the small group discussions where the women reflected back on their

many experiences over the years. Grace considered that she had *'tried everything'* (Grace, SG3, p.8), but felt her efforts had often been in vain.

5.3.1 Expectations and disappointments

Women had various expectations about the type of help and support which was available from lymphoedema practitioners and clinics. Joanne considered the lymphoedema practitioner as an *'expert'* and was prepared to follow her advice, having had conflicting information from her doctor, the appliance officer and a physiotherapist. Previously, a (non-lymphoedema) physiotherapist had commented to her that Joanne knew more about lymphoedema than she did herself, leaving Joanne feeling *'really disappointed and let down'* (Joanne, Interview 1, p.4). However, six months on, by Interview Three, Joanne had not yet had a follow up appointment with her lymphoedema practitioner:

'..even if she [the lymphoedema practitioner] had said 'Well we might not need to see you', but even a telephone call or something would be good so I could check out how I am doing...but there was such a battle to get there, to get myself referred to her and there are probably lots of people out there who need the resources more than me' (Joanne, Interview 3, p.6).

This suggested that Joanne countered her disappointment with the assumption that her needs were relatively minor compared to others. However, it is clear that a follow up, even by telephone, to enable Joanne to reflect on her progress may have been valuable. It is interesting that she did not pursue this with more confidence, given her background as an NHS employee which one might assume would imbue her with more confidence to negotiate the health care system.

In Interview One, Heather talked of having looked forward to going to the clinic, but recognising once she had been there that:

'...they're obviously limited in what they can dae [do] for it, I wish there was mair [more] but obviously there isnae [is not] and it's a bit upsetting' (Heather, Interview 1, p.16).

As the research interviews progressed, it was clear that due to the practitioner being off sick, there was also a delay in Heather's follow up appointment. Consequently, Heather became focussed on what she and her family could do by way of exercising and massage, although despite this, Heather's arm became noticeably more swollen over the six months.

When I interviewed Nina a week after her first visit to the lymphoedema clinic she reflected on how she had been unsure what to expect. She was also concerned that, despite her best efforts at self-care, as advised by the practitioner, her arm was still swollen. By Interview Three, like Joanne, Nina had not seen the lymphoedema practitioner for several months due to staffing problems at the clinic:

'I'm trying to find out how to get back to be seen at the clinic, and I was in contact with the physiotherapy department where I was seen to ask them, and they are going to find out and get back to me. But in another way I am not sure what they can do to help and when I did see her [the lymphoedema practitioner] that first time I didn't feel she really told me an awful lot to do really; I found out more through reading about it myself, to be honest' (Nina, Interview 3, p.4).

Kate talked of her first appointment with the practitioner as rather '*academic*' and lacking the practical advice that Kate felt was required. Six months on, she had not been sent a follow up appointment, nor contacted the clinic herself; however, she had followed advice from a friend to see an independent manual lymph drainage therapist whom she found '*helpful and positive*'. In Interview One, Olive talked of not expecting anything in particular from the visit to the lymphoedema clinic. However, she had anxieties about whether she could follow the advice given from the clinic as arthritis made it difficult for her to apply her lymphoedema sleeve. It appeared that the practitioner may not have anticipated these difficulties. Three months on, at Interview Two, Olive recognised that the clinic had little more treatment to offer beyond the sleeve. At our last discussion, six months after our first meeting, Olive commented that

any further visits to the clinic would waste her time, and that of the practitioner, as her arm was now much improved.

At their third interviews, Linda, Mary and Rona gave the impression of now feeling confident about caring for their arm, and not requiring further appointments with the practitioner unless their condition changed. Petra, who had ongoing problems with swelling, commented on her experience of the lymphoedema practitioner:

'She's a lovely girl and she understands what you've been through...she gave me these exercises and has been giving me regular treatment to massage me' (Petra, Interview 2, p.3).

This opportunity for fairly regular appointments contrasted with the experiences of Joanne, Heather and Nina, who had not had such easy access to their lymphoedema practitioner. Irene was also very positive about her contact with the lymphoedema practitioner. However, at her visit to the lymphoedema clinic, Irene was surprised to hear she would need to have her arm bandaged, but seemed to be fairly positive and realistic about this forthcoming treatment:

'I don't quite know what's going to happen there but I'll do the bandaging because I want to help as much as I can with this arm, see if it's going to help. It might not really go away but if this is going to help, I'll certainly do it' (Irene, Interview 1, p.16).

By Interview Two Irene had undergone a one week course of daily manual lymph drainage and bandaging, although this had clearly required some effort by her, which she appeared to feel may have been in vain:

'It was cumbersome and trying to sleep with it and doing chores, especially with the bandaging there, I had to keep putting a glove on or wash things with one hand, ...Getting clothes on of course, trying to fasten the bra at the back or do it at the front and turn it was difficult. The bandaging was okay but I was just wishing I'd seen a better result, probably [the lymphoedema practitioner] was looking for a better result too' (Irene, Interview 2, p.2).

At our final meeting, Irene was having difficulties with wearing the sleeve on a regular basis and considered:

'...just after the bandaging I started off being good;but now by lunchtime I realise I haven't put the sleeve on, and I think it's too late so I don't put it on. I know [lymphoedema practitioner] might be disappointed, as she has been trying to help me...I should get myself sorted out, but it doesn't work that way. If I don't feel it sore, I forget about it; but I know on the days I do wear it, it does make my arm feel lighter' (Irene, Interview 3, p.1).

Here Irene seems to feel that the lymphoedema practitioner might be equally disappointed with Irene herself for not wearing her sleeve after the bandaging treatment. Irene appeared to have quite regular and apparently supportive links with the lymphoedema practitioner, and, perhaps because of this attention from the practitioner, she frequently admonished herself in this interview for not following her advice. While Irene felt she should get herself '*sorted out*', significantly, she was not only a carer for her husband who was very ill with a chronic lung condition, but was also a carer for her grandchildren, and therefore appeared to have little time to spend on herself. It is interesting that while she appeared to feel a sense of duty to wear the sleeve, and noticed it was helping her lymphoedema, this was not enough to motivate Irene to wear it regularly. It is possible that, like Nina and Heather, Irene recognised a level of self-responsibility to follow self-care advice, but was disappointed and somewhat demotivated with the obvious lack of overall and sustained improvement in her lymphoedema.

Several women who took part in the small group discussions had experienced treatment with bandaging over previous years. Fiona and Grace talked of appreciating the opportunity to try a variety of approaches over the years such as bandaging by the lymphoedema practitioner, wearing a lymphoedema garment every day, and using a specialised pump every day at home to help reduce the swelling. However, both women agreed that treatments often did not have any long lasting effect on their arm. Fiona commented:

'I've had bandaging twice, and the first time I was chuffed to bits because the thing practically fell off. I thought I'm reduced, this is super. But [the lymphoedema practitioner] said "At the end of the day it has just gone back up to what it was"' (Fiona, SG3, p.13).

In Group Two, Dora had a similar experience:

'She (lymphoedema practitioner) has strapped it up and it has taken it down a little bit but not much' (Dora, SG2, p.11).

Elaine, similar to Irene, identified the restrictions of having this type of treatment:

'I had to be off work because of that...because it's strapped up so you know you're very limited, aren't you, what you can do, as it's very heavy' (Elaine, SG2, p.14).

While the accounts showed that treatments could be challenging and the result disappointing, the women who did have regular contact with their lymphoedema practitioner were positive about this experience:

'..she's very grounded and easy to talk to...she's not the least bit remote like some of the professionals are...and I feel we have got to know each other over the years' (Fiona, SG3, p.24).

Elaine also appeared to value the long term contact with her lymphoedema practitioner and had particular expectations:

'..I go every year, and she measures my arm, and gives me fresh sleeves...My arm's gone down over that time, from 60% to 16%' (Elaine, SG2, p.3).

These excerpts suggested that regular, even yearly, contact with the same lymphoedema practitioner with whom they could talk openly was valued by the women. Audrey and Betty in Group One talked of preparing themselves for seeing the practitioner, expecting to have their arm measured and taking the opportunity to discuss any changes or possible new treatments that they hoped might become available. However, the accounts suggested that to get to this stage, women had lived through various expectations and disappointments regarding the outcome of treatments and care.

5.3.2 The good, the bad and the ugly

The title for this particular category reflected words used by women when discussing their decisions about self care activities, such as wearing or not wearing a sleeve. Some women referred themselves quite specifically as 'good' or 'bad', in relation to not adhering to advice about self-care. Previously I showed that Irene considered herself as starting off by being 'good' but then

admonished herself several times in her interviews for not continuing to act on advice given by the practitioner. I have also used the word 'ugly' to reflect the strong views that women had about their lymphoedema sleeves.

Most women talked of various self-care activities such as caring for their skin, using moisturiser every day and wearing their sleeve where possible. Betty, Linda, Joanne, Nina and Olive were keen gardeners, and wore gardening gloves. Joanne explained how she took steps to protect her arm:

'I'm a lot more conscious now, I have one of those long oven gloves, and I've got gardening gloves to prevent scratches, and everybody laughs at me because I've got a wee first aid kit that I carry about in my bag with antiseptic and insect repellent' (Joanne, Interview 1, p.7).

In Small Group One, Audrey and Betty talked of moisturising their skin, avoiding burning their skin, avoiding lifting heavy weights, using their other hand or giving up cycling. In the same group Chris viewed herself as 'bad' in not following advice, but also gave reasons for this:

'I am afraid I am bad in a sense, I do carrying heavy weights sometimes in this arm when I shouldn't and something else you said, I thought "I don't do that either, I just do the bad points"...sometimes I'm forced and I go shopping and I am loaded down as I walk up the stairs' (Chris, SG1, p.4).

Most of the women were using or had used a compression sleeve at some point, and it became clear that these could provoke frustration but also ambivalence:

'I think the sleeve is an absolute nuisance' (Chris, SG1, p.5).

'You kind of resent but you know you should be wearing it' (Betty, SG1, p.6).

'I think it's completely antisocial and really uncomfortable and if I had the opportunity to do something else I would rather do it. But no, it definitely does work' (Joanne, Interview 2, p.12).

'I hate it. I totally hate this because I'm restricted if I want to do anything. I can't bear a rubber glove on top of it. I've tried huge big ones and I can't wear them... I just can't bear it on top of that. So I'm stuck there. But it [the sleeve] is part of my clothing every day. I don't feel dressed without it. I mean I know that sounds stupid. But I can get myself dressed and I will think 'I've not put my sleeve on'...' (Grace, SG3, p.5).

Audrey, Betty, Heather, Nina and Grace wore their sleeves quite regularly. Audrey, like Grace in the excerpt above, considered her sleeve very much part of her morning routine, and something she did not like to go without. Elaine in Small Group Two wore her sleeve mainly when her arm was at risk of swelling, when she was doing activities such as ironing or painting. Betty wore her sleeve at specific times:

'I don't wear it on the mornings when I go to my Tai Chi, but then I wear it again in the afternoon. I wear it when I am bowling or digging, anything like that' (Betty, SG1, p.5).

However, there was evidence that the sleeve impacted on women's social roles as Heather, who provided personal care for older people in their homes, explained:

'I had to dae [do] visits today and wee Jim that we go to, well the girls were in a bit of a hurry and didnae [did not] wash him properly so I thought 'Bugger it' so I took off my sleeve and put my gloves on and my apron and I said 'Come on, I'll give you a good shave' and he's like that 'You cannae [cannot] you better put your sleeve back on' and I'm like 'Oh for goodness sake, of course I can'...he needed the help. But if I had kept my sleeve on it would have got wet and dirty... I'll admit though, my arm was worse after' (Heather, Interview 2, p.8).

What is significant here is that Heather prioritised her work role as carer over her own needs and on several occasions during her interviews, she talked of removing her sleeve during her work day. Joanne was particularly concerned about the stigma attached to wearing a sleeve at her work, as described in the next theme in this chapter, and she also removed the sleeve at work. The

sleeve was seen by several women as unsightly, particularly if they wished to wear a sleeveless top or dress:

'If I am wearing a short sleeve top there is a gap between that and the top of the lymphoedema sleeve, and it doesn't look nice, so I sometimes don't wear the sleeve' (Audrey, SG1, p.6).

Comfort was mentioned by several women, who talked of the sleeve being too hot, especially if, such as Joanne and Nina, they experienced regular hormone-related 'hot flushes'. Sleeves and hand garments could be poorly fitting or too tight. Fiona and Grace compared notes about their different sleeves, talking of being pleased that their lymphoedema practitioner had given them a choice of sleeve, or more than the regulation two sleeves, and recognising how quickly sleeves wore out or became misshapen.

The accounts showed that women made decisions about their self-care in ways that suited their own lives and, as already identified, they did not always follow the advice given to them by the lymphoedema practitioner or others. However, the women appeared to grow very aware of what aggravated the physical symptoms of lymphoedema, and how they should respond, as I show in Irene's example of ironing in the next theme. Nina recognised that cutting her hedge had caused additional swelling, which she had sought to counteract by wearing a sleeve all of the following day. As I showed in Section 5.2.1, Betty appeared to be 'motivated' by noticing others with worsening lymphoedema due to not wearing their sleeves, and by noticing her own arm in the mirror. Betty also remembered going for a time without her sleeve, until she went back to the clinic to have her arm measured:

'She [the lymphoedema practitioner] said "How regularly are you wearing it?" and maybe I had become a bit careless, thinking "Oh it's maybe not making much difference", but that kind of drew me up and I do wear it'. (Betty, SG1, p.5).

This was a significant observation that the contact with a lymphoedema practitioner could motivate women to go back to certain aspects of self-care that they may have abandoned. However, it was not clear which aspects of this

contact were most significant, for example, the specific communication skills of the practitioner, or the opportunity for the woman to have her arm measured and reflect on the changes herself.

In another example, I had observed the lymphoedema practitioner advising Irene about how to position her arm. In a subsequent interview Irene explained:

'When I sit on the couch in the evenings I raise my arm up a little on a cushion, and get my arm straightened out and that swelling at the elbow seems to go down and I really feel it helps' (Irene, Interview 1, p.13).

Here, Irene seemed to have had taken ownership of this discovery, and had integrated it into her life. Doing this appeared to give her a sense of control in knowing there was something that would alleviate her discomfort at the end of a busy day. This suggested that specific but quite simple self-care activities initiated by the lymphoedema practitioner could have an enabling influence on women's behaviour.

Self-massage was mentioned by several women. In Interview One, Joanne talked of doing the '*drainage*' as often as possible, sometimes subconsciously while she was sitting in her office at work. She had learned the massage technique from a breast cancer website, and found it helped her. Heather's daughter Susie helped with the massage. Irene, who was caring for her husband, found she had little time to do massage. Petra, who did self massage in the shower, was unsure if what she did was correct. Betty considered:

'I was taught lymph drainage when I was in Australia...I use it on occasions when my arm has seemed to balloon a bit and it certainly lets me feel less pressure in it,...I don't measure to see if it's gone down but I think it does help' (Betty, SG1, p.11).

In Interview One Nina talked about the massage:

'When I saw [the lymphoedema practitioner] I asked her to show me the massage as I think I was a too heavy-handed, and when she did it, it felt like she was barely touching me...I've done it better this week... and I am trying to do it morning and night' (Nina, Interview 1, p.2).

However, by the third interview when her lymphoedema has become worse, Nina considered:

'I know I should do the massage to help myself, and I have lapsed as I was doing it quite regularly, but it is like everything, getting into the habit can be difficult and I am not sure it does really help anyway' (Nina, Interview 3, p.3).

At this point, Nina has also borrowed books out of the library at her local Maggie's Centre, and realised that there were two different techniques for the massage, described in separate books. She recognised that her interpretation of how and when it should be used was crucial if she was to be motivated to use the massage on a regular basis. These examples suggested that women could be motivated to undertake self-care activities such as massage if they felt they would be helpful, although it could be hard to maintain motivation in the face of worsening swelling, or if there was a lack of clarity about the technique.

Exercise was also discussed in detail by many of the women and several asked me specific questions about this element of self-care. Mary, despite undergoing chemotherapy treatment, continued to keep active by playing golf and walking when possible. The women in the small groups, such as Betty and Elaine, talked of finding it very helpful to attend a Tai Chi class at Maggie's Centre. Fiona commented: *'I teach dance fitness. I am quite active, and I think that helps'* (Fiona, SG3, p.17).

In Interview One, Kate appeared very motivated to exercise:

'I've got a small child, and I've been quite keen to move the arm right from the beginning. I certainly will be taking up more exercise but that's all to do with finishing radiotherapy when I'm able to...I want to do a yoga class too' (Kate, Interview 1, p.10).

By Interview Three, Kate had started swimming three times each week, and was clearly motivated and more confident about these aspects of self-care.

However, in our first interview, Rona was thinking of going to a yoga class but wondered if this would cause more harm. Similarly, Nina was uncertain about

exercising. She had previously attended a yoga class before having breast cancer, but now felt she required more specific advice on how to exercise and lose weight; Nina considered:

'I didn't feel I had been told by the hospital that you should exercise, but I had been reading and it said about swimming and water aerobics; I feel I need to do some sort of exercise so I'm sort of psyching myself up' (Nina, Interview 3, p.3).

Returning to the subject of exercising later in the interview, Nina added:

'You're scared to try things, you just assume that you shouldn't do weights like at the gym, well they say "Don't lift heavy weights" so that rules that out; you just think you can't do these kind of things' (Nina, Interview 3, p.16).

Linda had similar concerns:

Linda: 'The thing is I have thought about going to exercise classes, I used to, and I have thought about it but I'm kind of put off by thinking 'could I actually cope with a normal exercise class? Well could I actually manage it?'

Researcher: 'It sound like you are not sure if it would be right for you'

Linda: 'You would go if it was other people who had had surgery; that would be different. If somebody who was running the class was experienced and informed about it, then that would be a good idea' (Linda, Interview 3, p.5).

These accounts indicated that women wanted to take responsibility for self-care by exercising, for example, but could require specific advice and support from professionals or others who understood the needs of individuals with lymphoedema and breast cancer. During the course of the research I was aware that exercise classes were available at the cancer centre of several hospitals, but only for women who had recently undergone treatment for breast cancer, and not those with lymphoedema, who were several years on from breast cancer treatment. Petra who had ongoing problems with her shoulder, had been greatly encouraged by being referred to a local council gym, through an organised link between the NHS and local council leisure services. She commented:

'The gym instructor, well obviously he's done all his training on rehabilitation and he was very, very good and gave me different exercises which will definitely help my shoulder and help drain the fluid' (Petra, Interview 3, p.1).

This suggested that partnerships between health and other services may have an important role in meeting the needs of women with lymphoedema within the community.

As this research was focussed on the concept of 'supported self-care', I did ask most of the women about their understanding of the term. Significantly, most women appeared to find it relatively meaningless, and sometimes my question led to an obvious silence in the group discussion or interview, and I was left with a feeling of having used jargon. Certainly, it is perfectly feasible that women did not see themselves as 'self-caring' and requiring 'support', but rather as women living with the problems associated with lymphoedema. As such, the policy notion of women as a resource to be supported could appear banal and insensitive. Elaine considered her definition:

'I would say it [supported self-care] was if I was to be able to ring up like I have done in the past, you know, if I'm aware that something's not right maybe... so I could check out if I'm correct in what I'm surmising about that. Some of that could be answered on the telephone...so I would call that supported self-care personally' (Elaine, SG2, p.19).

Significantly, being able to talk to a lymphoedema practitioner on the telephone was seen by several of the women as an important point of contact and support, particularly at times of crisis. Dora and Audrey, for example, had called their practitioner on the telephone when they had problems with infection. However, I became aware that many of those women who had newly developed lymphoedema seemed more reticent or hesitant about contacting the practitioner, and as previously noted, did not have follow up appointments.

To summarise, women followed various 'good' activities, but also at times did not follow advice, for example, where they were forced to carry things, or when

the 'ugly' sleeve did not suit their choice of clothing or particular lifestyle activities. Several women expressed a lack of confidence in knowing how to safely and effectively undertake activities such as self-massage and exercise. Narratives around the compression sleeves were a prominent feature in many interviews and discussions, particularly as they appeared to lead to specific difficulties and frustrations, and epitomised lymphoedema treatments and options for self-care as sometimes impractical and lacking positive choice. Women found the term 'supported self-care' difficult to define and potentially irrelevant to their own situation. Undertaking aspects of self-care appeared to draw on an embodied awareness, for example, how their arm might respond in particular situations, or when to use their sleeve. Women's motivation could be influenced in various ways, including a visit to see the lymphoedema practitioner. However, there appeared to be various organisational barriers such as practitioner sickness that meant some women were not readily followed up in clinics. Furthermore, it is possible that some women did not wish to have this type of follow up, through a hospital-based clinic, and as a narrative in Small Group One suggested, women may have different needs:

Audrey: 'I know we're lucky to have [the lymphoedema practitioner] but that one person for this vast area isn't enough...I would like my clinic to be more local, this is a long way for me to come.'

Betty: 'I only come once a year, but even so passing the area where I had the chemotherapy makes me feel sick and brings it all back'

Chris: 'Well I think it is wonderful and I wouldn't want them to send me anywhere else'

(SG1, p.14).

5.3.3 Developing knowledge about lymphoedema

There were many examples in the accounts of how women were self-directed towards increasing their knowledge about lymphoedema, and how to deal with it in their lives. Not only did they acquire written information and advice from Maggie's Centres and from their lymphoedema practitioner, but several searched the Internet, for example for information on massage and exercise. Mary kept a Cancer Backup Lymphoedema information book near her bed,

reading sections of it as required. Nina, an avid reader, thoroughly read several books, checked the Internet and suggested that a DVD of the massage would be useful to her. Olive meticulously read her Cancer Backup book, curiously from back to front.

Clearly, aspects of self-care such as massage and exercise may be practical skills that are not readily learned from a book. However, my experience in the field observations was of minimal time spent by the lymphoedema practitioners on teaching these techniques to women, as I will show in the next chapter. It is possible that this would be covered in subsequent appointments. However, there was considerable evidence in the women's accounts that while women were relatively self-directed in wishing to educate themselves following on from their first appointment at the clinic, appropriate information was not always readily accessible to them. Although I did not explore this aspect in the interviews, it is also likely that other family members may have also wished for more information, and for example, could have become involved, as Heather's did, in doing the massage.

In the small groups Audrey talked of feeling '*competent*' with her self-care, but emphasised that she did not feel she was an 'expert' in caring for her lymphoedema. It was notable that women also appeared to learn from each other through shared experiences and, in particular, attending groups such as the support group at Maggie's Centre. Grace and Fiona exchanged information about infection during the small group discussion itself:

Grace: 'So he [the doctor] said I had cellulitis'

Fiona: 'Which is what, an inflammation?'

Grace: 'It's an infection'

Fiona: 'And do you get that from time to time?'

Grace: 'Oh no, I've had it quite a lot. I've had it four times this year.'

Fiona: 'Oh have you?'

Grace: 'It's like flu, and I know when I'm going to have it because I normally get a headache. I get the 'flu symptoms that's what I get, and I know straightaway; I look at that arm and then I think, 'I've got it again''

(SG3, p.6/7).

Similarly, Audrey talked in Small Group One of her first experience of cellulitis, and of recognising the symptoms from hearing others previously mention it at a support group. She was therefore able to quickly take action to ring her GP when an infection did arise one Sunday morning, and she also left a message for the lymphoedema practitioner:

'I telephoned her to get advice and she rang me back and it was good to check with her...I only see her once or twice a year but there is a relationship there, and a trust; that helps' (Audrey, SG1, p.15).

In this situation, Audrey clearly took action based on what she heard from the group, but also as she knew how to contact the practitioner. Thus, it appeared that shared experiences could be an important opportunity for gaining new knowledge about self-care. Significantly, this opportunity to leave a message for the lymphoedema practitioner on an answer-phone was also viewed by several of the women as particularly useful. The women had various thoughts on the idea of group-based support and those who took part in the small group discussions had all previously attended the Maggie's Centre lymphoedema support group. Elaine considered her experience of a group:

'I think also there is benefit from being in a group as you learn from them' (Elaine, SG1, p.15).

Grace, Dora, Nina and Heather were very enthusiastic about the support they had received from their local Maggie's Centres. However, some women who had previously attended groups at the centres more recently felt it no longer met their needs; several commented on their personal need to move away from the specific focus on living with cancer that was reflected in such organisations. Several women also reported feeling reticent about attending any type of group. In Small Group One the women expressed their upset on seeing someone with

grossly swollen legs at a previous Maggie's Centre group. Joanne, in Interview Two, told of her experience where a woman at a group said she was *'terminal'* and Joanne wanted to *'run out the door'*. Heather thought that sitting around at a group was not for her as she would get annoyed with others *'feeling sorry for themselves'*; however, she also recognised how much better she felt after a brief visit to Maggie's Centre, where she had talked with a member of their staff. Fiona in SG3 felt she did not like the idea of sitting around talking about lymphoedema, *'bringing it all back'*. Elaine talked of a potential *'downward spiral'* if women sat and talked about their lymphoedema problems. In contrast, Nina attended a group regularly and clearly found it a helpful way to learn more, pick up *'tips'* from other women, and gain support; her group was led by an experienced breast care nurse whom she clearly knew well and trusted.

It appeared that women had varied perceptions of the purpose and relevance of a group. Irene was interested in attending a group for support and to find out what others did to care for their arm. Mary, Linda, Fiona, Elaine and Kate suggested a group should involve a practical activity such as exercise, and should enable women to learn about dealing with lymphoedema, rather than just sitting and talking to others. Joanne, who worked within the NHS, was less positive about groups and had an interesting perspective on lay (i.e. person with lymphoedema) versus professional group leadership:

'People can be coloured by the nature of their own journey and can project that onto their work...if you are a lay person, your journey can become what you think everyone else should have, but a nurse treating 20 people a day can take a step back' (Joanne, Interview 3, p.6).

In summary, it was notable that women sought to educate themselves in various ways. However, several women were unsure about what information was relevant to them or could be trusted. Several women felt they would attend an active group for support and specific practical information. However, there was some ambivalence about activities that involved sitting around talking about their condition.

5.3.4 Looking for other options

Women such as Dora, Grace, Heather and Nina had ongoing problems with their lymphoedema. Heather and Joanne voiced their particular worries about future difficulties with lymphoedema. It is not surprising, therefore, that these accounts indicated that women were keen to explore other options beyond the routine self-care they were currently undertaking. Commonly, women wondered if the lymphoedema could ever be cured:

Dora: 'Yeh, I mean, do you think it will ever go away?; I mean I don't know'

Elaine: 'Well I wondered if it will ever totally go, that's gone through my mind actually...will it ever go away totally?'

(SG2, p.20).

Nina considered:

'You know you're never going to get rid of it [lymphoedema], that's the hard thing, I think. Well I don't know if that's true, you know you might get rid of it and it could come back again, but I just get the feeling that it's always going to be there; it's just the way I've had it spoken about to me'
(Nina, Interview 3, p.14).

In Interview Two, Irene talked of wishing she could push 'it' up and out of her arm. Heather and Dora both wondered if, in the future, doctors might find another way of removing the fluid from the arms of women with lymphoedema.

Over the time of data gathering, liposuction, a relatively new technique where fat tissue is removed from the arm under general anaesthetic, began being offered at a centre in Scotland. Several women asked about it in the interviews and group discussions. Heather was particularly keen to find out more as her lymphoedema was proving to be problematic for her. Grace was waiting to go for liposuction two months after the small group discussion, and talked confidently about the surgeon who was to operate on her as being someone who might solve her problems. Fiona recognised this was not an option that she would want to take, but commented to Grace:

'But I think you've had more discomfort than I've had and therefore you want to grab an opportunity' (Fiona, SG3, p.18).

Notably, nine of the women who took part in the research mentioned various complementary therapies which they had used or intended to use. Rona recognised these as a new addition to the broader approach to cancer care in the NHS. Some, such as Nina and Petra, had reflexology provided by their cancer centre, although Nina was disappointed that it did not have a better effect on her arm. Joanne used relaxation tapes to help her deal in an emotional sense with her situation. Kate talked of going for MLD with a private therapist:

'I did seek out some manual lymphatic drainage; I found it a really good experience, a very positive experience, the girl was fantastic... I had three treatments for the breast [swelling], I couldn't really afford the six treatments, and it seemed to make a difference...' (Kate, Interview 3, p.1).

Later in the interview she appeared bemused by her hospital consultant's reaction to MLD:

'I asked my consultant what do you think about MLD and he was quite dismissive about it and I was wanting more of a conversation about it, I was surprised, he normally embraces new ideas' (Kate Interview 3, p.5).

Similarly, Petra talked of her hospital doctor being very negative about her use of various complementary therapies. This is perhaps significant, as decisions to use complementary therapy options are an example of self-care. However, Fiona and Nina considered that they would wish to be sure that the therapy was safe for them in their situation, but did not know where to access this type of objective advice. This suggested that support with particular aspects of self-care was not readily available to the women.

Several women took a political stance. Joanne identified the inequality between the resources given to funding treatment for cancer and those identified for the long term care of 'cancer survivors'. She was also concerned that others

wrongly believed that the needs of women with breast cancer were met fully by current NHS provision. Nina recognised the inadequacy of lymphoedema services to meet her needs, while Rona and Heather felt that lymphoedema services should be available more locally. Heather, and the women in Small Group One, called for more health professionals to learn about lymphoedema care. Heather was critical of the money spent on other areas such as drug rehabilitation, where the recipients have '*brought the problem on themselves*', in direct contrast to her own situation.

5.3.5 Summary

These interpretations relating to the theme of 'What can one do?' appeared to reflect women's frustrations and limited expectations of the options available to effectively control their lymphoedema. This may provide further evidence of the oppressive nature of lymphoedema and its treatment. Importantly, many women appeared to come from a position of being relatively self-directed, independently seeking out information, and finding their own ways of dealing with the symptoms associated with lymphoedema. However, this was not always acknowledged by professionals such as their doctor or, as I will show in the next chapter, the lymphoedema practitioners. Self-care approaches such as the use of sleeve appeared unrealistic in terms of some women's lifestyles, and were adapted by women according to their individual needs.

Contradictory advice around activities such as self-massage may have prevented women from feeling confident about self-care decisions relating to exercise and massage. Some women had well established long term links to lymphoedema clinics, while others with newly developed lymphoedema appeared to experience difficulty in accessing practitioners. There was evidence that women would welcome local and specific types of support such as exercise groups, rather than only discussion-based support groups. Some women who were politically aware commented on what they viewed as limited public funding available for services to support individuals in their situation.

Given the policy emphasis on multi-agency support for people with lymphoedema, these interpretations did indicate a rather limited set of options relating to supported self-care for these particular women.

5.4 Life with lymphoedema

In this final section I present excerpts from the women's stories that reflected, albeit in a limited way, how they sought to accommodate lymphoedema in their lives, in a psychosocial sense. This builds on specific aspects already identified in the previous themes and categories.

5.4.1 Getting a life back

Getting back to work and returning, after breast cancer treatment, to other life roles, such as being a carer for grandchildren, featured in several interviews with women who had newly developed lymphoedema. However, around the time when Nina, Petra, and Heather were planning to return to work, their lymphoedema became a problem. Petra and Nina talked of losing confidence after being off work for a year. Both were on a staged return to work and worried about how the lymphoedema would impact on their work. Nina considered:

'I think getting back to work has been a good turning point because even earlier on this year you didn't see yourself getting back to work, just the way things were going. But the works doctor said I was fit enough to go back so I had to, but I don't really feel sure I am ready' (Nina, Interview 3, p.13).

Petra gave a sense of this as a lonely time:

'After all your treatment's finished, you're kind of left. Well, you've had the all clear, you've finished your treatment, everything's going fine, and you're trying to get control of your life, and dealing with things; but it is very difficult...you're not in your bubble anymore...you are out on your own' (Petra, Interview 2, p.21).

Thus, as women returned to their previous roles, they recognised that they no longer had the relative 'safety net' of regular visits to the hospital. As Heather

returned to her work as team leader in a social care organisation, she displayed a sense of determination, realism and also ambivalence:

'You want to be as normal as possible but sometimes you cannae [cannot] be, you've got to admit that to yourself...I'm really quite a hands on and I like to dae [do] things, but now I'm very limited because of the swelling, and that's upset me, but it's made me mair [more] determined to get back to work, because I thought I'm no lying doon [down] to this' (Heather, Interview 1, p.2).

Several women were carers for spouses and/or grandchildren. Irene cared for her husband who had chronic lung disease, and also for her grandchildren. She described the difficulties in dealing with lymphoedema in her home life:

'I try not to overdo things but there you go; see I like ironing and I was ironing a lot one weekend, and I even did my daughter's ironing like always do, and my arm got really bad... but now I've stopped that...it's things like that. But I try to keep on the go, and I take a bit longer at things like the vacuuming and I get my husband to help with the cooking. ...and I persevere with the sleeve, and wear it when I need to...and even some days I go without the sleeve just to see what happens' (Irene, Interview 1, p.12).

Here Irene appears to be balancing her various roles with the physical implications of lymphoedema and wearing a sleeve. The excerpt suggested there was a degree of trial and error to this as she negotiated social roles. She also spoke of being worried that her family would judge her as unable to continue caring for her grandchildren, something she really enjoyed. One day I visited, Irene had been painting, in preparation for her husband coming home from hospital, and her arm was significantly swollen and uncomfortable as a result. Her situation appeared to emphasise how women chose to prioritise these social roles before their needs in relation to the lymphoedema. These activities may have represented a psychologically important resumption to some level of normal life, even where this held a specific 'risk' for the women. Addressing the wish to restore some degree of normality to their lives meant women had to learn to adapt self-care activities to deal with their lymphoedema in various circumstances.

5.4.2 Seeking perspective

There were several examples in the accounts of the different perspectives that women took on lymphoedema. I identified earlier that some women were concerned about the limited resources given to lymphoedema treatment and care in some areas. As a result, several women appeared genuinely altruistic in wishing to contribute to the present research:

'...any research which leads to something to make a better system for people who are suffering anything is of value really' (Elaine, SG2, p.22).

Another perspective, taken by the women in the first small group, was reflected in the women's joint narratives. Chris, referring to herself and the other two members of her small group, commented *'we are the three lucky ones'* (SG1, p.7). Notably, the word 'lucky' was then used by the women a further eleven times in the discussion. Betty considered:

'I feel I am jolly lucky to be alive... you think...well there's people much worse off than yourself' (Betty, SG1, p.9/10).

Audrey also conceded:

'I suppose I feel that I am really quite lucky because my swelling's not much and seems to be quite easy to manage' (Audrey, SG1, p.7).

In SG2 Dora also took a similar perspective, viewing herself as being:

'...lucky to be alive when you know all these other people have died' (Dora, SG2, p.12).

Significantly, as the co-facilitator of the first group commented to the women, there was an obvious juxtaposition between hearing the women say they felt lucky, but also listening to them talk of the difficulties inherent in living with lymphoedema. Where I showed earlier in this present chapter that women may view lymphoedema as something to be feared, this alternative view appeared to recognise lymphoedema as a type of trade-off for being alive after breast cancer.

Another instance of a changing perspective was obvious in Elaine's account of how she made a conscious decision to change her thinking about

lymphoedema. She reflected on when the lymphoedema first developed, and how she had sought to reconcile her anger and distress:

'I knew from somebody who worked in the department that you could choose not to have the lymph glands removed, so for quite a long time I was really very, very angry that he had removed them all; but I thought "Well, you know, it's no good being angry, because it's quite wearying is being angry, you're not going to get anywhere with this"; and I was glad to be alive' (Elaine, SG 2, p.7).

These interpretations indicated that the meaning that women such as Elaine ascribed to her experience of lymphoedema could change over time. This suggested there may be various processes through which women incorporated lymphoedema, in a philosophical and emotional sense, into their lives. This may have been particularly challenging in this type of long term condition which was acquired as a result of medical treatment, and often had an unpredictable trajectory and limited options for treatment and self-care. I also recognised that several women exhibited a stoic acceptance of their condition, and were resigned to it as a long term outcome of their breast cancer treatment. Acknowledging these changing and different perspectives taken by women, may be particularly important to understanding how aspects of self-care and support were perceived and utilised by women with lymphoedema.

5.4.3 'How much of a story do you want to give?'

Betty used the phrase '*how much of a story do you want to give?*' (Betty, SG1, p.8) to describe how she dealt with friends and acquaintances asking about her swollen arm. Many of the women described being faced with various questions from people about their arm, leaving them to decide how to reply, and in some instances, seeking to find ways of hiding the condition from others. However, their accounts also showed that women struggled to find clothes to fit and enable them to hide their swollen arm from others. Fiona described clothing as her biggest frustration. Grace and Fiona both spoke together in some depth about their shared experiences of trying to find suitable clothes with a wide

enough sleeve, often resorting to large baggy clothing that they felt was unfeminine. Petra also commented:

'I must admit sometimes I feel quite restricted in what I can buy' (Petra, Interview 2, p.5).

While Fiona talked of keeping her arm and sleeve covered up and hidden from others, Grace stated: *'I've got past that stage'* (Grace, SG3, p.10). Similarly in Small Group Two, Dora talked of having to explain to others about her arm, while Elaine considered:

'I don't want to go there, really, I want to forget about it, but if you wear this thing on your arm, then people notice' (Elaine, SG2, p.15).

Likewise, Irene reflected on going without her lymphoedema sleeve:

'When I go out and take my jacket off, I don't think about my lymphoedema; I tend to forget about it, but I think wearing the sleeve draws attention to it and the minute I've got the sleeve on it's like a flag; "Look what I've got"...' (Irene, Interview 3, p.6).

This excerpt emphasised the stigmatising quality of lymphoedema sleeves. Joanne, who worked in the NHS, likewise talked of not wearing her sleeve at certain times at work, similar to Heather in Section 5.3.2. Joanne considered:

'...no matter how sore my arm was today I wouldn't wear the sleeve as I'm going to a meeting later on this afternoon and it would be noticeable...I mean, I can hide it until the minute I have to write something...and if someone asks what it is...and you tell them and then there's pregnant pause and you try to change the situation because they don't know what to say...and I don't want my identity to be, "Oh, that's that woman that had breast cancer". I don't want it to be the first thing that everybody thinks when they see me' (Joanne, Interview 2, p.5/7).

This is a powerful image of the potentially discrediting and stigmatising impact of the sleeve, as an aspect of self-care, marking Joanne out as someone with a 'cancer identity' amongst her NHS colleagues. It also appeared that Joanne had to negotiate, and perhaps protect, others' discomfort at being told she had had breast cancer. Nina described her experience of the sleeve drawing

people's attention but, in contrast to Joanne, used this as an opportunity to openly educate others:

'...she had obviously noticed it on me and she asked what it was. When I say to people about getting the lymph nodes taken away they say "Oh what do they do?" so you can kind of explain it a bit to them; I don't like to bore them with the details but some people are interested and so many people don't know about lymphoedema and I feel people should know more about it. Not many people know about lymphoedema' (Nina, Interview 3, p.8).

Here, Nina appeared to feel comfortable about discussing this with others and took the opportunity to educate others. She also told me of modelling at a breast cancer fashion show a few weeks before our meeting. Despite having continued problems with visible lymphoedema, it was interesting that Nina appeared to feel comfortable about presenting herself in this way. She reflected in the interview on how much she had moved on emotionally, in her recovery from breast cancer. These two contrasting examples of Joanne and Nina appeared to reflect the views of individual women who both recognised that lymphoedema and its treatment could mark them out with a cancer identity. They suggested that women may feel more or less comfortable about 'celebrating' their cancer survivorship and its consequences of living with a condition that was not readily concealed. Furthermore, approaches to self-care, for example using a sleeve, paradoxically brought further attention to what women might seek to hide from others. This may have important implications towards understanding explicitly how women either incorporated or rejected these aspects of self-care in their lives. However, apart from Nina discussing the fashion show, there was little evidence in the accounts that other women viewed lymphoedema as something to 'celebrate', a notion that is sometimes applied to other aspects of women's health or within a social model of disability.

5.4.4 Summary

This theme has drawn on the women's accounts to provide a flavour of the socio-psychological processes that underpinned the longer term aspects of living with lymphoedema. Their stories illuminated the various ways in which

women adjusted to lymphoedema, identifying difficulties for women in making the transition from acute treatment to living with an acquired long term condition. They provided evidence of the limitations and potentially oppressive effects of lymphoedema treatments that may influence the decisions women made about self-care. However, these accounts also showed that women had forged their own individual ways of addressing the challenges, particularly where they impacted on their social interactions with others.

5.5 Chapter summary

The themes and categories in this chapter provide my first-level interpretations of the accounts of women at different stages of their life or 'journey' with lymphoedema associated with breast cancer. There are several key points to take forward to the subsequent discussion in Chapter Seven. Firstly, that the conscious awareness of bodily changes and the embodied experience of lymphoedema associated with breast cancer appeared oppressive for women in that they had potential to raise existential fears and concerns. It is notable that these concerns had not been addressed in women's encounters with medical and other professionals, even within apparently well resourced breast cancer treatment centres. This indicated that the needs of women with lymphoedema may not be readily met from within an acute, treatment-focussed environment. Even where these symptoms were a result of medical treatments, it was notable that the specific signs of lymphoedema were not readily differentiated from other treatment effects, not only by women, but apparently also by health professionals. I will explore this further in the discussion chapter.

Secondly, various factors relating to the health care organisation and the nature of lymphoedema and its treatments appeared to influence the scope of women's self-care. The interpretations suggested that options for self-care and treatment for lymphoedema could be perceived by the women as limited, and the treatments themselves as potentially stigmatising. There was evidence of poor access to information and education about aspects of self-care such as self-

massage and exercise, approaches which might be viewed as reflecting lifestyle rather than medically-driven options. This apparent lack of choices appeared to contradict the stereotyping implicit in relevant policy documents of the active person being enabled and empowered to take on a range of self-care, with comprehensive support from health and other systems. These interpretations taken from the women's accounts suggested that responsibility for resourcing and supporting self-care for these women may go far beyond the structures of a lymphoedema clinic.

Thirdly, I suggest that interpretations in this current chapter draw attention to the processes through which women, as embodied agents, sought to gain control over their lymphoedema symptoms. The physical bodily nature of lymphoedema and the many practical skills relevant to self-care indicated 'the body' as a central feature within this understanding of supported self-care. It is through the body with lymphoedema that women sought to regain their self-identify after breast cancer. It was also through the inter-corporeal nature of their everyday lives that women developed knowledge and wisdom about self-care. Later in Chapter Seven, I will integrate the women's and the practitioners' perspectives, provided in the next chapter, and identify an anticipatory approach to supported self-care, drawing on this wisdom of the body.

Finally, these accounts have shown that lymphoedema associated with breast cancer was a significant and distressing challenge for women who were negotiating their recovery from breast cancer. A key argument in the thesis is that attention to relational autonomy theory illuminated the various structures of oppression that had potential to deprive women of opportunities to exercise autonomy and make choices within the context of lymphoedema associated with breast cancer. In the next chapter I will describe the practitioner perspectives, and show that relational autonomy theory is equally relevant to understanding the forces that impinged on the work of lymphoedema practitioners.

Chapter Six: Practitioner perspectives

6.1 Introduction

In this chapter I focus on the perspectives of the eight lymphoedema practitioners, developed from my first-level interpretations of the field observations of the mainly one-to-one practitioner: woman appointments and the interviews with practitioners. Through analysis of the accounts of the practitioners and my own field notes, I generated five themes, and several sub-themes (see Table 6.1). These represented features of: the professional context of the practitioners; the knowledge and experiential basis for their work; the ways in which they balanced the content of the appointment to meet their own and the women's needs; the practitioners' perceptions of the relationship they developed with women; and finally, how aspects of the body and body work existed and were addressed in the appointments.

Table 6.1: Themes and sub-themes relating to the lymphoedema practitioner accounts and observation field notes

Professional context

- Clinic settings
- Practitioner background
- Organisational factors
- Being seen as an expert

Developing practice wisdom

- The four cornered box
- Disciplinary background
- Formal approaches to lymphoedema education
- Reflection on practice

Finding a balance

Building the relationship

Bringing in the body

- Measuring and examining
- Discourses
- Bodywork

In total, I undertook 39 hours of observations; this included spending time with eight individual lymphoedema practitioners in their clinics, generating 110 pages of field notes. The interviews with the eight lymphoedema practitioners (Table 6.2), usually undertaken at the end of the observation periods, generated a total of five hours of taped discussions; some interviews were as short as a few minutes at a time, and the longest was 45 minutes. I have used pseudonyms for each practitioner.

Name and disciplinary background	Number of years as LP	Lymphoedema education level	Base/service setting
'Angela' (physiotherapist)	1-5	Specialist (part-Diploma level)	Hospital physiotherapy department
'Belinda' (nurse)	16-20	Specialist (Diploma level)	Primary Care outpatient clinic
'Celia' (nurse)	6-10	Specialist (Diploma level)	Hospice outpatient clinic
'Diana' (nurse)	16-20	Specialist (Diploma level)	Primary Care outpatient clinic
'Eileen' (physiotherapist)	16-20	Specialist (Diploma level)	Hospital physiotherapy department
'Fran' (physiotherapist)	1-5	Keyworker	Hospital physiotherapy department
'Gilean' (physiotherapist)	6-10	Specialist (Diploma level)	Hospital physiotherapy department
'Hilary' (nurse)	1-5	Specialist (part Diploma level)	Hospice outpatient clinic

In this chapter I show that these health professionals predominantly worked in fairly clinical settings, in apparently demanding posts that incorporated clinical and various other roles and responsibilities. Reconciling the title of 'specialist' was challenging, particularly for new practitioners, as they recognised their limitations in terms of providing women with choices around self-care.

Significantly, as I will show in Section 6.4, I found that experienced practitioners used experiential knowledge and showed evidence of an anticipatory approach to care and support. This approach enabled practitioners to bring some flexibility to the essentially positivist biomedical structures, and the technical model of symptoms and their treatment, within which they worked. However, I was aware that life-centred and person-centred approaches, that may have been more relevant to meeting the broader needs of the women I observed and interviewed, were not always evident. Nevertheless, practitioners emphasised the importance of building their relationship with women. Often working in isolated and poorly resourced posts, the practitioners appeared to have limited opportunity for personal and service development.

6.2 Professional context

I identified four sub-themes relevant to this theme: the clinic settings and their potential to influence the work of the practitioner; the disciplinary background of the practitioners; organisational factors; and, particularly for newer practitioners, the tensions resulting from being viewed by others as a specialist. I drew in this theme on observational data to illuminate each sub-theme, and will discuss each of them and the implications for understanding supported self-care.

6.2.1 Clinic settings

This category was established mainly from my field notes, written after observing the appointments between a lymphoedema practitioner and a woman with lymphoedema. Here I was concerned with the care environment and how it might influence the delivery of supported self-care. While the four lymphoedema practitioners with a physiotherapy background were all based in physiotherapy departments in NHS hospitals, the nurse lymphoedema practitioners worked either from hospice or primary care settings. During the observations, I became aware of the physical accessibility of the physiotherapy department clinics, usually sited near the front of a hospital. There was a routine and clinical atmosphere to these areas, which could be busy at times.

The reception areas were often welcoming, and in the waiting areas all had various information displays of posters and booklets. The hospice-based and primary care clinics were in much quieter settings, some of them located away from central city areas such that often they were less accessible than hospitals in terms of public transport. The reception areas in the hospices were quiet but welcoming, and were homely rather than clinical.

The appointments generally lasted between 30-60 minutes and took place in relatively private clinic areas; almost all were located in a room designated as a lymphoedema clinic. Four appointments were in general physiotherapy rooms. All the lymphoedema clinic rooms had treatment couches, various storage shelves and cupboards, a sink and an office desk with a computer. It was common to find that practitioners had various posters on the wall, sometimes with quite complex diagrams about the lymphatic system, placed at eye level to where the 'patient' would be seated. One clinic had an upholstered chair on which the women sat, placing her in a lower position to the practitioner, who sat rather authoritatively with papers on her knee. In another clinic, the practitioner sat at her desk, with the woman placed to the side of the desk, and various hospital notes located between them. However, in most appointments, the women and practitioner were seated at the same level, at a socially comfortable distance apart, with no barriers between them.

The point to raise here is how the location and environment may have influenced the potential for, or nature of, supported self-care. As I showed in the last section, Rona and Heather, two of the women who had lymphoedema, commented to me on the relative inaccessibility of their lymphoedema clinic, which was far from their homes and not easily served by public transport. Two other women commented on being initially dubious about attending a clinic in a hospice.

Where I observed all lymphoedema rooms as relatively clinical, these were predominantly private areas where the layout usually created an informal atmosphere. However, working in a one-to-one setting with women in clinics set away from other colleagues, the practitioners were also fairly isolated socially and physically. This may have influenced the potential for support in its broadest sense, both for the women and for the practitioners. As such, women would not necessarily meet other women with lymphoedema, unless briefly in a waiting room. Likewise, Celia, Diana and Angela talked of having to make specific efforts to make contact with other practitioner colleagues in relation to their own support and professional development.

Furthermore, the busy, clinical surroundings of a physiotherapy department and the quieter, more informal environment of a palliative care unit or hospice clinic represented very different environments for the clinics, with potentially contrasting ideologies of care. This is a point to which I will return later in the chapter. Significantly perhaps, a practitioner based in one of the hospices was the only one who did not wear a uniform. She was also the only practitioner who undertook home visits to people with lymphoedema, along with working in the clinic. Arguably, had I observed informants as they visited people with lymphoedema in their homes, or worked with women at a support group in a community-centre, it is feasible that I may have generated very different data from these environments outside the more traditional healthcare system.

I should point out that whilst clinical settings formed a context for the data gathering process, they were not analysed in depth, as might be undertaken within an ethnographic research approach. To undertake observation over a long period in one clinic would have been complex and potentially oppressive for practitioners, given the one-to-one nature of their appointments. Gathering field data from several clinics, however, provided the opportunity to contrast the different settings, albeit at a fairly superficial level, and to identify significant factors such as accessibility of services, that might impact on women. I was

also able to recognise that overtly clinical environments did not necessarily constitute a barrier to open communication. However, certain clinic environments could reflect a particular ethos of care that may have impinged on the women's perceptions of, or the practitioner's approaches to, supported self-care. I will explore this observation later in the chapter and also in Chapter Seven, when I consider the professional constructions of lymphoedema and the ideological assumptions and philosophies that underpinned professional lymphoedema practice.

6.2.2 Practitioner background

Here I draw attention to the broad roles and educational backgrounds of the practitioners, in relation to their work in the treatment and care of individuals with lymphoedema. Six of the practitioners had specific posts as specialist lymphoedema practitioners; two had wider responsibilities, for example, as physiotherapists in a hospice or hospital. My discussions with these practitioners indicated that all worked to some extent with individuals who had different types of lymphoedema, including cancer and non-cancer-related swelling. However, several practitioners focussed mainly on those with lymphoedema associated with cancer, as a result of their clinic being located near to or within a cancer centre or palliative care unit. In this current research study, I only observed appointments with women who had lymphoedema associated with breast cancer. Significantly, these women were the most commonly referred group of individuals to many of the clinics, and were often viewed by practitioners as more routine and less complex 'cases' than those with other types of lymphoedema.

Table 6.2 indicated that some practitioners had worked for many years within the speciality of lymphoedema, and a few were relatively new to the work. Notably, all of the nurses and two of the physiotherapists had specific previous experience in cancer and/or palliative care before moving to work as a lymphoedema practitioner. Educationally, they had all undertaken part of or a

complete post-graduate or graduate Diploma in Chronic Oedema Management qualification. Several had undertaken this previously in England, and others had completed or were currently undertaking modules of a Scottish-based diploma course. Both these educational programmes followed a model set out by the British Lymphology Society. This reflected a hierarchy of professional knowledge ranging from key-worker education, that prepared practitioners to work with people who had relatively uncomplicated lymphoedema, to education in specialist skills such as manual lymph drainage and compression bandaging, suitable for people with complex lymphoedema. One practitioner was educated to key-worker level only. Several had completed their Diploma qualification by undertaking specific modules on caring for someone with advanced disease and oedema, and management aspects of the lymphoedema practitioner role. As I will show later in this chapter, the courses followed an essentially biomedical model of treatment and care.

It is worth noting that, while there was some variety in their background and experiences, all the practitioners had followed fairly similar routes though cancer or palliative care specialities, and in their lymphoedema education. Notably, only one practitioner undertook visits in the community but she did not have a qualification as a community practitioner. None worked in the social care or voluntary sector with people with lymphoedema, or were significantly involved in the care of people with other long term conditions such as arthritis, where alternative models of care may have been in use. Several worked in clinics based in acute hospital settings; this contrasted with the general direction of social and health policy towards more community- or voluntary sector-based care for people with long term conditions. Arguably therefore, the perspectives identified here are relatively narrow, as they are very clinically based.

6.2.3 Organisational factors

It was beyond the scope of this study to explore the broader organisational aspects relating to the work of lymphoedema practitioners, such as the funding

of services, or the wider health care structures in which clinics were placed. However, this research data did provide insights into the practitioners' roles in the management of the lymphoedema services or clinics. Significantly, while the posts were clinical in nature, the work of the practitioners inevitably combined a range of other activities over and above their clinical work. I gained an impression during my observations of the practitioners having a significant administrative role, with many demands placed on their time. Three travelled between different clinic sites and one undertook home visits, as I have noted, covering an extensive rural area. Four practitioners were involved in mentoring other staff, and one practitioner was herself undertaking a lymphoedema training course.

During the observation periods, but not while working with the women, practitioners would often take telephone calls, from people with lymphoedema who were seeking advice, or from other professionals wishing to refer people to the clinic. Eileen had a waiting list of seven weeks and talked of women telephoning her as they were anxious about having to wait that long. During my visit Angela took a call to say a woman she had seen the previous week was dying and may require urgent care for her lymphoedema. Angela also described how her workload had increased as the referral rate to the clinic had risen by 400% from the previous year. Both Celia and Angela were expected by their managers to write a business case, with a view to seeking further funding for their clinic and increasing staffing levels. Indeed, two practitioners talked of forthcoming organisational changes that were designed to rationalise their services, which would confine access to their clinics to people with cancer-related lymphoedema only.

Celia considered:

'You need to be somebody who is quite organised because you are working on your own; you need to be quite a logical practical thinker' (Celia, Practitioner Interview 8, p.11).

Celia was one of three of the practitioners studied who worked as the only lymphoedema practitioner in the service. The others worked as in small teams of two or three practitioners, although they rarely worked together, but rather, ran individual clinics over a morning or afternoon. Some practitioners saw several 'patients' in quick succession putting them under particular pressure, as Eileen commented:

'I find now I just don't remember the details unless I write them down immediately, as the patients for me begin to merge together' (Eileen, Practitioner Interview 9, p.10).

Significantly, at the feedback session to the practitioners some months after the observations and interviews were completed, they talked together about proposed changes in NHS outpatient appointment systems, which would have administrative staff taking over from practitioners the organisation of the clinic booking system in some areas. Practitioners were emphatic that this would be unhelpful for them, identifying their needs for flexibility, control over the number and length of appointments, and the types of treatments being undertaken within any morning or afternoon clinic. It appeared that this might influence the practitioners' ability to make specific choices on how to manage their clinic. As such, practitioners preferred to have jurisdiction over arranging clinics around the needs of individuals who may require very different appointment lengths.

In summary, the accounts and observations indicated that practitioners faced a variety of demands from 'patients' and a range of others, including colleagues and managers. As already described, most appointments took place in a one-to-one setting; most of the women attended alone, although one came with her husband, one with her daughter, and another with a friend. The relative isolation of practitioners, I would suggest, may have limited the scope for their professional support and development. As I will show later, particular aspects of practice such as bodywork also placed specific physical and emotional demands on practitioners. Notably, two practitioners did discuss the potential for broadening the scope of their role to work with groups of women, for

example, to teach self-massage. A small number of practitioners also had some involvement with a lymphoedema support group in their area. However, there was little evidence of practitioners working with groups of women, as a particular approach to supporting self-care, or of staff actively working together in teams. Indeed, although medical staff did attend on a regular but infrequent basis at two of the clinics, the practitioners rarely operated within a multi-disciplinary team approach as might be evident in services providing care for people with long term conditions such as asthma or diabetes. As such, the organisational model for practice appeared to pivot around the role of the practitioner as a fairly isolated specialist with a broadly clinical and administrative remit.

6.2.4 Being seen as an expert

Field work provided opportunities to observe how practitioners worked with women to provide support. I explored various aspects of this work, with practitioners in the interviews. Several practitioners, particularly those with less experience, commented on the challenges of being perceived by the women, and by various professional colleagues, as an 'expert' specialist. Therefore, I believed the title of this category illuminated the tensions implicit within such a specialist role.

Diana reflected back to her early years as a practitioner:

'When I was new to lymphoedema...everybody referred to me as a specialist, and assumed that I knew everything....when I look back on my initial years of being a therapist I found them the most difficult.' (Diana, Practitioner Interview 7, p.6).

I observed Celia, who had been a lymphoedema practitioner for around two years, and had a nursing background, as she undertook a first assessment with a woman in the clinic. I recorded in the field notes:

'Celia asked the woman how she felt. I think Celia said something like "We've talked about the physical things, how do you feel in yourself about

the lymphoedema?”. Immediately the woman started to cry. Celia stopped, and gently touched the woman’s arm’ (Field notes 8, p.3).

I then asked Celia about this in the subsequent interview:

Researcher: *‘How did you feel when she got upset today?’*

Celia: *‘Well, I felt upset for her, I could see how the lymphoedema was affecting her, I did feel upset for her and to think that she was looking to me for all the answers, to help her. It’s quite an onus to have on you at times; especially when they’ve got these preconceived ideas that you’re the expert. I hate that because I’ve only been doing that for a couple of years, three at the most, and you’re viewed as that’ (Celia, Practitioner Interview 8, p.10).*

This honest account from a practitioner indicated how she viewed her role, and also suggested there were tensions for Celia in being perceived by women as a specialist who knew everything, and by implication, might provide a solution to their problems. Presumably it also illustrated Celia’s wish to minimise the woman’s (and perhaps her own) distress. Where this finding also mirrored the women’s accounts of their expectations and disappointments, described in the previous chapter, it is likely given the chronic nature of the condition, that even after many years experience, Celia would not be able to present the woman with a fully effective or quick solution to her lymphoedema. This represented the reality for practitioners of working with people who have long term, ‘incurable’ conditions. It also indicated that not only might a practitioner have to develop ways to talk with and support women with lymphoedema, in order to address their expectations and distress, but she may have to also reconcile her lack of ability as an ‘expert’ to produce a solution.

In this example, Gilean appeared to have shifted her expectations of herself as a practitioner as she became more experienced over the years:

‘Yes, now I am a specialist in my own right and I feel that I deserve that title, whereas 8 years ago I really felt I was very new to the whole area and in the beginning it was very difficult because I wanted to fix it for the women’ (Gilean, Practitioner Interview 14, p.19/20).

However, Hilary provided some evidence that as a new practitioner, she still had to reconcile her views of herself as a specialist:

'I need to get my head around the fact that it's not down to me that, even after having had treatment for lymphoedema, her arm is still swollen' (Hilary, Practitioner Interview 16, p.2).

Having observed and interviewed Eileen, an experienced practitioner with a physiotherapy background, I was aware of how one practitioner addressed these tensions with women. She commented:

'Patients have expectations...at the end of the day they come with a swollen arm, and they want to know what you are going to do about it' (Eileen, Practitioner Interview 9, p.10).

In all the observations with Eileen, I recognised how each time she saw new women at the clinic she invariably explored with the women their hopes and expectations in relation to coming to the lymphoedema clinic. A similar approach was taken by Gilean and Diana, who, like Eileen, used this as an opportunity for a fairly honest but sensitive discussion about the potentially long term nature of lymphoedema. Later in this current chapter I show in a subsequent theme, entitled 'Building the relationship', how practitioners used such discussions to establish a trusting partnership with a woman and reconcile them to the prospect of living with a long term condition.

Another aspect of this category centred on the expectations of other professionals. For example, Celia and Angela talked of doctors referring individuals to them and having particular expectations of them as specialists. This suggested that practitioners might need to be clear with colleagues about their role. Indeed, Gilean commented on how other general physiotherapists in her department did not fully understand the essence of her work as a lymphoedema practitioner, and how it differed to their own, short term and more solution-focussed approaches to physiotherapy practice. Importantly, this may also reflect the different ethos or ideology of various practice areas, which may

be imputed to specialists who work in that area. I alluded to this in the earlier category of clinic setting, however here I am drawing more precisely on the accounts of the practitioners, rather than my own observations alone. Hilary contrasted her work as a palliative care nurse with her new role as a lymphoedema practitioner:

'You come here [the lymphoedema clinic] and patients are coming in and out on their own steam rather than being brought along in a wheelchair, so they seem more well... and while it [lymphoedema] is still an incurable problem, your aims are slightly different because, there's still a lot more that the patient can do on their own' (Hilary, Practitioner Interview 16, p.1).

In this excerpt the practitioner appears to recognise the potential for a different ethos or philosophy of care for individuals with lymphoedema who are relatively independent. Where professionals such as Hilary move between different areas of practice, attention might be given to the potentially divergent philosophies of care that underpin different practice specialities.

In summary, the observations and accounts in this category pointed to the possible challenges for practitioners, particularly when they were new to the speciality, in reconciling others' expectations of them as a specialist. The evidence from several practitioner accounts and the field observations indicated that experienced practitioners developed ways of responding to these challenges, through exploring women's expectations with them at the first meeting. This would appear to provide some, albeit minimal, scope towards addressing the degree of disappointment that women described to me and was reported in the previous chapter. However, coming from their experiences of the biomedical framework of breast cancer care, it is also possible that women with lymphoedema may find it paradoxical that a 'specialist' lymphoedema practitioner does not have the 'expertise' to find a cure for her problems with lymphoedema. Arguably, however, in a framework of self-care, it is the woman with lymphoedema who acquires expertise and is the specialist in her own body. Where long term condition policy has identified the need for changing roles for

the professional and person with a condition such as lymphoedema, this may involve a re-location of knowledge, and potentially power, away from the professional but also a need to redefine the notion of 'specialist'.

6.2.5 Summary

This theme has illuminated the social structures within which the lymphoedema practitioners were placed. Their context appeared fairly clinical, often isolated, and demanding. It seems that the ethos of their practice area may determine how they viewed their role. The notion of 'expert' specialist in the context of supported self-care is particularly interesting. Arguably, it reflects the hierarchical professional healthcare structure, and in these study findings appears to have invested within it, connotations of expertise, evoking various expectations of a professional. Not only may these expectations be unrealistic, but they may be in tension with the ideal of 'expert' lay self-care.

6.3 Developing practice wisdom

In this theme, 'Developing practice wisdom', I provide specific insights from the data concerning the different sources of knowledge that underpinned the work of lymphoedema practitioners. Essentially, practice wisdom represented a type of experiential knowledge which practitioners used to make specific decisions related to supporting women with self-care, drawn from practitioners' reflections on experiences of working with different women, often over many years. Their accounts and my own observations suggested that practice wisdom was an amalgam of several specific sources of knowledge: accepted professional and 'empirical' knowledge, often referred to the four 'cornerstones' for lymphoedema treatment and care, as discussed in Chapter One; disciplinary influences on the work of the practitioners; and the practitioners' reflections on their learning from their own practice. In this theme I also show that while the scope of practice for practitioners was influenced by these areas of knowledge, the educational approaches used to prepare practitioners did not always match the realities of practice.

6.3.1 The four cornered box

As shown in Chapter One, the 'four cornerstones' have long formed a basis for lymphoedema treatment and care in the UK, and beyond. Skincare, exercise, self-massage and compression therapy might be viewed in a metaphorical sense in terms of the corners of a box. They provide a structure or framework for learning about or providing treatments and care. These cornerstones were referred to by all of the practitioners, either in the observations as they spoke with women, or in the subsequent research interviews. In my observation notes I recorded:

'Fran, the practitioner, said to the woman "That is what is called the four cornerstones"; she said the first two, skin care and exercise, were easy; she then explained to the women about the self massage, calling it 'SLD' or 'simple lymphatic drainage', and describing briefly how it should be done. There was some discussion about the possibility of a sleeve and the woman said she had seen someone with this' (Field notes 11, p.7/8).

In the following interview, Fran talked of how she ticked off the four aspects of treatment in her head, and it was clear that as a new practitioner this provided a checklist that guided her work. I also observed Celia talking to the women about the various 'options' for self-care or treatments, again talking in the interview of mentally checking off the four cornerstones during appointments. In contrast, Eileen used the four cornerstones in a more staged approach, introducing two or three of them as options in the first appointment. She commented:

'I think if you put four cornerstones of care into place straightaway, then how do you know what is working?...I mean, they are a guideline, and guidelines are a help but I don't know if they are the answer...I don't know that we want to go along the road of being too prescriptive' (Eileen, Practitioner Interview 9, p.16).

There was also evidence in the accounts that practitioners made decisions to omit aspects of the four cornerstones for particular reasons. Fran considered in the interview with me, after assessing a woman who had recurrent cancer:

'I don't know if there's any definite evidence to link SLD [simple lymphatic drainage or self-massage] specifically with increase in tumour size or, you know potentially increasing cancer spread, but that's why I decided against it for this lady' (Fran, Practitioner Interview 11, p.3).

Fran was also dubious about the evidence that self-massage was itself beneficial or effective, and talked to the woman about using exercise as her main focus for self-care, along with her sleeve. I also saw examples of other approaches being used, such as kinesio-tape, a type of adhesive tape used on the body to help drain fluid from swollen areas.

In summary, it was clear that the four cornerstones were to some extent a reference point, particularly for new practitioners, but they did not reflect a complete picture of what treatments might be available to women. Practitioners considered, as I showed in the literature review, that self-care approaches were not necessarily supported by an adequate evidence base.

6.3.2 Disciplinary background

I became aware from the observations and interviews of a significant source of knowledge derived from the disciplinary background of the practitioners. Significantly, most practitioners were named in terms of their disciplinary background, for example, 'Lymphoedema Nurse Specialist' or 'Lymphoedema Specialist Physiotherapist', rather than the more generic 'Lymphoedema Practitioner'. At the feedback session with practitioners, five months after I had finished gathering data, four practitioners talked of the relative unimportance of disciplinary background to the role of lymphoedema practitioner. However, I believe that this disciplinary knowledge was an important facet that underpinned their practice. The practitioners themselves provided some differentiation:

'With my physio's hat on, I probably do focus more on exercise than anything else at the start... I think physios are much more focused on the physical... on what we are going to do...but I have watched some of the palliative care nurses assessing patients...I have really been in awe of them; we arrive at the same end point but we do it in a different way' (Eileen, Practitioner Interview 9, p.10).

'One of the nurses...is absolutely terrified about doing her first assessment...and she came to sit and watch me and when we were finished she said, 'Oh I wouldn't know to do that' [shoulder assessment] and I thought, you know, it's probably because I'm coming from a physio background' (Angela, Practitioner Interview 1, p.4).

Angela considered how, as a physiotherapist, she would ask a nurse to advise her with wound care. Similarly Hilary, a nurse, talked of working in the clinic with her physiotherapy colleague, believing that the physiotherapist would be more focussed on shoulder assessment while a nurse would have knowledge about wound care, or be more aware of the emotional needs of women. Hilary also surmised that as a nurse she would be more likely to take a holistic view, which meant she would pick up cues that someone had a particularly low mood. In contrast, Belinda suggested that practitioners with nursing or physiotherapy backgrounds did in fact work in similar ways, based on her discussions with various colleagues over the years.

In the observations, I became aware that practitioners with a physiotherapy background were more likely than nurses to take a structured approach to their assessment, as I will show in the next theme. However, there were exceptions, with some nurses working in a structured way themselves. Those with a physiotherapy background usually integrated a form of muscular-skeletal assessment in the appointment. Although following the four cornerstones as a similar framework for their practice, nurses had a different set of disciplinary knowledge and skills that potentially precluded them from undertaking this muscular-skeletal assessment. Given that women with lymphoedema associated with breast cancer may often experience treatment-related effects that cause altered sensations, such as a painful shoulder, it may be argued that women seeing a lymphoedema practitioner who is a nurse rather than a physiotherapist may be at a disadvantage. However, in practice, most of the physiotherapy practitioners talked of referring anyone requiring specific physiotherapy treatments to other colleagues; feasibly a nurse, working in a team, might do the same.

Belinda and Hilary, both nurses, talked of referring women with pain to the medical staff with whom they worked, for further assessment. In one such example using observation, Belinda called a doctor in to see a woman who had a painful arm. In the subsequent interview Belinda reflected on how her actions in involving the doctor had worried the woman, as a scan of the woman's armpit had been ordered. A week later in our interview, Joanne, the woman, talked to me of over-riding the doctor's decision, cancelling the scan, and recognising herself that the rather medical approach adopted in the assessment was unnecessary. Hilary recounted a similar situation in which she felt the woman became more anxious when Hilary brought in the doctor, and thus, Hilary considered, making her possibly less likely to confide in her again.

Belinda reflected on the reasons for bringing in a doctor to assess women. Although she did not feel she required the doctor to diagnose lymphoedema, she did recognise the medical input as useful as a type of 'safety net', taking from her the responsibility for identifying other medical conditions or problems such as cancer recurrence. However, she also considered:

'I was thinking there must be aspects of our assessment skills that aren't honed because we rely on the medics' (Belinda, Practitioner Interview 5, p.1).

The accounts, which are taken here somewhat out of context, do suggest that practitioners were aware of the scope and limitations of their own practice. They also indicate that disciplinary background may have brought a different emphasis to an appointment. For example, it could be an integrated physical and psychological assessment, or one which might be drawn into an increasingly medical frame, involving different professionals, as a result of the practitioner's background and their distinct skill set in relation to the woman's situation.

It appears likely that disciplinary knowledge may have related to or influenced practice wisdom, perceptions of and approaches to supported self-care in individual practitioner. Thus, it might be expected that certain traits might be evident in specific practitioners, such as nurses taking a holistic approach to the appointments, showing an awareness of where physical, emotional and psychosocial aspects may all intertwine within the women's experiences. However, the accounts and observations indicated that this approach was not necessarily influenced by discipline. Gilean, a physiotherapist, appeared to take a very holistic perspective:

'You look at the whole picture, their arm, how it will affect them in other ways, in their job or in their social life, how it affects them psychologically...you can look at the whole human' (Gilean, Practitioner Interview 14, p.5)

In another example of a nurse, it appeared that a holistic approach was not necessarily taken, as the practitioner reflected on her observed appointment with a woman who had last been to the clinic several years previously:

'From my memory I remember [the woman] being very anxious and uptight, and depressed and weepy and that was one of the reasons why, when she started crying this time, I didn't delve too deep because I didn't feel it was right to bring it out at this appointment and not for me to do it at all because she's under a psychologist' (Diana, Practitioner Interview 15, p.1).

There may be many reasons for practitioners choosing to focus on or ignore various aspects such as the woman's apparent psychological distress. In this last example, it is also possible that my presence at the appointment had some influence on the process of the interaction. Thus there was some evidence that approaches to practice were not always readily differentiated in relation to the disciplinary background of the practitioner. However, there were some obvious differences, in that certain activities, such as assessment of women's function and shoulder movement, were usually undertaken in a specific and detailed way by the physiotherapists but not by the nurses. However, several nurses talked of learning how to undertake a muscular-skeletal assessment and referring

women to physiotherapists as required, indicating that they did recognise the deficit in their knowledge. However, as Eileen observed:

'If you took my last patient and put her in a room with five practitioners, we'd probably all do slightly different things....not only are we lymphoedema practitioners, but we have our areas of expertise; so you are going to be offering a different level of knowledge depending on what the patient presents with...and you are going to get different levels of service where ever you go' (Eileen, Practitioner Interview 9, p.15/16).

While a degree of uniqueness is inevitable, this quote suggested that ambiguities and potential inequalities may arise in terms of how supported self-care is provided, and may impact on the experiences of women and the type of supported self-care someone receives. Where the role of a lymphoedema practitioner is taken by individuals with different disciplinary backgrounds, practitioners appeared to bring different knowledge and skills to the work. Certainly, all practitioners are to some extent unique. However, the findings suggest that being explicit about what was to be offered, or not offered, in terms of support with self-care, could be important, as it may influence the opportunities that women had to make fair and autonomous choices about their self-care.

6.3.3 Formal approaches to lymphoedema education

As discussed earlier in this chapter, all practitioners had attended formal education courses and seven had undertaken the advanced study modules specifically focussed on specialist skills. However, several identified challenges in relating their education to practice. Hilary recognised her difficulties with the approach to learning taken in the education course, recalling her return to work in the clinic after the course:

'Initially it wasn't good because you feel "Oh I should be able to do this, I have done the module"...I put pressure on myself...I would have liked it to have been done differently...I think I would have preferred to have worked with somebody for a couple of weeks, and asked all the questions in a safe environment' (Hilary, Practitioner Interview 16, p.4).

Celia found it difficult to relate her specialist education to the realities of practice:

'It's such a steep learning process that you go through. You have an interest and you go and learn, but from the day you go in it's all this new information, and new knowledge [deep breath in]. Obviously there has to be a theoretical component to it but when you get out into the big wide world you're met with people who are individuals, and then you think "Oh my God, but they say you've to do this but that's not going to work"....I think it is the way it is taught to you at university, it is very much the ideal...but if they maybe said "You will find from experience, or we find from our experience that this might not work in all cases"; so that you don't feel as if you are getting everything wrong' (Celia, Practitioner Interview 8, p.4).

The comments from these two practitioners identified specific difficulties both in the structure of the opportunities for learning and the process by which knowledge about practice was shared; clearly not always in a realistic way. Angela also considered that knowledge from her course did not always reflect day to day practice. Notably, Celia, a nurse, and Gilean, a physiotherapist, both recognised that it took around two years to acquire adequate knowledge to enable them to feel confident in their practice. Reflecting back on previous courses, Diana, an experienced lymphoedema nurse, commented:

'When you read the literature and when you go on your courses... your goal is to carry out the treatment... you're going to use your manual lymphatic drainage and you get the purpose of doing that and the bandaging. But nobody ever tells you it may not work or it may not last; that doesn't come over when you are doing your courses...and initially you think to yourself 'Have I done something wrong?' (Diana, Practitioner Interview 15, p.6/7).

The above accounts suggested that some practitioners considered the approaches taken in education courses to provide unrealistic outcomes in terms of what might be expected from treatment and/or self-care. This may be significant, particularly given the accounts of the women regarding their disappointments at the outcomes of treatment. Clearly, education approaches may have set up specific expectations which were not always met, both from the perspectives of the women and the practitioners.

6.3.4 Reflection on practice

In the example below, Diana, an experienced practitioner, reflects on the changes in her practice:

'Initially when I started we did the limb volume measurements and patients were very focussed on these and watched every measurement we took, wanting to know the results. But now I don't make an issue of it; you would see me; I quietly took the measurements while we talked and I asked her about her lifestyle and things; I did show her the difference [between the size of her arms] but I didn't focus on it; I think that comes from experience' (Diana, Practitioner Interview 15, p.7).

This excerpt suggested that Diana had developed a way of working that may be viewed as supportive, presumably from her previous experience of knowing that the woman's arm size may not reduce. As such she did not place an emphasis on the size of a woman's arm, nor focus treatment on a specific goal of a measurable reduction in arm size. Instead, Diana talked to me of preferring to draw on a woman's own perceptions of how her arm had changed. This is in slight contrast to the accounts in the last chapter, where some of the women appeared to value learning the details of the changes in their arm size.

Eileen talked in some depth in her interviews of using clinical reasoning processes, and reflection to enhance her learning and develop her practice:

'I only make the decisions I make because I have been doing this job for twenty years; and so I make decisions, reflecting on past experience; I'm looking at her arm, feeling her arm, listening to what she's telling me about her swelling, getting an idea of what motivates her' (Eileen, Practitioner Interview 9, p.12).

This suggests that *'doing the job'* for so long meant that Eileen was likely to be able to recognise the patterns of symptoms and identify salient details, obtained through observation and examination of the woman's body, and in listening to the woman. Both Eileen and Gilean were aware of how their regular work with women with lymphoedema associated with breast cancer enabled them to recognise the common patterns of symptoms in women. I observed another example of this with Eileen as she worked with a woman who had nerve damage, leading to complex sensations in her swollen arm. Later Eileen talked

in the interview of how she used previous knowledge of how other women with similar problems had coped, to inform the support and information she had given the woman during the observed appointment. Diana also described a similar process of sharing knowledge from previous experiences of helping to motivate women, as a reference point for dealing with other women with similar problems.

Fran was a new lymphoedema practitioner who had recently finished a lymphoedema course. In the field observation during an appointment with a woman who had lymphoedema, I became aware of Fran's lack of knowledge and experience around breast cancer treatment, and her difficulties in identifying and individualising a plan of care for the woman. In this situation the lymphoedema was exacerbated by the woman having chemotherapy, something that Fran did not appear to fully recognise or communicate to the woman. However, she was honest as she reflected on her lack of knowledge in the subsequent interview:

'It's a whole new [experience] for me, I didn't have any oncology experience, so even knowing what happens when you have a mastectomy and what chemo you go on afterwards, and what side effects that can cause; I didn't know any of that... you are taken completely out of your comfort zone and I know I have a lot more to learn' (Fran, Practitioner Interview 11, p.15).

Notably, the physiotherapists all talked of using clinical reasoning and reflection in their practice, although nurses were less explicit about this. Belinda found it difficult to articulate this reflective process, considering her work to be based partly on intuition:

'I've been trying to take a step back and say "Why did I do that and what made me think that?";...you kind of vaguely know why...but you can't put it clearly in words' (Belinda, Practitioner Interview 6, p.2).

The evidence in this sub-theme suggested that experienced practitioners drew on reflective processes to develop a practice wisdom that underpinned their work in supporting women with self care. However, not all practitioners appeared to readily reflect on their learning from experience, and two

practitioners commented on knowing other practitioners who tended to follow the same approach, without fully questioning or reflecting on their work.

6.3.5 Summary

In this theme, *'Developing practice wisdom'* I have described the sources of knowledge that appeared to shape the work of the lymphoedema practitioners. To an extent, frameworks for practice used in education may be useful for new practitioners, but they also had the potential to be oppressive as they represented the myth that lymphoedema may be readily controlled. Practitioner experience developed over many years of working with individuals with lymphoedema appeared to provide a basis for recognising the salient patterns of women's symptoms, and building practice wisdom. In the discussion I will return to the work of John Dewey, to further explore the notion of reflection on practice as a basis for professional and lay knowledge relating to supported self-care. The data suggested that the different disciplinary and professional backgrounds of practitioners may lead to inequalities and differences in the nature of support. Education courses appeared to prepare practitioners within a dominantly biomedical paradigm with a focus on attaining specific measurable outcomes

In the previous chapter, my interpretations indicated that for some women, the policy notion of 'self-care choices' was rather lame. This may leave the lymphoedema practitioner in a tenuous position, unless she can readily articulate the ideological basis for her work, and extend her focus beyond the dominant biomedical model. It was apparent that experienced practitioners drew on their practice wisdom to adapt this framework to one that was more realistic and relevant in seeking to support women with self-care for this group of women. However, not all practitioners gave an impression of being able to reflect on their practice. This may be a cause for concern, given that practitioners often worked in fairly isolated roles, with limited opportunity for exchanging ideas, professional development or peer support.

6.4 Finding a balance

In this theme, I have brought together examples from the observations and interviews to illustrate the various ways in which practitioners sought to find a balance as they worked with women with lymphoedema. The notion of balance refers firstly to how the practitioners sought to balance the time in the assessment between hearing the women's stories and specific concerns, while also gathering the information they required to make decisions about treatment, care, and ultimately how they would support her. This could be viewed in terms of the contrast between, on the one hand, a biomedical assessment designed to focus on the physical condition, based on the practitioner's need to make a diagnosis and plan treatment, and, on the other hand, a more person-centred approach that took its cues from the woman herself, considering her lifestyle, needs and experiences. Secondly, practitioners appeared to seek a balance in deciding how much information or detail they should provide for women, for example at the first appointment, or at a later date. The evidence suggested this could be challenging, as practitioners did not always find it easy to anticipate the progression or changes in women's lymphoedema, or her response to treatment and self-care.

Observation of appointments, often with the same practitioners, indicated that there was an element of routine within the work. For example, the role of practitioners in the appointments usually encompassed a blend of activities common to a fairly biomedical model of practice based around the four cornerstones of care. This included activities such as 'assessment' of the woman and her arm:

'The important thing for me is that the first appointment is about an assessment that allows me to make a diagnosis which allows me to plan treatment' (Eileen, Practitioner Interview 9, p.4).

Another practitioner provided a further perspective:

'You want to know all the things in assessment to be able to give her the right information at the right level, that she can understand' (Celia, Practitioner Interview 4, p.2).

These two quotes appear to provide slightly different views on the purpose of the assessment, and it is possible the two are not mutually exclusive. However, the first appears to represent a rather professional-centred perspective, oriented towards the practitioner's need to develop a plan of care, whereas the second appears to locate the woman and her need for relevant information as central.

Celia was one of the nurses who, alongside Belinda and Diana, talked of listening to women's stories, noticing their facial expressions, and picking up cues about how an individual was feeling about her situation. Celia recognised how she used this information to help formulate goals that would be relevant and meaningful for the individual woman. I observed that Celia established medical and treatment details about the women from their hospital notes before the appointment, so she did not have to spend time discussing these in depth during the appointment. At one observation I watched her assessing a woman who had come to the clinic for the first time. The woman was very open and was keen to tell her story. Celia, therefore, let the woman have a fairly free rein in the initial part of the appointment, but talked later of how this unstructured approach could be challenging, and required skill from the practitioner to try and guide the discussion to focus on important areas:

'She (the woman) would give you wee snippets and then I would be thinking "Oh I better try and get back to that"; quite important things she would say and she was obviously quite focussed on her arm and why it had happened....She had a lot to speak about but I felt it was fine to be a wee bit more drifting; I suppose it comes with experience as well doesn't it?' (Celia, Practitioner Interview 4, p.4).

When I first observed Belinda, also a nurse, she used a fairly structured approach to her assessments, sequenced according to her clinic assessment form. After we had discussed the process of assessment at our first interview, I

noticed she changed her approach the next time I observed; she commented at her second interview:

'Even although I didn't work methodically through the assessment form, come the end of it I think I had covered most of the bases; I was thinking the assessment was all over the place and it was really led by her, but I still managed to get all the information that I needed; and there's also having the confidence to know that if you've missed anything you'll get it next time round' (Belinda, Practitioner Interview 5, p.2/3).

In contrast, Eileen, a physiotherapist, worked from quite a structured format. I observed her assessing several different women; each time she undertook the assessment in a similar way by working through the form, questioning the woman and writing down as she went along, obviously keen not to be sidetracked by the woman. I asked her about this in the interview:

'It helps my clinical reasoning if I stick to a similar format so that I don't miss things out, because if you're seeing a lot of patients, and especially if you've got somebody who's a poor historian or somebody who has a lot to tell you. I'm now quite ruthless. I say as I did with the lady today, I'll come back to that' (Eileen, Practitioner Interview 9, p.6).

When I observed her appointments I noticed that Eileen structured her questions in such a way that focussed on certain aspects, and she also left time for the women to ask questions. Certainly, this more focussed approach was possibly useful in a short appointment time, and skilled questioning can elucidate important and specific information. However, it is also possible that this structured the appointment in such a way that women's emotional needs and feelings could be disregarded. Indeed, this may partly explain why Kate, one of the women I observed with Eileen, referred back to the appointment as '*academic*', and then sought advice through another route, by seeing a private MLD practitioner.

However, newer practitioners such as Fran, who was a physiotherapist, appeared to use a fairly structured and physically focussed assessment to enhance what she referred to as the '*deductive logic*' that guided her treatment planning process. Hilary, a nurse, recognised that her assessment form was quite biomedical and she had decided to develop a more person focussed

section that explored emotional aspects of the women's experiences and her support networks. Celia had sent out a short questionnaire to one of the women, prior to the appointment. It posed specific questions such as how the woman was feeling about having lymphoedema, and what types of support were available to her. However, it was only after the woman had left the room that Celia checked what the woman had written. Thus it is possible that Celia did not necessarily pick up during the appointment on the issues which the woman had identified in her questionnaire. This suggested that practitioners may need to develop skills in integrating this type of tool within their practice.

As I showed in Chapter Five, practitioners did not always address aspects of support such as information on exercise in the appointments. It is possible that they may have covered these in subsequent appointments with the women. However, in several of the observations I noted that a woman gave clues about aspects of her life that practitioners did not fully acknowledge, despite their potential relevance to supported self-care:

'The woman seemed to have knowledge and expertise of how best to care for her skin; she talked about how she used a small pillow to press under her arm when it felt swollen, but the practitioner didn't seem to pick up or build on any of that information in a way that might help the woman build confidence in her self-care' (Field notes 1, p.5).

Clearly, skilful questioning and active listening may be central skills to an effective assessment in relation to supported self-care. Watching Diana and Gilean, two experienced practitioners who were respectively a nurse and physiotherapist, I observed how they skilfully balanced the gathering and sharing of information, within a warm and genuine interaction with the women. After one such observation I recorded in my field notes:

'I observed Gilean today as she talked with the women who attended the appointments. She was warm and friendly and they opened up to her; she balanced social talk with establishing important information from the women, and giving relevant information in response to various cues. She integrated this with the examination of their arm and upper body; there was a feeling that everything flowed and was effortless, I recognised that she was a skilled practitioner. I noticed that she was clear with them that

the lymphoedema was likely to be a long term problem, saying something like "You will always have some swelling".' (Field notes 14, p.4).

I was aware that Gilean appeared to have established an effective relationship with Petra and Rona, the two women I originally observed her with, and followed up over the period of six months of the study period. Gilean explained to me her rationale for this regular contact:

'I want to get to know her arm, by seeing her several times, if necessary because I don't know how her arm's going to behave' (Gilean, Practitioner Interview 14, p.9).

This quote emphasised a possible problem for practitioners in being unable to fully anticipate the progression and outcome of lymphoedema treatment and self-care. This inability to anticipate appears to reflect the possibility that, as I showed in the previous chapter, lymphoedema could be unpredictable and difficult to control with self-care. However, from a practitioner perspective this appeared to present two challenges: how much information to give the woman at any given stage; and how often to see her. Belinda described her difficulties in finding a balance in terms of how much information to give someone with early lymphoedema:

'You don't know whether you are sort of burdening them with some condition greater than they actually have, or are you preventing it from getting it worse, we don't know' (Belinda, Practitioner Interview 2, p.2).

All of the practitioners talked at some stage in their interviews about bringing women back for a further appointment. For example, Belinda talked of teaching self-massage at a subsequent appointment and considered:

'It depends on how motivated, or knowledgeable or self-directed they are, if I thought someone was a bit floundering a wee bit or I didn't know what might happen, I would bring them back sooner' (Belinda, Practitioner Interview 6, p.3).

Celia also recognised the need to bring women back to the clinic:

'At that first meeting there is just loads to cover, so I give them leaflets at the first meeting so they can have a read up on it... but you really do have to get them back in that first little while so you can follow things through and check out how they are getting on with their sleeve and things' (Celia, Practitioner Interview 4, p.5).

I was aware that these examples provided some insight into how support with self-care might develop over a period of time. I also noted in the previous chapter that the opportunity to easily come back to the clinic was not available to some of the women, mainly due to staff sickness which meant that, in one case, a clinic was closed. As I also showed in the previous chapter, several women did not necessarily feel they needed to return to the clinic, as their lymphoedema had apparently disappeared, and this suggests that women have varying needs for follow up. However, given the difficulties in predicting the trajectory for lymphoedema in individual women, and anticipating future problems, it would appear important for practitioners to establish a flexible system for long term support and access for women who require it. In Section 6.2.3 I showed how practitioners themselves identified the importance for them to have control over the booking of appointments, to enable a degree of flexibility.

In several observations I was aware of how a type of negotiation had taken place where the practitioner was unable to anticipate what was required, but also left the options open:

'Eileen said the sleeve was an option but that she was sitting on the fence regarding this; the women said she'd be guided by her. Eileen said "Is it something you would like to try?" She also said "I am happy with your arm the way it is for now, if you are comfortable about going without a sleeve". To which the woman replied "I am used to the swelling and it doesn't bother me". Eileen said "I have explained what to look for, so if anything happens in the meantime before you come back, then you can just telephone me, leave a message and I will get back to you" (Field notes 9, p.7).

In the subsequent interview, Eileen then talked of being reluctant to provide a sleeve, as she felt this would be more of a problem for the women than the swelling. Although this may not have reflected accepted practice, according to the four cornerstones, this appeared to be another example of practice wisdom. As such, Eileen sought find a balance between intervening by providing a sleeve, which we have already seen may have had stigmatic implications, and

waiting to see what happened over time. An important point to consider here is that Eileen was relying on the woman feeling adequately able or empowered to contact her at the clinic if she had a problem.

Similarly, Diana drew on her practice wisdom in talking to a woman about how to recognise cellulitis, a type of infection, and what steps to take if this happened. She explained her rationale in the interview:

'I was trying to put the patient in control, you heard me telling her about infection, and from experience if I went through that with somebody they might think "Oh this is another problem don't tell me this" but you could see the way I handled it today. I was giving her knowledge that could prevent it from happening, but also letting her know that if it should happen she knows what to do. I've heard so many ladies say "I was on holiday and all of a sudden it got red and I didn't know what had happened, I thought the cancer was back" ' (Diana, Practitioner Interview 7, p.4).

These last examples are interesting for several reasons. Not only do they appear to reflect the practice wisdom of experienced practitioners, but they also indicate that these experienced practitioners used a type of anticipatory approach as part of supporting self-care with these women. However, in doing this they also delegated responsibility for self-care and specific surveillance of the body to women, who might be expected to find access routes back to the practitioner in the event of a problem.

In another example of the anticipatory approach, Diana described how she talked with women after she fitted them with a sleeve:

'I do warn patients when I give them the garment; I say this is an opening for conversation from all walks of life; from shopkeeper, to your work colleagues, to their family; there's some people you'll want to tell the whole story to, there's some you might just want to say "it's a swelling and the sleeve is stopping it getting worse"; that's enough for them; but it's up to you to dictate' (Diana, Practitioner Interview 7, p.7).

This excerpt appeared to reflect the women's comments in the category 'How much of a story do you want to give?' discussed in the previous chapter. It is

possible, however, that the processes that underpinned these anticipatory approaches may be barely visible to the women, and also not fully acknowledged by the practitioners. They are a subtle part of the appointment's interaction, but are highly relevant to the thesis for several reasons. Firstly, they may be viewed as attempts to develop in women their own awareness and knowledge of their body with lymphoedema. This links to the theme of *'Knowing lymphoedema in the context of breast cancer'* in the previous chapter. Secondly, they are also examples of potentially enabling ways of working that may underpin approaches to supporting self-care. They appear to engage women in self-assessment and reflective practices relating to their lymphoedema and self-care, recognising salient aspects of their physical body changes, and responding by taking appropriate action. However, the effectiveness of this approach is also likely to depend on the accessibility of follow up support available from the clinic or other services, and the quality of the relationship between the professional and woman.

Significantly, this type of support may be subtle and almost intangible, and so is not amenable to being readily quantified or recorded, as within a biomedical model. It may therefore be undervalued and under-acknowledged as a professional skill. That it is subtle may also partly explain why women, as reported in the previous chapter, perceived their options for support to be so limited. However, I suggest that these exemplars do illuminate specific ways in which experienced practitioners drew on practice wisdom, while also seeking to develop a degree of embodied wisdom in the women. Just as reflective practice is central to the work of professionals it is possible that developing this type of anticipatory approach also draws on the reflective abilities of women with lymphoedema. I discuss this in more depth in the next chapter.

The accounts of experienced practitioners also showed that they recognised the challenges in providing women with choices regarding their self-care:

'I try to keep encouraging patients with self-care...but sometimes you find as time goes on they fall away, and that's the patient's choice and you just have to let them live with their condition as they choose' (Diana, Practitioner Interview 7, p.2).

'If we are wanting people to self manage we need to give them the tools and we need to support the decisions they make...they may not be the decisions we would make or think they should make; some people come with very clear ideas of what they want' (Eileen, Practitioner Interview 9, p.18).

These excerpts appeared to reflect the notion of the active person who makes a personal choice about self-care, as identified in the policy documents in Chapter One. However, given the nature of lymphoedema, as epitomised by the women in *'What can one do?'*, they may also reflect the relative lack of positive choices available to women from lymphoedema practitioners, in relation to self-care.

In summary, practitioners appeared to seek to find a balance within the appointment, both in the structure of the assessment, and in how they sought to anticipate women's needs, choosing how much information to give or what 'interventions' such as sleeves to use at particular times. This type of approach may capitalise on the women's ability to recognise and reflect on her self-care needs, and also relies on an effective relationship between women and practitioner, through which women might access the necessary support.

6.5 Building the relationship

In this theme I will show how in recognising the fact that they may have long term contact with many of the women with lymphoedema, practitioners placed particular emphasis on the quality of this relationship as a key element to effective supported self-care. Knowing women over the longer term could also be a positive experience for the practitioner:

'I think that is probably why I really like my job and why this particular area of physiotherapy, is something that really suits me. You actually do have a chance to build up that relationship, because you know they will

come back, you know, for many, many years to come' (Gilean, Practitioner Interview 14, p.5).

Gilean talked also of having an open door policy where women could refer themselves back to the clinic as required. As I showed earlier, Celia viewed the first appointment as crucial in establishing the basis for an effective relationship that enabled her to understand how women would deal with the lymphoedema over time. Similarly Eileen talked of getting to know people as individuals at the early stage of meeting them, to find out what motivated them to make certain decisions. She recognised some women came to the clinic with significant anxiety and considered her role:

'Some of the patients I'm seeing who have got early swelling are so distressed that they can't focus on anything...and then as you work with them over time, they come to a point where they are quite independent in their self-care, and they come back for the review appointment and all that is happening is you're just reinforcing, supporting what they are doing, but they have taken control' (Eileen, Practitioner Interview 9, p.19).

This suggested that the practitioner sought ways to enable women to establish some feeling of control over their situation. However, I also observed another version of control in one field observation:

'The practitioner seemed to be controlling the appointment by working through a rather medical approach to the assessment. I noticed the woman was visibly trembling and I thought she looked close to tears at one point and it did not appear that the practitioner picked up on this. As an observer I felt quite emotional myself and was surprised that the practitioner seemed so unaware' (Field notes 1, p.3).

There may have been various reasons for the practitioner apparently not picking up on these signs of distress, as I noted with Diana in a previous section. My presence may have had an influence, leading the practitioner to focus on specific aspects of the assessment. An alternative is that she may have sought to block out the emotional distress, as she may have believed that dealing with it would delay her work. This is possible, given that my impression was of her being fairly busy in managing her clinic. It is perhaps notable that both Angela and Eileen, two physiotherapists, were keen for women to be referred to the

local Maggie's Centres for emotional and psychological support rather than providing it themselves:

'Well, one woman I have seen for several years, she has never coped, so I got her referred to the psychologist and I got a letter back and he said they'd seen her, and she had lots of unresolved issues...so she came back here and I thought 'Well, I do need to have some boundaries or she would have me sitting here all day', and it can be very draining...so I said to her, what about going down to Maggie's Centre; so I took her down there...it was all I could think of to do' (Eileen, Practitioner Interview 9, p.21).

This excerpt suggested that the practitioners may recognise women's distress but realise they are limited in how they can help. They may also have to identify boundaries for their work in order to protect themselves, particularly as they work in such isolated roles, with potentially limited support. This may also make it challenging for practitioners to provide the type of open door policy mentioned earlier in this section. In Section 6.6.3, I show that Diana recognised her need to protect herself emotionally when undertaking MLD with individuals. At the same time, however, there was an overwhelming sense from practitioners that women should feel comfortable with them so they could have an open and honest relationship:

'I feel patients have to be relaxed with me so they can feel free to ask me anything...I need to be approachable...so they telephone me if they have difficulties, and we can negotiate and share goals...you have got to build on the relationship to achieve that. Some patients come and their mood's low, they can be a bit negative and need more encouragement, and they don't keep up the massage, so I have to be open to anything in that relationship' (Diana, Practitioner Interview 7, p.3).

Within this sense of openness and the need to build the relationship to underpin their support with women's self-care, Diana and Hilary also recognised that they shared more about themselves as they got to know people over the years. In one observation I watched as Diana worked with a woman. Diana wove the conversation around aspects of social talk, but also gathered quite specific information about how much exercise the woman had been taking and how this had affected her arm. Later Diana talked of setting up an atmosphere where

she would have an open and honest discussion with the person as the basis for exploring aspects of self-care:

'They come back for a review when you have an open discussion; patients will tell you that they don't find it helpful, that they don't like wearing their sleeve, that they don't always wear their sleeve. So you get it from the patients themselves as you build up your relationship or ask them questions' (Diana, Practitioner Interview 7, p.2/3).

The point here is that the process of support took place in a relaxed and open environment where the women felt able to share their feelings honestly. Given the dynamic nature of lymphoedema, the alternative, a prescriptive model focussed on compliance, may have little benefit to either woman or practitioner. The evidence from the interpretations was that these practitioners did not subscribe to a compliance model of practice.

In summary, practitioners emphasised the importance of establishing an effective relationship with women as a basis for long term support with self-care. However, in Chapter Five, I described how several of the women who had newly developed lymphoedema had been unable to arrange a follow up appointment, suggesting that the notion of relationship may be tenuous in some instances. I noted that while two of the women were particularly anxious at their first appointment, the reality was that they had not had any further contact with the practitioner over the subsequent six months. Significantly, many of the women I observed at the clinic had relatively mild lymphoedema, and may have been identified by practitioners as requiring minimal help, although this is something I did not explore with the practitioners. Given the various demands of their work, and the fact that some practitioners worked in isolated roles, which were not filled when they were off sick, it was perhaps inevitable that practitioners could not always provide regular appointments for women. Indeed, it cannot be assumed this is what women wanted or required. However, significantly, the accounts of the women who attended the small group discussion indicated that they valued yearly meetings with the practitioner, or telephone calls for advice. This suggested that these approaches to maintaining contact with women and

providing support may be of particular relevance, and may represent less resource-intensive options for practitioners, and perhaps, the women.

6.6 Bringing in the body

In this final section, I focus on how practitioners worked with the body, and the discourses of the body that were evident in the field observations and in the practitioner accounts. In the small group discussions, and also very early on in the observations, I became acutely aware of the various ways that practitioners touched and used 'the body' in general, and specifically the women's swollen arm, as they worked. For the practitioners, 'the body' was part of the routine, taken-for-granted work. However, I noticed illuminating differences in the ways that touch and language was used in relation to the body.

6.6.1 Measuring and examining

In the observations I noticed that the practitioners took slightly different approaches to the same skill of measuring the arm. Some undertook the limb volume measurements in a deft, routine, and quite business-like way, taking hold of the arm, marking dots at intervals up the arm with a pen, and using the tape measure to take the series of circumferential measurements, often with minimal explanation. Several times, the dots were not wiped off and in one instance, a practitioner handed a wet wipe to a woman to wipe off the dots without explanation; the woman clearly did not understand what she was to do, shrugged, and threw the wipe in the bin.

While a particularly new practitioner appeared less familiar with and quite slow in her measuring technique, other more experienced practitioners also used deliberately methodical movements, combining the measurement with purposeful conversations. During the process of measuring, practitioners often gained quite important information from women. I recorded in my field notes:

'When it came time to examine the woman, and measure her arm the practitioner explained the procedure very clearly to her. She positioned

herself on a stool next to the woman, at equal height, so she had eye contact with her. She took her time, marking the woman's arm and then gradually measuring each circumference. During that time the conversation flowed, and seemed quite casual but I noticed that some very relevant information had been exchanged including how the woman felt about her arm, and her worries about returning to work. The practitioner appeared to use the task of measuring (and the opportunity for touch) in quite an enabling way that combined the physical and the emotional' (Field notes 14, p.8).

This excerpt indicated how an apparently routine task that involved touch could be beneficially integrated in the appointment. I noted that while the woman and practitioner were in close proximity while the measurements were undertaken, as the practitioner moved away to calculate the actual limb volume on a calculator or their computer, this had the effect of interrupting the flow of conversation. Celia talked at one interview of favouring the conversation for her attention and leaving the calculations to be done once the woman had left the room. Practitioners also had their own methods for examining or 'palpating' the swollen arm. In two instances (a nurse and a physiotherapist), I noted this being done in a particularly gentle way by stroking the skin. More commonly, practitioners squeezed the arm or applied pressure to different parts of the arm, as such the 'pitting test'. In examining the upper body, physiotherapists were more likely to make a 'hands-off' observation of the body, from a slight distance. In one instance, Eileen made various comments such as, '*very interesting*' and '*that's a mystery to me*' as she examined. This might suggest to the woman that Eileen was taking her condition seriously, but on the other hand, may have alarmed the woman. In contrast, Gilean, also a physiotherapist, used very reassuring noises while examining, and I reflected on the possible implications of the subtleties of practice that practitioners portrayed as they work.

Where I showed in the previous chapter that women in the small groups were generally positive about having their arm measured, and talked of wanting to know the details of their limb volume, the practitioners that I observed did not always share specific details of limb volume with the women, as I indicated earlier. I did not explore these apparent discrepancies at all, nor what the

women inferred from the emphasis on examining them and measuring their arm, although this approach appears to reflect a rather medical model that may minimise the importance of the subjective experiences of the women themselves.

6.6.2 Discourses

As I showed in the previous chapter, women may come to the appointments with particular anxieties. I became aware that, as in the last category, the use of particular language by the practitioner may have the potential to reassure, defuse or worsen the anxiety. I heard several women in the appointments use various descriptive words: for example, one woman talked of feeling that her armpit might ‘*snap*’ if she stretched, another that it felt ‘*corded*’ in her armpit. I also noted that practitioners used various metaphors or symbolism as they talked to women. For example, during the observations I heard various words used to describe lymphoedema, for example, ‘*blockage*’. Women’s arms were referred to as ‘*thicker and doughy*’ or ‘*full*’. I also heard a practitioner talk on one occasion of possible ‘*nerve damage*’ that appeared to surprise and alarm the woman. Several practitioners such as Fran and Diana also used particular analogies; for example the notion of ‘*lasagne*’ to explain the layers of skin, or the idea of a ‘*fragile buttercup*’ being full of water to illustrate the need for gentle touch with self-massage. This suggested that attention should be given to the discourses used in supported self-care as having particular symbolism for women or practitioners.

6.6.3 Bodywork

The final aspect of this theme concerned the use of bodywork as part of the treatment for lymphoedema. Notably, three practitioners talked of manual lymph drainage (MLD) a type of massage as a way to relax someone. In one example Belinda considered:

‘If she had been extremely up tight and really needing some sort of down time I would have brought her in for MLD and not because of the swelling

in her arm but just to give her time to relax, and as reassurance' (Belinda, Practitioner Interview 2, p.3).

Diana also reflected on how she had booked a woman into the clinic for six sessions of MLD and we discussed this decision:

Diana: 'Psychologically to try and help her come to terms with it, sometimes you need time like that on a one-to-one'

Researcher: 'Do you feel those six appointments will be helpful in developing your supportive role with her?'

Diana: 'I think with the hands on, we're streets ahead of any other practitioners because we've got that with the MLD' (Diana, Practitioner Interview 15, p.3).

This suggested that Diana recognised a specific role for MLD in perhaps giving her an opportunity to build the relationship with and support the woman through close contact and touch. She felt it might also enable women with lymphoedema to gain confidence in their changed body, and perhaps begin to reconcile the changes in their body image resulting from breast cancer and/or lymphoedema:

'Some ladies straight away accept the change in their body, accept that you give them a sleeve, and whatever comes their way. Others seem to block it all out...so when I am examining them or using MLD I am quite relaxed about how they are, and I accept whatever I see in front of me, and I think that in itself is reassuring for them; they see that I am not shocked about their body, and I gently introduce my touch' (Diana, Practitioner Interview 15, p.4).

However, where Diana talked of using touch to enable people to relax and open up to her, she recognised how this affected her:

'When I'm massaging them every day they speak about their feelings, and it's a two-way conversation. I mean some days we laugh and we joke...and the other thing is that you're a bit isolated in this room and I think people may open up more because of the privacy, and you're touching them, you're relaxing them, you're getting to know them so some days you carry quite a lot of psychological [breathes in slowly]...well initially I felt quite exhausted, actually, but I know now when to switch off, I listen and just switch off, because you can't carry it all' (Diana, Practitioner Interview 8, p.5/6).

This excerpt emphasised the potential intensity of the practitioner's work and her need to find ways to deal with, rather than absorb, women's distress, particularly if using types of bodywork. In contrast, Eileen suggested that using MLD massage in this way had the potential to create dependency on a therapist-based treatment, and so did not reflect a self-management approach. Clearly there may be very different ideologies that underpinned these views. Indeed, the relevance of certain bodywork activities as part of supported self-care may be up for debate. It is perhaps also significant, however, that I saw very few instances of practitioners teaching the self-massage to women in a way in which they touched the body, or enabled women to touch themselves, for example, on their chest. This may be partly due to practitioners protecting women during my presence at the appointment, or could suggest that integrating support that enables women to undertake their own bodywork may be complex, and require specific skills. As I showed in the previous chapter, most women who were interested in learning self-massage followed written massage instructions, but they remained fairly unclear about the method of self-massage.

In summary, bodywork was used by several of the practitioners and appeared to represent a type of embodied practice that provided comfort, reduced symptoms, and encouraged a woman to feel comfortable about her body after breast cancer treatment. While treatments such as MLD may provide women with time for discussion with the lymphoedema practitioner, they may also enable some degree of recovery of self-image after breast cancer. However, MLD is a therapist delivered treatment that may not fit with the ethos of self-care approaches. Given that women could experience significant anxiety from the physical changes related to lymphoedema and breast cancer, as shown in the previous chapter, enabling women to undertake aspects of self-bodywork, with appropriate teaching and support, may be an important part of self-care for some women.

6.6.4 Summary

This theme provided insights into how practitioners and women worked with and talked about the body. It suggested that touch and discourses relating to the body may be more or less supportive or enabling. However, evidence in the previous chapter suggested that women found it difficult to access appropriate advice about self-massage, exercise and MLD, all types of bodywork. This may indicate that alternative ways may be required to support women with these aspects of self-care.

6.7 Chapter summary

The series of themes from the observations and practitioner accounts indicated that practitioners worked in mainly clinical environments and were often quite isolated in their work, spread out over various centres where they did not all actively work in teams. Professional practice appeared framed by various social structures and sources of knowledge that appeared to be constraining, and even oppressive, at times. Education and professional frameworks were biomedical in nature and favoured a rather technical, practical model of care rather than life-centred approaches. Furthermore, these specialist knowledge frameworks did not reflect fully the realities of practice and appeared to have potential to propagate myths, for women and practitioners, that lymphoedema could be readily controlled with treatment. Practitioners developed their own ways of working, based on experiential knowledge, although this was likely to be undertaken in a fairly individual way, given the relative isolation of practitioners in their clinics. Despite this, the strategies used by some of the more experienced practitioners indicated various enabling and anticipatory approaches to supporting women with self-care. These approaches appeared to illustrate the potentially therapeutic nature of their work.

Practitioners recognised the importance of building relationships with women over the longer term to enable open and honest discussions, used to help shape women's knowledge about self-care. Some approaches to assessment could

be formulaic and viewed as less practical than women may have wished, given the evidence in the previous chapter. However, as I also showed in the previous chapter, women who had lived with lymphoedema for longer periods appeared socialised into this structure for follow up, and found it useful.

Certain types of bodywork were viewed by some practitioners as a possible vehicle through which psychological adjustment and assimilation of body changes might be enabled. However, practitioners were essentially gatekeepers, influencing women's access to various aspects of support. Not all of them viewed treatments such as MLD as within the remit of support. This suggested that practitioners had different perceptions of what constituted support, perhaps relating to different ideologies for practice, or varied professional backgrounds, and different levels of access to resources. These factors may lead to inequalities in care, and present barriers to women's ability to access services or to make informed choices about self-care.

The 'specialist' role represented the potential for a power differential within the relationship between women and practitioner, although practitioners could be ambivalent about this title. Self-care ideology may provide challenges for practitioners who need to reconcile their role as specialist with the implications for sharing their 'expertise' with women who undertake self-care. Developing the capacity for their own reflective practice, together with acquiring professional wisdom derived from experience, and enabling women to develop similar reflexive skills within a supportive, accessible relationship, are likely to be significant aspects of supported self-care.

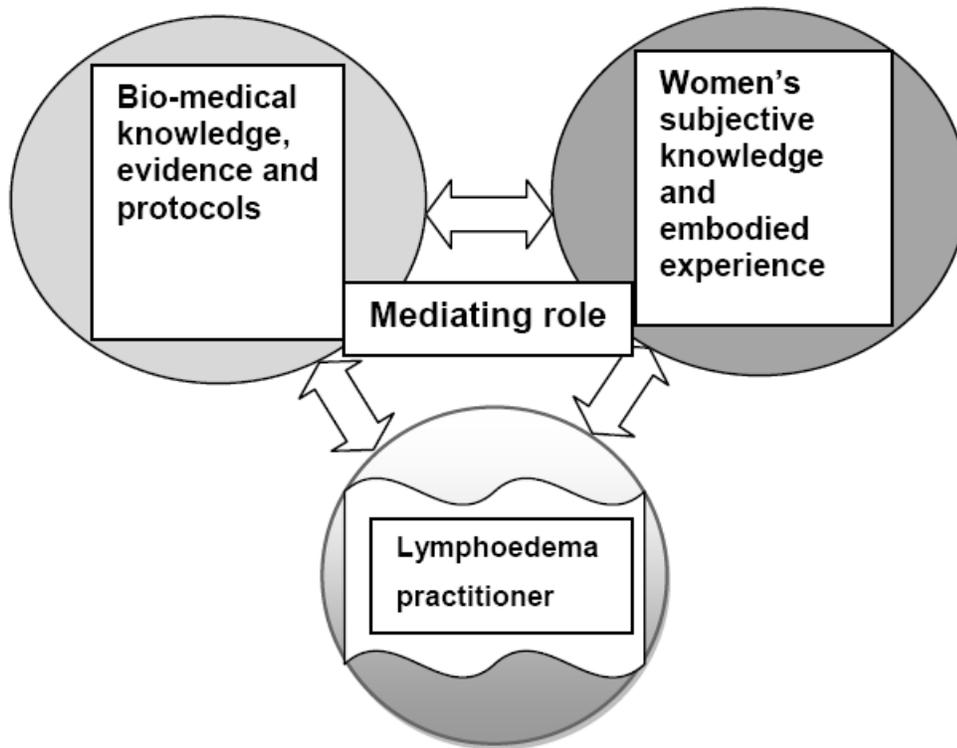
Chapter Seven: Discussion

7.1 Introduction

In Chapter Five I presented my first-level interpretations from the accounts of the women with lymphoedema. In Chapter Six I presented my interpretations from the accounts of the lymphoedema practitioners who took part in the research, supplemented by my own field observations. In this current chapter I provide a synthesis of these interpretations in relation to relevant theoretical and empirical literature. I firstly return to the theory of relational autonomy, previously discussed in Chapter Three as relevant to the feminist-informed approach to the thesis. I identify the main factors that appeared to influence autonomous agency in the women and lymphoedema practitioners who took part in the study. I then discuss key aspects of the interpretations in Chapter Five and Six in relation to the literature. I develop a number of arguments that are relevant to a proposed anticipatory approach to supported self-care. I finish by identifying particular limitations and strengths of the research process, reflecting on my work as a researcher.

The thesis argues for an anticipatory approach to supported self-care, recognising that the concepts of reflexivity and self-discovery are equally relevant to the women with lymphoedema and the lymphoedema practitioners. Women with lymphoedema are viewed as having potential to anticipate and respond within their dynamic and embodied experience of lymphoedema and self-care. Practitioners are placed in an enabling role, situated between the positivist stance of biomedical knowledge and evidence, and the woman's subjective knowledge and embodied experience of lymphoedema (see Figure 7.1). Thus, the practitioner provides support as a type of interpreter or 'mediator' who has responsibility to women to *'interpose between parties as a friend of each'* (Chambers 2006, p.928). This provides a particular perspective on the concept of changing roles for those with a long term condition and for health professionals, identified in Chapter One as relevant to health policy.

Figure 7.1: A mediating role for the lymphoedema practitioner



I suggest that the perspective proposed here is one in which the 'partnership' of the woman with lymphoedema and the lymphoedema practitioner is a source for the creation of new knowledge for self-care. It also recognises that both come to this 'partnership' with their own knowledge and potential for developing wisdom relevant to supported self-care. I propose that creating opportunity for self-discovery and reflexive activity, in both women with lymphoedema associated with breast cancer and lymphoedema practitioners, fosters opportunity for autonomous agency as a central feature of anticipatory approaches to supported self-care. However, this also draws attention to the wider structures of power that influence the scope for autonomous agency in women with lymphoedema and lymphoedema practitioners. I will therefore show at the end of this chapter that while I believe I have met the research aims, further work is required. I will argue that the research findings did illuminate elements of the nature of supported self-care as it related to women

with lymphoedema. As such, the findings do address the research aims set out in Section 3.5 of the thesis. However, the evidence pointed to there being a need to build on current practice, and move away from traditional and apparently narrow ways of working with women who have lymphoedema associated with breast cancer treatment.

7.2 The relevance of a relational view of autonomy

As I indicated in Section 3.3 of the thesis, taking a feminist-informed approach to the research brought to me an awareness of relational autonomy as an alternative to the more individualistic view of autonomy that predominates in biomedical ethics and healthcare. This alternative is a view of autonomy as dynamic and contextual, involving a socially embedded and embodied self (Mackenzie & Stoljar 2000). Individuals are viewed as interdependent and having the ability to foster or inhibit each other's capacity for autonomous action (Sherwin 1998). Equally, relational autonomy draws attention to the oppressive socialisation practices, and structures of power that can influence the scope for autonomous agency.

Feminist philosopher Diana Meyers argued that personal autonomy may be best understood in relation to '*autonomy competency- the repertory of co-ordinated skills that makes self-discovery, self-definition, and self-direction possible*' (Meyers 1989, p.76). The point here is that this type of autonomy may be enhanced as a result of social relationships (Agich 1993) and reflective processes. Also, it is precisely when obstacles or challenging events are encountered, and not despite them, that an autonomous agent can be enabled to project a course of action into the future (Agich 1993). I believe that this relational view of autonomy supports my argument for encouraging reflexive activities in both a woman with lymphoedema and a lymphoedema practitioner.

As I showed in Section 3.3, it has been argued that health professionals drawing on this view of autonomy must be skilled communicators and have the ability to

reflect on their own practice (Moser, Houtepen & Widdershoven 2007). This notion of reflection is already a widely recognised concept within professional practice (Schon 1983). It is also central to the thinking of John Dewey who argued, as I showed in Section 3.4, that reflection is key to developing '*wisdom*' and '*powers*' towards '*the better living of life*' (Dewey 1933, p.63). Thus, I believe it is equally relevant to women with lymphoedema who undertake self-care, and to professional practitioners.

It will be clear from the interpretations in Chapter Five, that the women who took part in the research were socially embedded and embodied individuals, undertaking self-care within a social world in which they had various roles such as mother, partner, carer, and employee. However, I also showed in Chapter Five that different factors appeared to have an oppressive influence on the women such as: their physical symptoms and the lack of constancy of the body; the women's existential fears of cancer recurrence; their frustrations with the poor outcome and choices relating to treatments and self-care; their lack of access to trusted information; and that the medical world of breast cancer care often failed to appreciate or fully address the women's anxieties. Likewise, in Chapter Six, the interpretations showed that the lymphoedema practitioners were socialised within their various practice settings in which they were influenced by organisational and educational structures of power, and technical and biomedical frameworks for practice. Importantly, most of the practitioners sought to overcome some of these by developing, often in a rather isolated way, reflexive practice wisdom.

I now consider key aspects from the interpretations in Chapter Five and Six, in each case, discussing these in relation to relevant literature.

7.3 Approaches to self-care

In Section 2.4.6 I indicated that self-care may be an evolving process, with approaches being formed and reconstructed throughout life (Berman & Iris

1998), often in response to illness (Chapple & Rogers 2001). I also considered in Section 1.5 that different ideologies may underpin views of self-care as, for example, the adherence to professional instructions, or the independence to shape one's own life. In Section 2.4 I showed that self-care may be constructed in various ways: as dynamic; as associated with issues of control (Kidd *et al.* 2009; Kralik *et al.* 2004); as influenced by social variables (Anderson, Dyck & Lynam 1997); or supported by the professional: person relationship (Rees & Williams 2009).

In Chapter One I considered that self-care in lymphoedema was often broadly described in relation to specific activities, drawn from the professional practice model of lymphoedema treatment. I also identified evidence that activities such as wearing a sleeve could be particularly challenging for individuals with lymphoedema (Lam *et al.* 2006). In Section 2.4.11 I discussed the limited literature relating to lymphoedema self-care and support. Research evidence suggested that women with lymphoedema made decisions to avoid activities that made their lymphoedema worse, and continued with those that were easier to maintain (Fu 2005). Motivation for self-care could be associated with an intention to minimise the threat of uncontrolled lymphoedema (Fu 2005).

The evidence from the current study interpretations, particularly in Section 5.3, suggested that self-care for the women who took part in the research evolved over time. The dynamic nature of self-care appeared to reflect the changeable nature of lymphoedema itself, which was often unpredictable, such as for Heather and Nina, as shown in Section 5.2.1. Self-care activities were also influenced by the women's changing social context. Women such as Betty, in Section 5.3.2, made self-care decisions based on activities in their own lives. As they became more 'experienced' in living with lymphoedema, they grew more confident in their self-care abilities to respond to situations. They also recognised the likely consequences of taking various decisions such as going without a sleeve. However, rather than avoiding consequences, as Fu (2005) identified, the women in this current study often prioritised their social roles and

then dealt with the consequences later. This was similar to the findings in another Scottish-based study, where individuals with long term conditions placed meeting the obligations of their social roles and related responsibilities above their own self-care needs (Townsend, Wyke & Hunt 2006).

In this current study, the physical and social restraints associated with living with lymphoedema were powerfully obvious, as I showed in Sections 5.3.2 and 5.4.1. The physical nature of the condition, as I explore in more depth in Section 7.5.1, could be oppressive, restricting the women's scope for autonomous agency. Self-care treatments or activities, such as wearing a sleeve, could themselves be constraining and limiting, impacting on women's self-identity; I further explore this in Section 7.5.3. Similar to the individuals surveyed in the study by Lam *et al.* (2006), many women in this current study were ambivalent about their sleeves, often recognising that this self-care option had a stigmatic element that they were forced to negotiate.

As I summarised in 5.3.5, women gave the impression of being self-directed, seeking information and undertaking various self-initiated activities, such as carrying a first aid kit, finding ways to position their arm, or deciding to do self-massage. However, the field observations suggested that lymphoedema practitioners did not always appear to acknowledge the resourcefulness of the women who came to appointments with specific skills and knowledge that were left unidentified or unexplored. This suggests the rather biomedical frameworks on which professional practice was based may have hindered practitioners in identifying the more subjective and personal aspects of self-care undertaken by the women. Alternatively, it is possible that the practitioners did recognise these, as reflected in their decisions to not provide a follow up appointment for women such as Joanne, who may have appeared to the practitioner to be effectively 'managing' her symptoms.

Women could be influenced or motivated by seeing others with worsening swelling as a result of not wearing a sleeve, as Betty and Nina described in

Section 5.2.1. I found evidence that visiting the lymphoedema practitioner and having the opportunity to have her arm measured, and reassess her own progress, could be potentially motivating, as for Betty and Elaine. Thorne, Ternulf Nylin and Paterson (2000) suggested that clinicians should guard against being judgemental about individual self-care attempts. In this current study, practitioners did not appear to make judgements about women's self-care. As Eileen and Diana noted in Section 6.4, practitioners expected women would make their own choices. However, the women certainly appeared to judge themselves. Indeed, in Section 5.3.2 I identified a theme which reflected specific terminology such as 'good' and 'bad', used by women with lymphoedema to describe their own behaviour. This seems to reflect other research reports that individuals who undertook self-care for their long term condition may feel a sense of moral obligation to control their symptoms 'well' (Townsend, Wyke & Hunt 2006, p.192). Interestingly, there is little empirical evidence to inform the relationship between 'good behaviour' such as adherence to wearing a sleeve for example, and a 'good' outcome in relation to lymphoedema being controlled. It is possible that by being active in their self-care, women felt they were doing everything in their power to avoid any deterioration in their condition. However, it is clear that women enacted a form of self-surveillance, and self-judgement upon themselves and their 'behaviour'. The reflective processes that were undoubtedly part of this self-monitoring activity were not always readily recognised or articulated by the women, but inform our understanding of how individuals predicted and anticipated their needs over the longer term.

The research interpretations suggested that those women who had more recently developed lymphoedema, or had unstable lymphoedema, experienced particular physical symptoms that may have prompted self-care actions. I will discuss this in Section 7.5.1. At her final interview, Kate was able to reflect back on the earlier period when she was in a state of flux due to the uncertainty of her physical body changes. In Section 5.2.1, I considered that Kate's

changed approach to her predicament at the third interview may have been due to a physical reduction in swelling or that she felt more able to deal with the problem; as such, improved self-efficacy. Significantly, at the later time point, Kate felt she was no longer 'alarmed' by the situation. It appears that this change in Kate may have reflected her developing confidence, suggesting a perception of increased control over her condition, and an increasing ability to anticipate her self-care needs.

7.3.1 Choice and control

In Section 2.4.8 I identified research evidence indicating that individuals may seek to maintain control over their condition, rather have than it control them (Kralik *et al.* 2004; Thorne, Paterson & Russell 2003). In their study of self-care in people with colo-rectal cancer, Kidd *et al.* (2009) suggested that nurses might seek to support self-care by drawing on approaches that enhanced an individual's perception of control. However, post-modern feminist theory has questioned the masculine illusion of control that has sustained biomedical knowledge (Shildrick 1997). Paterson, Russell and Thorne (2001) also challenged assumptions in the literature that people who are actively involved in self-care can achieve and sustain symptom control, recognising the reality of the personal and social context of people's lives as often characterised by multiple and conflicting goals.

In this current study, the *in vivo* theme '*What can one do?*' appeared to capture the frustrations of women regarding their lymphoedema self-care. In Section 5.3.1 we saw that Irene felt her efforts to put up with the burdensome treatments and self-care aimed at controlling her lymphoedema had been in vain. In 5.2.1 Heather's comments indicated that, for her, the issue of choice was closely related to her difficulties in controlling her lymphoedema. In Section 6.4, Diana, a lymphoedema practitioner, indicated that she sought to put women in control, by alerting them to their capacity for anticipating problems and taking autonomous action should, for example, an infection occur.

There may be various reasons for women's frustrations and perceived lack of control, including the lack of physical improvement in their arm, the distress of being unable to find a cure for this iatrogenic problem of lymphoedema, or the stigmatic nature of treatments. As a researcher I realise, in reflection, that I did not always explore this in detail with my research participants. However, as I showed in Section 5.3.1, the disappointment associated with treatments and self-care in women who were newly learning about lymphoedema, and also for those such as Fiona who had experienced nearly 20 years of life with lymphoedema, were very evident in the women's accounts.

Evidence from the category '*Expectations and disappointments*' suggested that a woman who was referred to a 'specialist' may have expected to receive specific information and advice that enabled her to control the physical changes in her body. However, in Chapter Six we saw that practitioners such as Celia could find it difficult to reconcile some elements of the 'specialist' role, given the limited power she had to improve a woman's lymphoedema. In this current study there was also evidence that professional treatments had limited sustainability in reducing women's arm size, as Irene and Fiona commented in Section 5.3.1. This indicates that control may be a significant feature to be negotiated by women and practitioners within the supported self-care context. Furthermore, controlling swelling and 'feeling in control' are almost certainly two very different concepts.

Thorne, Paterson and Russell (2003) suggested that 'being in control' was characterised by a shift in perception where individuals developed a belief that they could mediate the effects of their illness condition. Johnston and Smith (2006), in their study of nurses' and dying patients' perceptions of expert palliative care, suggested that being in control may be associated with an individual having a '*fighting spirit*' (p.705). Kidd *et al.* (2009) identified individuals who were '*high-perceived controllers*' (p.2295). These were identified as individuals who felt they could control the side effects of their chemotherapy, and were reported by the researchers as proactively using self-

care strategies (Kidd *et al.* 2009). Kidd *et al.* (2009) considered that nurses might enhance individuals' perceptions of control by undertaking individualised assessment and involving people in self-care activities.

Similar to Kidd *et al.* (2009), the findings from my own study indicate the importance of exploring with individuals who have lymphoedema their perceptions of control. Furthermore, it would seem desirable to avoid pursuing an ideology for lymphoedema treatment and care that prioritises control, for example in the form of reduced arm swelling, as something readily achieved. Certainly, I did observe practitioners such as Gilean (in Section 6.4) being open about the chronic nature of the condition with women at their first appointment. This is an important point for practitioners to consider, as to how they broach the subject of lymphoedema chronicity with women who may still be having active treatment for breast cancer, a disease from which they hope to fully recover and leave behind. It appeared from the findings in Chapter Six that professional educational frameworks had further emphasised the 'myths' of control, and not fully prepared practitioners for this type of negotiation with women. The research evidence suggests that developing skills in listening to the individual narratives of women, and asking salient questions, may provide practitioners with insight into women's perceptions of control, as part of a process of enabling self-discovery and reflection.

7.3.2 Self-care discourses

Foucault (1989) argued that discourses shape the way people think about the body, they can reflect the power of the 'medical gaze' on the body, and influence how the body is viewed in relation to the disciplinary power of medicine (Armstrong 1994). In her discussion on the myth of empowerment, Paterson (2001) argued that health professionals could be compassionate with 'patients' but often betrayed an allegiance to professional dominance by using professional jargon, and discounting the experiential knowledge of individuals. In section 2.5.5 I referred to Rudge (1997) who argued that the discourses used

by nurses in caring for people with severe wounds may draw 'patients' into a medical frame of reference. In Section 6.6.2 I talked of the language used within the appointments I observed in this current study.

It is my contention that professionals must consider the language used in relation to lymphoedema self-care; in particular, how language may enable women to comprehend and internalise positive (or negative) notions of self-care. The term 'self-management', commonly used in professional literature (NCAT 2009; Todd, Harding & Green 2010), appears to have a metaphorical, and given the evidence above, a rather mythical association with regulation and control. Similarly, I suggested earlier in the thesis that the term 'maintenance therapy' may conjure up visions of the mechanical body likened to a car. There are several other examples of the language of self-care in lymphoedema that are symbolically interesting. The term 'simple lymphatic drainage' is often used to define the specific type of self-massage used in lymphoedema (British Lymphology Society 2001), linking this self-care activity to the professional concept of 'manual lymphatic drainage', while also appearing to suggest 'simplicity'. From the evidence in this current study, it could appear to women such as Nina that learning this technique and gaining access to unambiguous information about self-massage, as shown in Section 5.3.2, was far from simple. Indeed, it may not feel like a simple matter to women such as Heather in 5.2.2, who struggled to reconcile her mastectomy scar, and to touch an area of her body that felt alien and tender. I would contend, therefore, that language can promote an ideology that locates self-care in the realm of the professional, when it should belong to the person; thus it may distance individuals, inhibiting opportunity for autonomous agency. This indicates that practitioners should consider how, despite believing themselves to be driven by ideals of empowerment, they may continue to exert professional power through using language that emphasises a biomedical, and potentially hierarchical, model of self-care.

7.3.3 Summary

To summarise, in relation to the proposed anticipatory approach to supported self-care, the findings suggest that women were self-directed, undertaking self-care and monitoring their body. They indicate that women could be supported to develop their capacity to anticipate changes and respond to these, often to counteract the effect of previous self-care and lifestyle choices. It is likely that exploring the nature of their 'illness trajectory' with individual women may be useful in exploring issues of control.

Self-care appears to be much more than learning new skills to care for the physical body. It is also how a woman adapts to the emotional and psychosocial aspects of living with a condition that is a result of medical treatment, potentially marking her out with a new identity, as I will explore in Section 7.5.3. An anticipatory approach provides potential to recognise the unique social contexts in which women undertake self-care. It would appear that an ideology for self-care relating to lymphoedema associated with breast cancer must view a woman as having the independence to shape her own life, as articulated by some of the practitioners in this study, rather than prioritise adherence to professional instruction.

7.4 Approaches to support

The literature review in Section 2.4.3 of the thesis showed that supported self-care could incorporate a variety of approaches and views, but was underpinned by limited evidence, particularly for individuals whose conditions were not readily managed and evaluated within a medical framework. Support could be seen in the context of the individual, one-to-one relationship between the person with a long term condition and a health professional. It might also take different forms such as group support (Kennedy *et al.* 2007), on-line support (Lorig *et al.* 2008), and broader models of community-based support (Vassilev *et al.* 2010). Anderson, Dyck and Lynam (1997) considered that professionals providing support must recognise the social restraints that impact on individuals and their

ability to access support structures. In a study of women with lymphoedema associated with breast cancer, Armer, Brooks and Stewart (2011) suggested that support for self-care may be a more complex matter than merely giving information, but required attention to aspects of a person's social context. These authors suggested that professionals might also draw on behavioural change approaches, such as motivational interviewing, on an individual basis, to enable women to explore their 'ambivalence' about self-care (Armer, Brooks & Stewart 2011).

Thorne and Paterson (2001) considered that health professionals might use their awareness of an illness trajectory, as I discussed in the previous section, to help people move from the more passive processes characteristic of the earlier phases of a chronic condition, encouraging individuals towards '*strategic experimentation*' (p.88). This approach is likely to engage individuals with long term conditions in exploratory strategies, akin to the reflective processes used by professional practitioners in Section 6.3.4 to develop practice wisdom.

7.4.1 Access to information and support for women

In this current study, support with self-care provided by the practitioners was observed as predominantly of a one-to-one, individual nature, occurring mainly within clinic appointments. The use of action plans was not evident, although some lymphoedema practitioners did provide women with written advice, often in the form of printed booklets. A key point from the interpretations, as discussed in Sections 5.2.3 and 5.3.3, was the women's apparent difficulty in accessing information about lymphoedema and self-care. This included a lack of access to health professionals who had expert knowledge about lymphoedema, at the early stages of the condition. The interpretations in Chapter Five indicated that some women who attended lymphoedema practitioner clinics had sought, but did not necessarily find, other options for obtaining trusted and local information, advice and support. This lack of access to information is echoed in several other studies of individuals with

lymphoedema (Hare 2000; Johansson *et al.* 2003; Thomas-Maclean, Miedema & Tatemichi 2005).

The current study findings indicate that some women looked for support from a much wider context than the lymphoedema clinics alone. There were also key points when women sought information and support from a lymphoedema practitioner; for example, when a crisis such as an infection arose, or specifically when they first developed lymphoedema. Significantly, women did not always appear to have easy access to the lymphoedema practitioners themselves, even after their initial appointments. In a Scottish study of 31 individuals with respiratory conditions, Kielmann *et al.* (2010) found that individuals wished for flexible access to trusted healthcare professionals. However, the research report of them feeling 'abandoned' by the professional services to undertake their own self-care responsibilities resonated with the accounts of women in my own study (Kielmann *et al.* 2010). Similar conclusions may be drawn from this current study regarding the need for flexible systems to improve access for women with lymphoedema between their own self-care and professional care. This may be particularly important in an anticipatory approach to supported self-care, and in the context of a dynamic and unpredictable condition such as lymphoedema.

It is also possible that some women in this current study may have wished not to attend a clinic in a hospital setting, for example, as indicated by Betty and Audrey in Section 5.3.2. Furthermore, the experience of Joanne may be relevant; on attending the lymphoedema clinic Joanne mentioned she had a painful arm and then found herself being examined by a doctor, on the request of the lymphoedema practitioner. The doctor ordered a bone scan, which Joanne later cancelled, arguing it was unnecessary and irrelevant to her situation. This appeared to be an example of Joanne exerting autonomous agency, and challenging the medicalised context of her self-care support. Furthermore, it is also possible that this scenario created various barriers for

Joanne who, as I identified in 5.3.1, appeared to be unsure about when she might next see the lymphoedema practitioner, but also rather ambivalent about making the contact herself. This situation also highlighted how providing support for women with lymphoedema also interfaces with the complex issue of cancer recurrence and the challenges of identifying disease progression.

The findings indicate a need for exploring the scope of inter-disciplinary working, identifying ways in which the work of lymphoedema practitioners might interface with other forms of support within the wider setting. For some women, the support from a clinic could be tenuous, for example, where a lone practitioner was not replaced during staff sick leave. Equally, specific approaches may provide women with local and less clinical types of support. For example, Petra was very positive about her experience of the collaborative partnership between health and leisure services, when she was referred by her doctor to a trained exercise therapist at her local 'gym'.

7.4.2 Emotional support

There is overwhelming research evidence, as I showed in Sections 1.3.3 and 2.5.3, that women with breast cancer, and with lymphoedema, are likely to experience emotional and psychological challenges. However, Kennedy *et al.* (2011) reported in their study of anticipatory care that professional disease-orientated advice for people with long term conditions may take precedence over emotional support, particularly in the context of time-limited healthcare clinics. The data interpretations for this current study suggested varied views of practitioners as to their role in providing emotional support, but indicated that addressing women's anxieties may be a necessary precursor to effective self-care. I also considered in Section 6.5 that working with many individuals who are distressed, in a relatively isolated setting, may exert a significant emotional burden on lymphoedema practitioners themselves, although it is outside the scope of this thesis to examine this important consideration in detail.

Several practitioners referred women to the Maggie's Centre for emotional support. However, as I indicated in Section 4.6.1, women could consider that this setting was not necessarily appropriate for someone with a long term condition. Equally, dissatisfaction with the outcomes of the relatively narrow opportunities for support available through clinics meant that women looked for other options, as I indicated in Section 5.3.4. Approaches such as complementary therapies may be particularly relevant in enabling women to manage symptoms and adjust in an emotional sense to living with lymphoedema. However, the evidence from my interpretations indicated that women's attempts to take autonomous action relating to these options, for example seeking trusted information about complementary therapies, could be thwarted. Other studies have indicated how self-care may take various forms that are complementary to biomedical approaches (Ryan, Wilson, Taylor *et al.* 2009). The current study findings suggest there is a need to improve access to information and support for women, particularly where this enables them to deal with the emotional aspects of their lymphoedema experience and develop their capacity for effective self-care.

7.4.3 Group support

McCorkle *et al.* (2011) suggested that the late effects of cancer and cancer treatment move cancer into a similar paradigm as other chronic conditions, in which self-management approaches such as group support may be relevant. The potential content of group support programmes for people with long term conditions was described in Section 2.4.3. As yet, there has been no robust evaluation of the relevance and effectiveness of group support for individuals with lymphoedema. Current examples of group-based exercise approaches, such as the Lebed programme, developed for individuals with lymphoedema (Sandel *et al.* 2005), also require further evaluation.

A few women in the study, such as Betty and Nina, did attend either the discussion support groups at Maggie's Centres, or Tai Chi classes. However,

there was some ambivalence about group support amongst the women who took part in the study, as I indicated in Section 5.3.3. Audrey noted that attending a group prepared her to deal with an infection when it arose in her arm. Joanne, in Section 5.3.3, had been upset by hearing other's stories in a group. Several of the women, such as Heather, Petra and Linda, were keen to attend an active group, where support with self-care such as exercise might be provided in a trustworthy setting.

In Section 2.4.11 I showed that there is some evidence, albeit limited, that exercise may be beneficial for women after breast cancer treatment (Mutrie *et al.* 2007). Exercise is now gaining prominence as a feature of self-care for those with lymphoedema, as I showed in Section 2.4.11. This suggests that the interest of the women in this current study in accessing opportunities for appropriate exercise should be taken seriously, and evidence sought to inform any future developments. Developing a group structure for support would have various implications, and could fit within an anticipatory approach to supported self-care. The findings from this current study may be useful in developing such a programme. It is suggested that the course content for individuals who have had cancer might need to be flexible (Wilson 2008). Any development and evaluation of a group programme for women with lymphoedema associated with cancer, should consider not only the outcome, but also the process and nature of support such as exercise, and its meaning, relevance and accessibility in relation to women's lives.

7.4.4 Summary

In summary, it has been suggested that individuals with long term conditions may have a particular need for support at specific times in the illness trajectory (LTCAS 2008). In Section 1.4 of the thesis I indicated that supported self-care may be defined as a collaborative process through which an individual with a long term condition is enabled to '*develop the knowledge, skills and confidence to care for themselves and their condition effectively*' (Department of Health

2005, p.6). The findings from this current study suggest that, while some degree of collaboration was evident between women with lymphoedema and lymphoedema practitioners, fairly limited options appeared to be currently available to support women with lymphoedema. This may reflect the relative newness of the speciality of lymphoedema care, and that it attracts limited interest and funding to establish the type of well-resourced services available, for example, to the larger numbers of people with chronic heart disease or respiratory conditions. An anticipatory approach to supported self-care should recognise a variety of ways in which individuals with lymphoedema might be supported with their self-care. An evidence base to inform any developments should be sought.

7.5 Women's experiences

In this section I explore three aspects of the women's experiences: their physical symptoms of lymphoedema; the notion of objectification of the body; and women's self-identity as a context for self-care. I consider their relevance to an anticipatory approach to supported self-care.

7.5.1 Women's experience of the physical 'symptoms' of lymphoedema

In Section 2.5.3 I indicated that the various side effects of breast cancer treatments such as surgery, radiotherapy or chemotherapy can be complex (Schmid-Büchi *et al.* 2008) and may exist alongside lymphoedema. Equally, I provided evidence in Section 1.3.2 of the various physical symptoms that may be experienced by women with lymphoedema, indicating that these could be oppressive in triggering fears of cancer recurrence (Fu & Rosedale 2009). Corbin (2003) described how specific symptoms and sensations could have significant meaning for individuals. Kelly and Field (1996) drew attention to the particular difficulties for individuals with chronic illness, due to their lack of control and the inconstancy of the embodied self.

In his personal account of male breast cancer, Horlick-Jones (2011) described his experience of the 'cacophony' of physical sensations that resulted from cancer treatment and provoked a fear of cancer recurrence, peaking around six months after his breast cancer treatment finished. Although his experience was not specifically about lymphoedema, he reflected on his '*fearful and obsessive state of being*' (Horlick-Jones 2011, p.12). As a social scientist himself, Horlick-Jones (2011) recognised salient points; that his fear of cancer recurrence was completely rational given the fact that his original disease spread in a life-threatening manner without pain, initiating a silent and apparently innocent beginning to his cancer trajectory. Horlick-Jones' (2011) description of a continued loss of order seems to reflect a lack of constancy of the body (Kelly & Field 1996). In the context of a life threatening condition such as breast cancer, this may be viewed as a threat to the person's ontological and existential security (Giddens 1991), having a potentially dis-empowering effect on individuals who seek to anticipate, predict and plan their actions and self-care activities.

Horlick-Jones (2011) considered the notion of 'everyday health competence' as relevant to how individuals might be expected to '*learn to read their bodily sensations in socially responsible ways*' (Horlick-Jones 2011, p.11). Interestingly, he also identified that many 'fellow patients' resisted acknowledging their anxieties about bodily sensations, or were reluctant to share them with health professionals, resulting in these insights not being readily accessible to researchers (Horlick-Jones 2011). However, it is my contention that my present study has illuminated these concerns, and that the observation of clinic appointments, in particular, provided the opportunity for me to document them as a researcher. Gathering narrative data from women at different 'stages' of their lymphoedema provided a specific dimension, revealing how the physical aspects of lymphoedema may lead women to reconstruct meaning relating to lymphoedema in different ways, as I will further explore in Section 7.5.3. Similar to Horlick-Jones (2011), the women in my own study

appeared to experience the lack of constancy of the body as distressing, and found it difficult to assess the salience of certain symptoms, particularly in the early stages of lymphoedema.

Women in the study appeared to have particular difficulty in differentiating the temporary side effects of cancer treatment from the potentially long term condition of lymphoedema. As I will show in Section 7.9, this could also be difficult for health professionals. The accounts in this current study indicated that interpreting physical symptoms was challenging, particularly as there was not one clear trajectory for lymphoedema. Some women had symptoms of swelling that subsequently disappeared. Others had symptoms that continued to be problematic or became worse, making it difficult for women to make realistic decisions about self-care, or to predict what was required. For Mary, the symptom of lymphoedema swelling was a 'clinical' sign of cancer recurrence. The women's accounts showed that symptoms often developed just at a time when they sought to leave breast cancer behind, provoking existential fears, particularly around the recurrence of cancer. These physical symptoms, developing in association with lymphoedema, and occurring at various points after breast cancer surgery alongside other side effects of treatments, appeared to represent an interface between the trajectories of acute breast cancer treatment and the chronic condition of lymphoedema. This potential overlap of trajectories, and the paradigms of acute and chronic healthcare, may be problematic, as I will further discuss in Section 7.9.

There are two important points to make. Firstly, women who had lived with lymphoedema for a longer period appeared more able to judge the salience of their symptoms, and to use and interpret cues from their changing physical body, to plan, predict and initiate self-care activities. A second point concerns an observation by Horlick-Jones (2011) that there is a need to establish a conceptual model to inform the approaches taken by health professionals in responding to and supporting people with existential concerns. It is my

contention that the view of the health professional as a mediator between the biomedical world and the subjective experiences of individuals after cancer treatment, and the development of reflexive anticipatory approaches to professional and self-care practice, may be one step towards developing a such a conceptual model.

7.5.2 The objectification of the body

Paterson *et al.* (1999) argued that a 'transformational' process of adjusting to self-care for a long term condition may involve individuals in differentiating the 'self' from the object body. Thus individuals with diabetes were perceived by the researchers as recognising their body as an object that could be controlled; as something with which they could feel confident about dealing (Paterson *et al.* 1999). In Section 2.6.2 I showed that certain theories may reflect a more or less objectified view of the body, and a potentially fractured nature of the relationship between the body and the self. Oakley (2007), in her personal narrative, argued that professionals may impose further objectification on individuals by taking a medical history in a certain way that invites people to view themselves as objects. I also previously recognised that the nursing literature has sought ways to better acknowledge and address the embodied existence of a person who is ill (Benner, Tanner & Chesla 1996; Lawler 1991).

Forbat, Hubbard and Kearney (2009), in a Scottish study of 66 individuals with cancer, described how some individuals appeared to externalise cancer, creating a boundary that separated 'self' from the 'disease', as an apparent means for making sense of their illness. In her longitudinal study of 16 people with a variety of chronic conditions, Charmaz (1995) identified that individuals may separate the illness from the self, seeking to allay disquieting feelings associated with physical symptoms. In Section 5.2.1 of this current study, Grace talked of 'the arm', appearing to refer to her lymphoedema as somewhat distanced and self-determining, perhaps unsurprisingly, given that she had

continued problems with swelling and was also soon to have surgical liposuction.

Where, in one sense, this reference to 'the arm', and other similar objectifying discourse, may reflect a type of distancing from the self, it may also represent a objectifying process that provides the basis for teaching a woman about her self-care, attuning her to salient changes in her body. This may be relevant to the way in which practitioners mediate between the symptoms of the women and the biomedical 'truths', and provide opportunity for reflection on changes relevant to self-care. Some degree of objectification may be pertinent to an anticipatory approach to supported self-care for someone with a physical condition such as lymphoedema, and may be a dynamic process (Paterson *et al.* 1999). Measuring and examining, as I showed in Section 6.6.1, was an integral part of all the appointments I observed, and to some extent it was imposed on women as a means for objective assessment of their condition. Significantly, several women who had lived with lymphoedema for many years appeared to value and expect this measuring process, as a way of judging the 'progress' of their arm. To some degree, these women may have been socialised into the appointment format; other women newer to lymphoedema may have been surprised or even alarmed at this focus on measuring their arm. I may have been so socialised into the appointment process myself as a clinician that I possibly did not always notice the women's reactions.

However, I did notice that different ways of examining and measuring by the practitioners could represent a more or less objectifying approach, as I showed in Section 6.6.1. As I indicated in Section 2.6.2 of the thesis, the anatomical and naturalistic body, the basis for the biomedical model underpinning much professional practice, may be in tension with the phenomenological approach that practitioners might draw on when working with someone who has a potentially threatened sense of self (Charmaz 1995; Lawler 1991). The findings suggest that, within an anticipatory approach to supported self-care, attention

should be given to how professionals examine and measure in ways that will alert a woman to salient information, enabling her to check out any concerns, while also re-establishing her embodied sense of 'self' and self-identity. Arguably, it is the post-modern view of the body, discussed in Section 2.6.2, that might underpin the reflexive and self-discovery processes that are integral to the proposed anticipatory approach to supported self-care.

7.5.3 Women's self-identity as a context for self-care

In Section 2.5.4 I discussed how empirical research and personal accounts provided evidence that chronic illness may threaten the integrity of the body and self, challenging self-identity (Charmaz 1995). Drawing on social constructionist theory, Charmaz (1995) identified how individuals reframed their experiences of illness in relation to reconstructing their self-identity. In their study of individuals with cancer, Forbat, Hubbard and Kearney (2009) drew attention to the sense of identity as being, for some people, closely related to the physical sense of self, with the impact of cancer on the identity of individuals appearing to shift on a *'moment by moment basis as it entered and then left people's conscious awareness'* (p.96). An experience of physical illness that leaves individuals with sustained changes in the physical body and body sensations may present significant *'faulty ground'* on which to develop a new sense of our embodied selves (Oakley 2007, p.69). As I discussed in 2.6.2, Goffman (1963) identified the challenges for individuals in managing their 'spoiled identity', and in particular, the significance for individuals with a visible, and potentially discrediting 'stigma', in relation to how they manage social encounters and make decisions on how much to conceal from or to disclose to others.

In Section 2.5.3 I discussed research showing how breast cancer marks the body and has the potential to change women's personal identity (Langellier & Sullivan 1998). Cromptvoets (2006) argued that medicine and breast cancer groups tended to present a dominant message of the restored body after breast cancer. However, the findings from this current study suggest that the

physicality of lymphoedema may not be so readily hidden. As such, the potential impact of lymphoedema on women's self-identity may be significant. It is not surprising that lymphoedema has been shown to challenge many aspects of women's home and work lives (Fu 2005; Fu 2008; Johansson *et al.* 2003), thus leading women to find various ways to reconstruct meaning, for example, through viewing themselves as '*lucky to be alive*' (Hare 2000, p.38).

The present study findings reflected a number of ways in which women sought to reframe their identity in the face of lymphoedema, particularly in relation to their different social roles and responsibilities. In 5.4.2, I showed that, as in other studies (Hare 2000), women in my own research appeared to view lymphoedema as a 'lucky' trade-off for being alive. This was despite the apparent juxtaposition where the condition also constituted a constant reminder of breast cancer demanding daily self-care. It was clear from Section 5.4.1 that, for Nina and Joanne, lymphoedema was a stigma that could be discrediting as it literally marked them with a cancer identity. Irene talked of the flag-like quality of her sleeve. Thus, the introduction of self-care approaches such as wearing a sleeve represented further possibility for women to be identified as having a socially impaired body (Charmaz 1995; Goffman 1963).

For these women, one strategy for dealing with the visibility of their lymphoedema was to seek to hide it with clothes, as Fiona and Grace discussed in Section 5.4.3. Both women found this frustrating, as appropriate clothing could be difficult to find. As Joanne considered, there was the question of how to deal with the '*pregnant pause*' that followed her disclosure of breast cancer to colleagues, after they asked about her sleeve. Notable in the interpretations in Section 6.6.4 was the example of Diana's efforts as a practitioner to prepare women for anticipating and managing potentially uneasy social encounters, when she fitted women with a sleeve.

These findings have implications for understanding how different women might seek to integrate or reject self-care measures offered to them, constantly reassessing the value of using approaches such as sleeves, weighing up their benefits against the stigmatic element and the possible implications. As Forbat, Hubbard and Kearney (2009) have suggested, the impact of a condition such as cancer on self-identity may be dynamic as it enters and leaves conscious awareness. For many women, the physical sensations discussed earlier in this chapter, and the use of a sleeve, may serve to heighten this awareness at specific moments. At other times it may be forgotten or have limited priority in women's lives, as Elaine noted in Section 5.3.

It is not surprising that many of the women prioritised their social roles over self-care activities, as discussed earlier in this chapter. Irene (in Section 5.3.2) appeared to work hard to sustain her role as carer for her husband and grandchildren. However, as a result of wearing her sleeve, Heather experienced particular practical problems in returning to the work role that she loved. These experiences of women in relation to their work mirror other research findings that suggest women should be supported in addressing and seeking to resolve work-related problems with their employers (Tiiedtke *et al.* 2010). This suggests that supported self-care must also incorporate approaches that enable people with lymphoedema to explore how they will communicate with family, friends and work colleagues about their lymphoedema (McMahon 2005).

7.5.4 Summary

In summary, we have seen that there is significant potential for women with lymphoedema to feel ambivalent about some aspects of self-care as a result of the meanings that lymphoedema has in their lives. This has implications for support where, as Diana recognised, self-care may be a dynamic process. Thus, as Gilean considered, she should have an 'open door policy' to enable women to return for support as and when they wished. There are two key

points from this section: firstly, the extent to which practitioners might be alert to the particular words used by women that suggest some degree of objectification, or difficulties in reconciling her self-identity; and secondly, the ability of practitioners to enable women to recognise and reflect on the dynamic tensions and positive solutions they encounter as they negotiate their social worlds. Where Armer, Brooks and Stewart (2011) might define this as 'behavioural change' techniques, within an anticipatory approach to supported self-care, this may be more usefully described as an opening for self-discovery, reflection and personal agency, rather than pressure on women to change behaviour according to professional advice.

7.6 Structures of lymphoedema practice

In Chapter One I described the structure of services for lymphoedema in the UK, outlining the various approaches to treatment and self-care provided by these services. I showed that physical treatment has evolved within a therapist-driven model, with many services developing in cancer and palliative care settings. The present study indicated the prevalence of a similar model, with practitioners mainly situated either in relatively isolated hospital clinics, with a link to a cancer centre, or in palliative care settings. Having a link to a hospital cancer or a palliative care unit may be useful to some extent, as it could enable the seamless transition of women between the various services, particularly during the early stages of lymphoedema while women are still recovering from or undergoing breast cancer treatment. However, evidence from this study suggested that, even where the services were on similar sites, women such as Kate and Joanne did not necessarily experience a smooth transition in being referred from acute breast cancer care to the lymphoedema practitioner.

It is possible that other less clinical lymphoedema services are established elsewhere in Scotland and the UK, but were not studied in this current research, given its scope. However, it is pertinent that in this particular study, self-care support was provided from the same setting in which individuals with

lymphoedema underwent clinical treatments such as bandaging or MLD. Working within this type of medical setting it may be difficult for practitioners to identify alternative ways for supporting women with lymphoedema, as might be expected within long term condition health policy. As noted earlier in this chapter, some women said that they would prefer to access support in local and potentially less clinical settings that were not a reminder of their breast cancer treatment.

Notably, none of the practitioners who took part in the study had a background or education in community health care, although Celia did undertake visits in the community, and was the only practitioner who appeared to present herself as less clinical as she did not wear a uniform. It is interesting, but not surprising, therefore, that the models of care evident in this study did not reflect the community-based approaches espoused in long term condition policy. As I indicated in Section 1.3.4, organisations such as the International Lymphoedema Framework have undertaken to evaluate primary-care based services for people with lymphoedema (Sneddon 2007). However, it must be considered to what extent the ethos of these services remains steeped in a medical model approach.

In their study of anticipatory care, Kennedy *et al.* (2011) showed that in working with people with long term conditions, Practice Nurses tended to focus on the medical management of a condition, where Community Nurses took a more life-centred approach when working with individuals. The authors noted that the employment context of the professional, for example, as a Community or Practice Nurse, influenced their mindset and approach to anticipatory care (Kennedy *et al.* 2011). In this current study there was evidence that the professional or disciplinary frame of reference provided a significant background, influencing ways of working, even in professionals with apparently similar job titles. The interpretations also suggested that lymphoedema practitioners did not always embrace a life-centred view. That they did not do

this may be the product of various factors; the medical framework of treatment upon which self-care approaches have developed; the clinic or hospital-centric model of care; or the expectations of the women themselves.

In this current study, services did not appear to embrace the concept of multi-agency care, as identified in long term condition health policy discussed in Chapter One, and practitioners did not necessarily work within a multi-disciplinary team approach relevant to lymphoedema. This may lead to the proliferation of a rather narrow approach that may not necessarily meet the needs of women who wished, where realistically possible, to move beyond the hospital and clinical structures, and adjust to living 'normally' with a long term condition.

7.7 'Partnership' as a basis for supported self-care

As I showed in Section 1.4, the notion of a 'partnership' between an individual with a long term condition and the health professional is a key aspect of health policy. In their review, Rees and Williams (2009) suggested it was important to explore what factors might inspire effective partnership between a professional and a person with a long term condition. McCormack and McCance (2010) considered a therapeutic relationship as involving health professionals in taking a person-centred approach, treating people as individuals, respecting their rights, building trust and understanding. Researchers have identified that specialist nurses may find it easier than generalist nurses, to enter into a therapeutic relationship, and to articulate their role in providing emotional support (Wilson, Kendall & Brooks 2006).

Evidence from the current study indicated that practitioners and women recognised the relationship and some form of partnership as relevant to support and self-care. Some of the interactions I witnessed were evidence of open communication and a trusting relationship, indicative of the specialist and potentially therapeutic role taken by these practitioners. Given the possible

intimacy of bodywork undertaken in measuring and examining women, and teaching self-massage, for example, it is particularly important that these potentially vulnerable women felt comfortable within the relationship.

There was some evidence that practitioners were comfortable with their role in supporting women over the longer term, although this was not examined in depth in the study. My impression was that practitioners such as Gilean, as I have indicated in Section 6.5, gained particular job satisfaction from having the opportunity to build up relationships with women over a period of time. Equally, women such as Audrey, Betty and Elaine, appeared very positive about having had a long term relationship with the same practitioner, viewing a visit to her as a potential source of re-motivation. This appears to emphasise the importance of women being able to establish some type of ongoing access to a practitioner, within a familiar relationship, as a feature of an anticipatory approach to supported self-care.

In a condition such as lymphoedema associated with breast cancer, which may appear to be relatively 'mild' and amenable to self-care, women's contact with professionals may be minimal, and there may be challenges to developing a partnership. Some practitioners talked in this current study of using regular treatments with MLD to get to know women. However, in a supported self-care context it is arguable that a period of sustained contact would not be feasible. Indeed, these women with arm lymphoedema are likely to be significantly less demanding on the resources and time of a lymphoedema practitioner than a woman with bilateral leg lymphoedema, for example, who requires daily bandaging of her legs. Thus, the challenge for practitioners is in working with women in ways that quickly establishes a trusting relationship and effective lines of communication relevant to each woman they support.

The concept of partnership suggests some level of equality, collaboration and sharing of power. The findings did not suggest that practitioners exerted power

over women, for example, within an authoritative model where they expected women to 'comply' with their instructions. However, as I have shown earlier, power was exerted in subtle ways, such as the approaches taken for measuring and examining women, and the structures of professional knowledge that were sometimes privileged over women's 'lay' knowledge about self-care. An indirect source of power influencing the partnership between the woman with lymphoedema and the lymphoedema practitioner was also evident in the disappointment of women who came to recognise the apparently limited options available for 'controlling' this long term condition. Indeed, in one example, Irene believed that both herself, and Celia the practitioner, were likely to be disappointed with the outcome of treatment and self-care. These findings resonate with work by Thorne (1993) who identified that individuals with chronic conditions may experience a sense of '*disenchantment*' (p.86) as they recognise the limitations of self-care and support. Thus, it is argued that women might develop a partnership with practitioners based on a type of '*guarded alliance*' (Thorne 1993, p.90), within which the person with a long term condition comes to recognise the limited scope of meaningful professional care, within the large and complex health care system (Thorne 1993).

Given the limited repertoire of treatment options available for them to offer to women, it is possible that the practitioners may believe it is pointless or unnecessary to see women on a regular basis. However, this appeared to contrast with the needs of women such as Joanne and Heather who, fairly new to lymphoedema, still appeared to require support with 'managing' their condition. This evidence suggested that practitioners may need to clarify for women the nature of available long term support and establish effective routes for women to access professional and other support systems. Recognising partnership as a basis for the anticipatory approach emphasises the role for practitioners in enabling a woman to reconcile the trajectory of her condition, predict changes and patterns of symptoms, anticipate and respond to self-care needs. The current study findings indicate, however, challenges for

practitioners, particularly those who work in acute settings, in establishing on-going collaborative partnerships that draw on relevant areas of the woman's personal and social context.

7.8 Knowledge for self-care

In this section I build on my argument that the partnership between the women with lymphoedema and the lymphoedema practitioner is a potential source and site of new knowledge and wisdom for self-care. However, each person clearly comes to the relationship with their own knowledge, and as we saw in Section 6.3, there may be several sources of knowledge influencing the development of practice wisdom in the lymphoedema practitioner. Kennedy *et al.* (2011) suggested that the relationship between a health professional and a person with a long term condition is the basis for a type of 'surveillance' that may underpin anticipatory care. Their study identified two models of anticipatory care based on different knowledge: a protocol-based model focussed on meeting health targets, set within the knowledge of biomedicine, and reflected in the work of Practice Nurses; and a more individualised approach often taken by Community Nurses as they drew on knowledge of a person's home life (Kennedy *et al.* 2011). The point here is that these two models may not be mutually exclusive, and that my own evidence in Section 6.4 suggested that there may be potential for similar distinctions in approaches, but also scope for integrating the two perspectives in relation to lymphoedema supported self-care. I have indicated earlier that a view of the professional as mediating between biomedical knowledge and the women's own experiences of lymphoedema self-care is one way in which this may be conceptualised (see Figure 7.1). This view, I believe, is integral to understanding the processes through which women with lymphoedema, and others with various long term conditions, may be enabled to develop individualised wisdom relevant to their self-care.

Referring back to the discussion in Section 3.4, my argument also draws on the observations of Dewey (1933) who described how individuals learn from

experience and develop wisdom through reflection on experiences. Significantly, the social nature of knowledge for groups such as nurses is such that it is produced as a result of experiences and dialogue with others who have different vantage points and perspectives (Benner, Tanner & Chesla 1996). Thus, working in a team, novice learners can develop their knowledge and skills (Benner 1984). Equally, Benner, Tanner and Chesla (1996) argued that expert nurses may develop an embodied knowledge as they learn what counts as a disease or symptom, distinguish the pattern of responses in any given disease or situation, and integrate this knowledge with the individual narratives of the 'patients' with whom they work. I would suggest that a woman learning about self-care might accommodate a similar process, influenced by the reflective capacity of an effective and enabling encounter with a health professional.

Atkins & Ersser (2008) considered that the sharing of power, responsibility and knowledge may be a central feature of the collaborative health care partnership between 'patients' and professionals. Drawing on Foucault, Armstrong (1994) has argued that the social encounter between an individual 'patient' and a professional produces knowledge but is also a site for dynamic power relationships which are constantly renegotiated. It is argued that the socio-cultural nature of knowledge for health care is often placed within a professionalising and specialising agenda which favours reductionist, cognitive and behaviourist paradigms (Larsen, Loftus and Higgs 2008). The findings from this current study suggest that this may be the case for lymphoedema knowledge, which as we have seen in Chapters One and Two, is at a relatively early stage of development in terms of evidence-based practice. It is perhaps not surprising, therefore, that given the limited evidence relating to the work of nurses and other AHPs in relation to people with long term conditions, professionals are often firmly entrenched in an acute paradigm that is biomedical in nature, not necessarily empowering, nor relevant to the self-care support of individuals with long term conditions (Anderson & Funnell 2005).

To some extent, the site and source of this new knowledge is the embodied experience of women and the physical body itself. Women may therefore learn to 'read' the physical signs of their condition, and anticipate their self-care needs. I would argue that this is enhanced by a practitioner undertaking a collaborative assessment, drawing a woman's attention to body cues, the tacit knowledge of the body, and the salience of physical signs; in a sense, capitalising on processes of objectification. Furthermore, the approach to examining, measuring and working with the body, to teach self-massage for example, must draw on integrative processes that reflect the phenomenological theory of somology described by Lawler (1991). Thus, this approach recognises the dynamic nature of the embodied experience of both the women with lymphoedema and the lymphoedema practitioner.

Significantly, however, evidence-based knowledge or 'truths' relating to lymphoedema supported self-care remain uncertain in many instances. This further emphasises the importance of women's subjective knowledge. Nevertheless, the lack of objective evidence may threaten the autonomous agency of practitioners who often work within an environment heavily influenced by a positivist science. In Section 2.4.11 I showed that there was no empirical evidence to support the use of self-massage. As such, it may not be surprising that new practitioners such as Fran were unconvinced as to its effectiveness and agonised over whether they should even teach it to women. Thus, where Diana and Belinda might use MLD as a form of support, Eileen did not work within a similar ideology, possibly as she believed that she had no 'hard' evidence for it as a legitimate form of support. Indeed, the evidence that Diana had was 'soft' evidence, insofar as it stemmed from her practice wisdom and experience of how MLD helped women to relax and feel better inside their changed body. This lack of consensus as to what constitutes support further emphasises the need for reflexive processes in practitioners as well as women, particularly where, as the study showed, many practitioners worked in isolated roles which might limit the scope for their professional development.

It will be clear here that I am indicating a potential for generating an anticipatory type of knowledge and wisdom for individual self-care, based on a dynamic, reflexive and collaborative health care encounter. However, the scope of developing this type of knowledge may be subject to powerful influences including access to resources, education, time, location of clinics, and organisational, policy and strategic decisions. As I noted near the start of this chapter, it is through attention to relational autonomy theory that practitioners, in particular, might seek to deconstruct their current view of supported self-care. Working from a relational view of autonomy draws attention to the potential sources of power within and upon their work, encouraging practitioners to identify the dominant ideologies that underpin their practice. Arguably, this is a crucial step towards recognising and developing opportunities for autonomous agency in terms of professional practice and women's self-care.

7.9 'Other' views of lymphoedema

Here I briefly consider the ways in which others such as doctors, and also the wider society, may construct meaning in relation to lymphoedema. Although the data were limited in this respect, the accounts from women and practitioners gave useful insights which inform this discussion and are relevant to the thesis.

I have already indicated that the physical symptoms of lymphoedema could be particularly oppressive for women, particularly where others such as doctors did not take their condition seriously and did not necessarily acknowledge the 'diagnosis' of lymphoedema. Other literature has indicated difficulties for individuals with various long term conditions in achieving a medical diagnosis, particularly if their symptoms are non-specific (Soderberg, Lundman & Astrid 1999), or invisible to others (Witavaara, Brulin & Barnekow-Bergkvist 2008). In contrast, in Section 2.4.7, I indicated that individuals with diabetes may be 'diagnosed' by medicine using biomedical means when symptoms are not 'clinically' obvious (Lawton *et al.* 2005). In her feminist critique, Malterud (1999), a doctor, considered the critical distinction between the subjective

symptoms experienced by an individual, and the clinical signs used by health professionals such as doctors to identify specific disease conditions.

The difficulty experienced by some women in this current study, on finding their lymphoedema was not taken seriously or readily 'diagnosed' by doctors such as their GP or hospital doctor, reflects the findings from other lymphoedema studies such as Johansson *et al.* (2003), described in Section 1.3.3 of the thesis. It is likely that breast surgeons working within an acute paradigm of curative breast cancer treatment will construct meaning of lymphoedema symptoms as side effects and so, by implication, temporary. It is also likely that for some doctors, as Audrey observed in Section 5.2.3, a symptom of lymphoedema may confer an element of blame. For others, such as Irene's GP, lymphoedema literally appeared to be 'off his radar', with Irene's pattern of symptoms being linked by the doctor to conditions such as 'tennis elbow' or osteoarthritis. As such, the evidence from the study reported here suggests that doctors may not fully understand the origins of lymphoedema and may, for many reasons, fail to view it as a legitimate side effect of breast cancer treatment.

Earlier in this chapter I identified the potential for lymphoedema to represent an overlapping or blurring of the boundary between the acute breast cancer care trajectory, and the trajectory of a long term condition. In Section 2.5.3 I identified that there is an abundance of literature seeking to quantify and organise side effects of breast cancer treatment within a biomedical domain. As such, medicine constructs breast cancer care predominantly in the framework of a disease trajectory that requires an objective and rationale approach to its control and cure. This view may not readily legitimise a condition such as lymphoedema or differentiate it from the 'normal' side effects of cancer treatment, such as 'post-treatment swelling'.

Thus, what is construed as women's 'lay' knowledge and truths about lymphoedema and how it is experienced, may differ from what is constructed and accepted as clinical professional 'truths'. It is clear therefore, that lymphoedema swelling may quite literally challenge the boundaries of the physical body, and also the body of knowledge that is breast cancer medicine, with its inability to always provide a perfect aesthetically pleasing, symmetrical body (Cromptvoets 2006). Notably, most other long term side effects or symptoms of breast cancer treatment such as fatigue, nerve damage, hot flushes or early menopause (Macmillan Cancer Support 2009) can be fairly invisible to medicine, though not to the women affected by such symptoms. Thus, it appears that lymphoedema potentially moves the acute biomedical field of breast cancer treatment into a new paradigm for which it is not entirely prepared.

Over thirty years before this thesis was written, Sontag (1977) considered the metaphors used about cancer as relating to the strength, weakness and energy of a capitalist economy:

'The language used to describe cancer evokes a ... economic catastrophe... of unregulated, abnormal incoherent growth. The tumor has energy, not the patient; 'it' is out of control' (Sontag 1977 p.62-63).

It is my assertion that lymphoedema swelling may produce a lack of constancy and physical control that extends this cancer metaphor. Furthermore, it appears that the increasing 'body' of 'breast cancer survivors' who live with lymphoedema may be constructed in long term condition policy rhetoric as an uncontrolled threat or 'burden' to the health economy (Department of Health 2005), as I identified in Chapter One.

The different ways in which groups such as women with lymphoedema, lymphoedema practitioners, doctors or policymakers socially construct lymphoedema may be a product of many factors. This may include the experience and context of the 'symptom', professional schemata in which

knowledge is organised, and the economic capacity of public sector and other organisations. It is my observation that women with lymphoedema associated with breast cancer are also positioned at several intersections: between acute and chronic illness paradigms; between the paradigms of cancer treatment and cancer survival; and between different disciplines of nursing, physiotherapy and the many other professionals with a vested interest. There are implications for supported self-care, where so many different constructions exist and compete for funding and legitimacy. Thus, where the thesis proposes an anticipatory approach to supported self-care, there is an ongoing need for critical awareness of the political and professional agendas that impact on the experience of women with lymphoedema associated with breast cancer.

7.10 Towards an anticipatory approach to supported self-care

Denzin (2003) has argued that qualitative, interpretative inquiry should incorporate a well plotted narrative, clearly identified cultural and political issues, and should articulate a *'politics of hope'*, seeking *'new ways to locate and represent the gendered, sacred self in its ethical relationship to nature'* (Denzin 2003, p.488.) I believe that this thesis addresses each of these areas. In particular, in Chapter One, I drew attention to the health policy that suggested that people with long term conditions have the ability to exert control over their life and long term condition, with support at key stages, and through timely access to resources and services, appropriate information and education (LTCAS 2008). In this current chapter I have explored various influences on this perspective, and the relevance to women with lymphoedema, identifying elements of an anticipatory approach to supported self-care relevant to lymphoedema practice.

I believe the thesis has illuminated the invisible everyday 'work' of women with lymphoedema and lymphoedema practitioners, and I have drawn the various concepts together in a conceptual map (Figure 7.2), as the basis for further theory development. In essence I have sought to identify the sources of

knowledge relevant to developing reflective wisdom in women with lymphoedema, and lymphoedema practitioners. The conceptual map in Figure 7.2 indicates the equal relevance of a range of concepts to both the women with lymphoedema and the practitioners: roles and responsibilities; the embodied experience; resources and support; and timing and experience. Also important are the structures and processes through which autonomous agency may be fostered, which I have identified as: access to services and support; 'assessment' of need; anticipation of change; and action and responses.

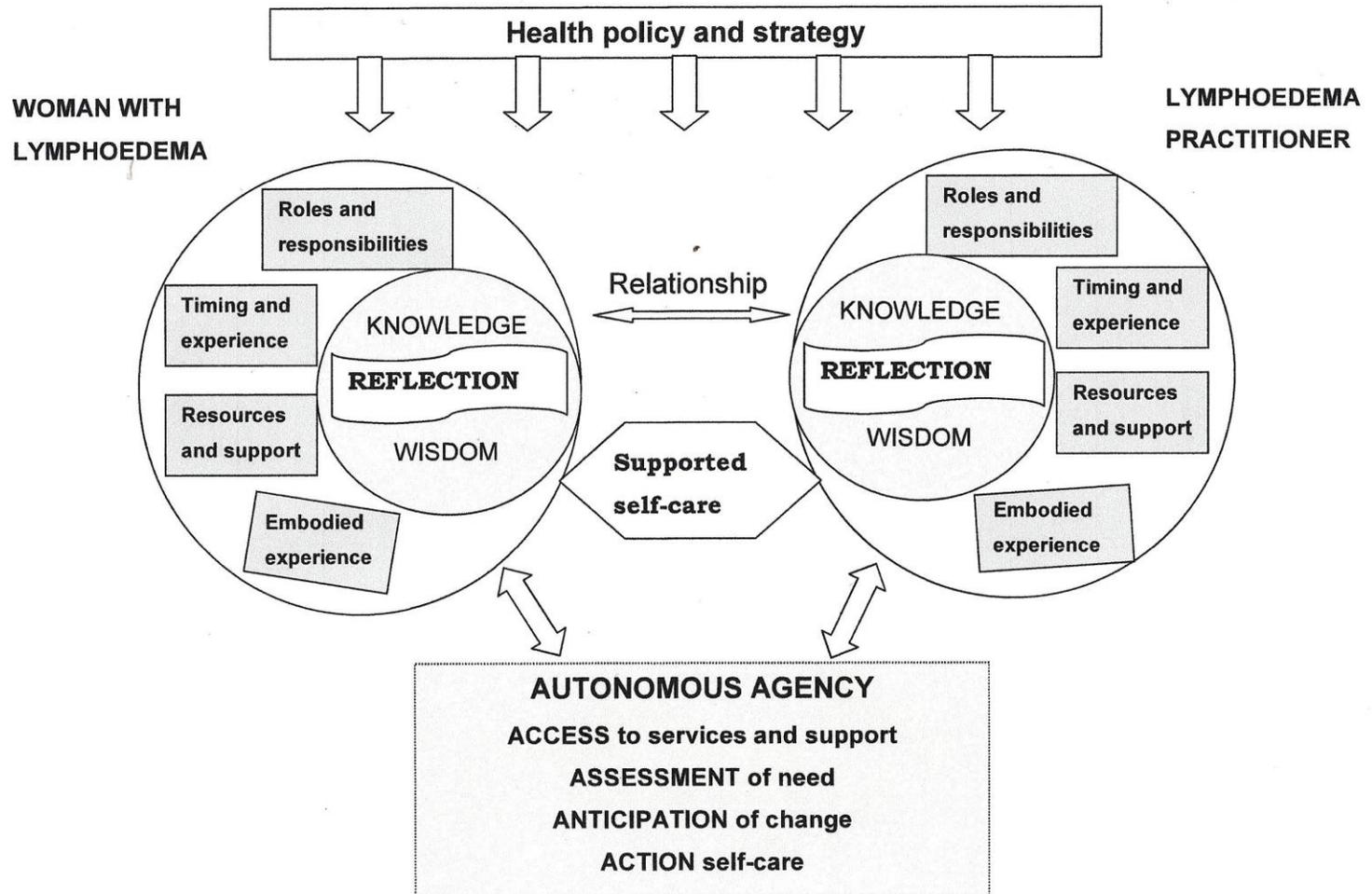
Access: to services and resources is relevant to women with lymphoedema and lymphoedema practitioners. These structures are influenced by local and national policy and strategy. They may include group or individual community-based forms of support, and will involve varied technologies such as on-line, telephone and text. They may be created by professional practitioners, and require participative and potentially emancipatory activities in identifying the need for and developing services.

Assessment: approaches to identifying need should draw on a collaborative partnership model, be two-way and reflexive, acknowledging the subjective narrative, and locating the embodied individual as central.

Anticipation: is a key focus that draws on tacit knowing, observation, reflection, self-knowledge and discovery in order to develop the wisdom that enables an individual with a long term condition to recognise change, or the potential for change, in their health or self-care.

Action: this incorporates the different types of self-directed activities relating to self-care, drawing on a women's (and practitioner's) knowledge of available resources, but also supported by appropriate written and other types of information and support.

Figure 7.2: An anticipatory approach to supported self-care: a conceptual map.



7.11 Reflections on the research design and process

At this point I am able to take a critical retrospective look at my work as a researcher in developing and implementing the research study. In reflecting on the research process I will consider the limitations and strengths of the study, reviewing my own development as a researcher.

7.11.1 Limitations and considerations

I recognise various dilemmas that I faced in being a practising lymphoedema practitioner and a doctoral student, while also being known to the lymphoedema practitioners who took part in the study. I have previously noted in Chapter Four, that as a researcher clinician I was likely to have brought my own cultural identities and assumptions to the study. This would have influenced how I worked in developing and implementing the research. As I had my own knowledge base, it was possible that I asked questions and made observations, assumptions and interpretations that reflected this personal culture. Indeed, Morris, Woodward and Peters (1998) have argued that the closer a subject area is to our lives, the more our beliefs about the world will shape the work we undertake as researchers. I believe that undertaking the study, the analysis, and writing up over a period of nearly five years, provided me with the opportunity to take a rigorous and reflective approach to the research activities. Coming to the research as an 'insider', may also have enabled a richer, albeit value-laden, analysis which has informed the proposed conceptual map that I believe has relevance and applicability.

In seeking to recognise and manage the potential tensions between my researcher and practitioner roles, I had to decide what 'camp' I was in as I presented myself to women and practitioners, and how I would answer any questions they put to me in the interviews. I addressed this in Chapter Four where I also discussed how I managed the interface with practitioners who were my professional colleagues, during the period of the study. Throughout the

research, I strove to protect the interests of the women with lymphoedema and the lymphoedema practitioners, and I remain well aware of my ethical responsibility to maintain the privacy, confidentiality and wellbeing of the informants. As such, I have a particular concern that practitioners may recognise themselves in the thesis, and I see this as a potential limitation of the work. During some of the period of analysis and writing up, I removed myself from my role as a practitioner and from the field of lymphoedema itself, partly due to employment challenges. I thus recognise that, to some extent, I deserted the colleagues who had supported me with the research and I am aware that not all were provided with sufficient feedback at the end of the data generating period.

Access to research participants was negotiated through the Maggie's Centres and NHS clinics, and via practitioners personally known to me. Thus, there was an important element of purposive 'sampling' that may have influenced my interpretations and findings. Women may have believed I was associated with and had a vested interest in the organisations taking part in the research. They may have responded in specific ways as a result, potentially limiting the depth and honesty of their accounts. Relying on lymphoedema practitioners and staff at Maggie's Centres as gatekeepers to my participants meant I recruited limited numbers to the small groups, and a larger group of women for the focus groups would have been useful. However, this may have resulted in more complex data analysis, and as it was, I had a relatively substantial dataset. Drawing participants from outside these organisations, through a 'snowballing' technique for example, would have been an alternative approach; however, this may have made it difficult to reach and recruit relevant women. Alternative approaches for recruiting women to represent minority or particular groups of women, relating to age, sexual orientation, socio-economic factors, or women who were unlikely to utilise Maggie's Centre groups, may also have enriched the data. Indeed, I am aware that the findings provide no insight into how lymphoedema affected the women's personal relationships and their sexual lives. Although this was not

the aim of the study, it appears that the focus on self-care drew attention away from some aspects of women's personal experiences.

A longer period of follow up, of up to one year, for example, may have been useful in providing further depth, informing processes of change relating to women's self-care. Particularly, a longer field observation period could have enabled me to further explore and develop the theoretical direction of the conceptual model. However, opportunity for prolonged data generation was not possible within the timeframe of the research fellowship. A wider set of sites or participants incorporating community areas, lymphoedema key-workers, or MLD therapists with a complementary therapy rather than health professional background, may have provided scope for a broader understanding of supported self-care, potentially enriching the findings.

The proposed model for an anticipatory approach to supported self-care requires further refinement, exploration and evaluation. Although I did hold a feedback group with four of the lymphoedema practitioners who took part in the study, this was at an early stage of theoretical development. I have not, therefore, had an opportunity to share and check out the conceptual ideas with practitioners, to any extent. I also did not share the interview transcripts with women or practitioners, but did offer this opportunity to a few of the women at their subsequent interviews. None were particularly interested in reading the transcripts but instead we drew on salient points from the previous interviews. Forbat and Henderson (2005) reflected on the process of sharing transcripts with research participants, recognising that, within a social constructionist framework, experience is dynamic with individuals moving beyond a period previously captured in earlier data. I do recognise, however, that using focus groups with both practitioners and women with lymphoedema, to explore the findings in more depth, could have potentially strengthened the research and enabled me to further develop the theoretical ideas.

A potential limitation of undertaking a doctoral study relates to the relatively independent and fairly isolated nature of data analysis. In retrospect I could have sought further opportunity for integrating the work within a more team-based approach or situating it as a type of evaluation or development process, more closely aligned to NHS services. However, I am also aware that producing independent and innovative work, at doctoral level, within the framework of rigorous supervision, has been highly important.

7.11.2 Strengths

The study set out with particular aims which I believe have been met. It had a specific and unique theoretical underpinning, which I outlined in Chapter Three. As such, it took a feminist-informed standpoint that identified a relational approach to autonomy, providing a particular perspective on supported self-care as a result. The research also drew on social constructionist theory which has usefully underpinned some of the discussions earlier in this chapter.

I used a combination of methods to gather data through the narrative accounts from women and practitioners, and my own field observations. I believe this is a particular strength of the doctoral study as a research training opportunity. Using the phenomenon of 'supported self-care' prompted this attempt to establish a fairly comprehensive approach to understanding a rather nebulous concept. A further strength of the study was, I believe, my rigour in transcribing, organising and analysing the accounts. Thus, my approach reflected the iterative processes of analysis and synthesis that are crucial to qualitative research (Barbour 2008).

Drawing on a combination of methods to gather data, including field observation in particular, was of particular importance in developing my skills and wisdom as a researcher. Undertaking field observation brought attention to aspects of the physical body and the embodied experience of lymphoedema for women that I believe has enriched the proposed model. The accounts generated from the

research participants appeared to be open and honest. In relation to the women, this may have been helped by meeting them first in the clinic and then on a series of three other occasions, over which time we got to know each other quite well. It was notable that all ten of the women completed the three interviews, and I feel this may be a reflection of my approach in supporting them during the research process. I believe that my professional background helped me to establish rapport with the research participants, and as a researcher and nurse, the settings were fairly comfortable territory for me.

Another key strength of the study was that it incorporated a variety of settings including a voluntary sector organisation, NHS and other lymphoedema clinics, women's homes, and in one case, a woman's workplace. This provided insight into the broad settings in which support and self-care might take place. Women and practitioners were also recruited from different areas of Scotland, although all were from city or small town environments, with none from very rural areas. The practitioners varied to some extent, in relation to their background and work setting, but none, as I have indicated in Chapter Six, were based in the community.

From a personal perspective, I came to the research with extensive experience, as I have outlined in Chapter One; this was a benefit and a challenge. However, I believe that my open, and reflexive approach, locating myself in the thesis, keeping a research diary, and being subject to PhD supervision and critical scrutiny, were all features that emphasised my rigorous approach to research. My stance as a researcher was to view the women with lymphoedema as 'women', rather than 'patients'. Along with writing the thesis in the first person, where appropriate, this was one way in which I sought to deconstruct my professional perspectives and move from the familiar objective and biomedical paradigm from which I had previously learned and educated others.

7.12 Conclusion

This chapter has sought to provide a robust analysis of the data interpretations in relation to relevant literature. The discussions underpin the conceptual development of an anticipatory approach, to inform an understanding of the nature of supported self-care in women with lymphoedema associated with breast cancer treatment. This situates the practitioner in an enabling and mediating role through which she collaborates with a woman to generate new knowledge for self-care. I have argued that reflexive and self-discovery processes are equally important to women and lymphoedema practitioners.

However, as I indicated at the start of the chapter, the structures and processes of support available for women with lymphoedema appeared to be relatively narrow in nature, and based on professional frameworks of knowledge. There is a need to build on these approaches, by enabling practitioners to recognise the anticipatory processes that underpin their work, encouraging them to look beyond the traditional clinic-based types of support currently provided. Understanding the embodied experience as relevant, and the physical body as a potential site and source of power, provided a particular perspective that is, as yet, unique to research in the field of lymphoedema. Further work is required, however, to develop and evaluate the conceptual ideas that underpin the anticipatory approach in relation to the physical and emotional elements of the experience of lymphoedema.

The findings from this research study provide significant insights into a fairly neglected area of healthcare. From the discussion in this chapter, it is clear that they resonate with, and potentially extend, other research findings. Importantly, this study represents an attempt to explore the interface between the acute and chronic healthcare paradigms. It illuminates some of the tensions that are experienced by health professionals as they negotiate the various power structures that influence their work. In particular, it also exposes the distress experienced by women living with a long term condition that is

iatrogenic; as such, a result of biomedical treatment. Importantly, it also draws attention to the women's tenacity and self-determination in recovering from their experience of breast cancer and living with lymphoedema.

Chapter Eight: Key arguments and recommendations

8.1 Introduction

In Chapter One I showed that various health policy approaches viewed the person with a long term condition as having a central role in undertaking self-care, with support from a multi-agency framework. Also, we saw that the language of self-care and self-management may reflect different ideologies, for example, adherence to professionally-driven approaches, or the freedom to shape one's own life and health choices. In this final chapter I will conclude by summarising the key arguments, identifying the recommendations from the study, based on four main areas: professional practice; education; the organisation of lymphoedema services; and suggestions for future research. I also discuss the processes for disseminating the main findings of the thesis.

8.2 Key arguments

My contention is that in seeking to understand the nature of supported self-care, a critical view should be taken of the individualistic notion of autonomy that views a person as making autonomous and empowered choices in terms of their health. Instead, I argue for an anticipatory approach, which recognises that knowledge for self-care can develop through reflection and self-discovery (in relation to the woman with lymphoedema and the practitioner). This also brings attention to the embodied experience of a long term condition such as lymphoedema, and the significance of the physical body in enabling an individual to anticipate and respond to their condition. This is a view of professional practice in which the lymphoedema practitioner applies their knowledge framework in a flexible and reflexive way, seeking to enable similar processes in women. It also draws attention to the structures and processes which may influence and foster the scope for autonomous agency, as it relates to women with lymphoedema associated with breast cancer and lymphoedema practitioners. This conceptual approach raises a number of issues for

educators, professional practitioners, and policy makers, which I will now outline.

8.3 Recommendations

8.3.1 Clinical and professional practice

- Practitioners should develop the scope for collaborative relationships with women with lymphoedema, developing and drawing on skilled communication in approaches to assessment. These should enable self-discovery and reflexivity in relation to women and practitioners. Reflexive approaches enable women to learn about their body with lymphoedema, developing the personal wisdom through which they might recognise and anticipate change.
- Practitioners should adapt and bring flexibility to their biomedical, technical model to individualise support, and seek to identify and reconcile the constraints that impact on women's ability to access support through lymphoedema clinics as currently organised.
- Practitioners should actively seek opportunities for professional development that includes reflection on practice and the ideologies that underpin their work.
- Effective mechanisms for supporting practitioners new to the field should be developed.
- Practitioners should explore and identify opportunities for referring and signposting women to other forms of support, where appropriate.
- Practitioners should reflect on and develop their approaches to using bodywork with women, and teaching specific skills such as self-massage in ways that recognises the embodied and subjective nature of lymphoedema,

and the potential for bodywork to enable recovery of the embodied self, in the context of a long term physical condition.

8.3.2 Organisational

- Opportunities for stronger team and inter-professional working in lymphoedema treatment and care should be sought, where different areas of expertise can be shared more effectively, and practitioners do not work in isolation or as lone professionals within a service.
- Practitioners should identify systems for the assessment and follow up of women, exploring opportunities for varied ways in which women might access advice and support from clinics.
- The scope for further development and evaluation of information resources, including written, web-based and audio-visual materials for people with lymphoedema should be explored.
- Developing opportunities for partnership working with relevant organisations in the social, leisure and voluntary sectors may enable more locally-based support for women with lymphoedema. These may be based on current models for cardiac and respiratory rehabilitation or cancer support groups available in Maggie's Centres and elsewhere.
- Opportunities should be explored for developing innovative ways of sharing knowledge about lymphoedema with other professionals such as BCNs and medical colleagues.
- Professional leaders in the speciality of lymphoedema should examine critically the implications of institutionally-driven policy agendas for their professional practice.

8.3.3 Educational

- Current educational approaches that are based on a technical model with professionally-derived outcomes should be reviewed, and opportunities for supporting practitioners to work with people in enabling ways that reflect the concepts identified in the anticipatory approach should be sought.
- Practitioners should be provided with opportunities to develop skills in reflective, collaborative working, group facilitation, and using motivational techniques relevant to working with individuals with lymphoedema.
- Attention should be given to identifying processes for mentoring and supporting new lymphoedema practitioners, during and after educational courses.
- Consideration should be given to developing the scope for 'inter-professional' learning, including courses that incorporate 'patients' and 'professionals'; for example, in teaching self-massage.

8.3.4 Suggestions for future research

- The proposed conceptual ideas for an anticipatory approach require further refining and theoretical scrutiny. This could involve further research, drawing on field observation and narrative approaches with individuals who have lived with lymphoedema for extended periods.
- A similar study may be undertaken to explore the nature of supported self-care in groups of individuals with other types of cancer and non-cancer-related lymphoedema, to examine differences and similarities across groups, and explore the experiences of men undertaking self-care.
- An experimental evaluation of a group intervention for supporting self-care in individuals with lymphoedema should be undertaken.

- An exploratory study should be undertaken to examine the work of lymphoedema practitioners in different settings and within different teams, to identify models of care/service and to evaluate different service models relevant to supporting self-care.
- Development of information resources related to lymphoedema supported self-care should be undertaken within an exploratory framework and fully evaluated in relation to their relevance and applicability to individuals with lymphoedema, their families, lymphoedema practitioners and other health, social and voluntary sector professionals.

8.4 Dissemination of findings

The findings from this study will be made available in various formats that are accessible to a variety of people who may be interested, including: women with lymphoedema; Maggie's Centres; lymphoedema practitioners and their managers; organisations such as Breast Cancer Care and Breakthrough Breast Cancer; the Lymphoedema Support Network; and the British Lymphology Society.

The findings will be disseminated through a variety of approaches including conference papers/posters, and submitted for publication in peer reviewed journals.

8.5 Final summary

The processes of undertaking the research study and writing this thesis have been both an intellectual and personal journey. They have challenged many of the fundamental assumptions that have accompanied me through over 30 years of professional nursing, and many years of working as a clinician, educator, massage therapist or researcher with individuals who have lymphoedema. As I showed in Chapter One, my varied experiences provided quite a broad

perspective on the field of lymphoedema practice and cancer care, and I believe this has underpinned the development of a unique thesis. Despite, and perhaps as a result of this, it has also been humbling to recognise the extent of distress experienced by, and also the determination of, women who live daily with the challenges of lymphoedema.

The critical approach to health policy undertaken in this thesis provides an important perspective on the strategic developments that affect individuals with long term conditions and health professionals. We have seen that tensions exist in terms of the changing roles that appear to be integral to long term condition policy. Many of these tensions relate to the various sources of power that impact on health care 'consumers' and professionals alike as they undertake self-care or provide support. However, this research has identified ways in which individuals with lymphoedema, and lymphoedema practitioners, might work collaboratively to extend the knowledge and wisdom within their own environments, enhancing the broader scope and quality of lymphoedema care provision.

The depth of study and tenacity required for doctoral research presented challenges for me as a researcher, and in a personal sense. The opportunity to undertake this research study and create the thesis also opened up to me a wide range of sources of knowledge and wisdom. The findings from the study emphasise the fundamental importance of reflexivity and self-discovery to the development of personal wisdom within wide and varied aspects of life.

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Appendix 1: Data extraction tool: literature review

Literature reference:

Type of literature: paper, book, policy document, other:

Relevance to research/thesis:

- Supported self-care in long term conditions
- Supported self-care in cancer, nursing, therapy or other:
- Supported self-care in lymphoedema
- Body/self
- Autonomy
- Other

Study type/design or literature category:

- Meta-analysis/systematic review/review
- Randomised controlled trial
- Qualitative study: details:
- Other quantitative study: details:
- Theory: details:

Main focus of the review/theory/research question:

Details of sample/groups to which applies (numbers, randomisation process, drop-out etc):

Methodology

Methods used, comparisons etc:

Outcomes measured/ follow up, attrition rates:

Findings:

Summary of key points:

Quality of resource/limitations:

Relevance to research/thesis:

Other comments:

Appendix 2: Summary of relevant Cochrane systematic reviews 2000- 2010

Authors	Aim of the review	Method/background	Key findings	Comments
Bradley & Lindsay (2009)	To compare the effectiveness of distinct intervention types in improving outcomes for adults with epilepsy.	Reviewed 16 reports incorporating 13 trials.	Interventions: specialist nurse; self-management education; alternative models of patient care delivery; lifestyle interventions; strategies to improve 'compliance'. <ul style="list-style-type: none"> Evidence of improved outcomes from specialist nurse and self-management education only No single model of service provision advocated. 	Reviewers recognised that benefits may be situation specific and cannot be generalised to other settings. Studies limited by weak methodology; no scope for meta-analysis.
Deakin <i>et al.</i> (2005)	To assess the effects of group-based, patient-centred training on clinical, lifestyle and psychosocial outcomes in people with type 2 diabetes.	Reviewed 14 reports incorporating 11 studies. Meta-analysis: n=1532. Trials compared group-based education with routine treatment or no intervention.	Programmes varied: 6-15 hours in length; primary care or hospital setting; most led by health professionals; one lay-led group; and comprised 4-16 participants. Meta-analysis indicated group education programmes were effective in improving: <ul style="list-style-type: none"> Fasting blood glucose levels Glycated haemoglobin Systolic blood pressure Body weight. 	Programmes based on: empowerment model; adult learning model; public health model; health belief model; or trans-theoretical model.
Effing <i>et al.</i> (2007)	To assess the settings, methods and efficacy of COPD self-management education on	Reviewed 15 group comparisons drawn from 14 trials.	Self- management education (compared to those receiving usual care) resulted in: <ul style="list-style-type: none"> Significant reduction in probability of hospital admission Inconclusive results for changes in number of doctor and nurse visits 	Meta-analysis not possible due to heterogeneity among studies.

	health outcomes and use of health care services.		<ul style="list-style-type: none"> No significant effect on COPD exacerbations, exercise capacity, emergency department visits, lung function and days lost from work. 	
Foster <i>et al.</i> (2007)	To assess systematically the effectiveness of lay-led education programmes for people with chronic conditions.	Reviewed 17 trials involving 7442 participants.	<p>Lay-led programmes may lead to:</p> <ul style="list-style-type: none"> Modest short-term improvement in self-efficacy and perceptions of health Increase in frequency of exercising Non-clinical improvements in pain, disability, fatigue and depression No effect on quality of life, number of doctor visits or reduced time in hospital. 	Interventions were similar but there was heterogeneity in the conditions studied, outcomes measured and the effects.
Gibson <i>et al.</i> (2002)	To assess the effects of limited asthma education on health outcomes in adults with asthma.	Reviewed 12 trials; limited education defined as information only.	<p>Limited asthma education:</p> <ul style="list-style-type: none"> Did not reduce hospitalisation Did not have a significant effect on number of doctor visits, lung function and medication use Effects on asthma symptoms varied. 	Authors identified variable quality of trials.
Markes, Brockow & Resch (2006)	To assess the effect of aerobic or resistance exercise interventions during adjuvant treatment for breast cancer on treatment-related side effects.	<p>Reviewed 9 trials involving 452 women.</p> <p>Meta-analysis for: cardio-respiratory fitness (n=207); fatigue (n=317); and weight gain (n=147).</p>	<ul style="list-style-type: none"> Meta-analysis (n=207) suggested exercise improved cardio-respiratory fitness Exercise groups led to non-statistically significant improvements in fatigue, weight gain, compared to control Exercise viewed as a supportive self-care intervention, and improved fitness. 	
Murray <i>et al.</i> (2009)	To assess the effects of Interactive Health Communication	Reviewed 24 randomised controlled trials involving 3739 participants.	<ul style="list-style-type: none"> IHCAs may influence self-efficacy, and have some effect on clinical outcomes Emotional and economic outcomes could not be identified. 	Authors suggested larger studies required.

	Applications (IHCA) for people with chronic disease.			
Powell & Gibson (2003)	To evaluate programmes that used written actions plans, self-management plans or other service delivery methods to improve health outcomes in adults with asthma.	Reviewed 15 trials; six compared self-adjustment of medication using a written plan, to adjustment by doctor. Others compared regular review and intensity of education.	<ul style="list-style-type: none"> • Optimal control and self-management of asthma by adjustment of medications may be aided through a written action plan or regular medical review • Reducing the intensity of self-management education or clinical review may reduce its' effectiveness. 	
Renders <i>et al.</i> (2001)	To assess the effects of different interventions targeted at health professionals or the structures in which they deliver care, on the management of patients with diabetes in primary care, outpatient and community settings.	Reviewed 41 studies: 12 targeted at professionals; 9 at the organisation of care; and 20 targeted both.	<ul style="list-style-type: none"> • Organisational interventions such as computerised tracking improved regular recall • Regular contact of patients by nurses may improve outcomes through patient education and facilitating adherence • Effect on physical outcomes such as glycaemic index was not clear and was rarely assessed. 	Authors identified studies as heterogeneous, of poor methodology using multifaceted interventions.
Riemsma <i>et al.</i> (2003)	To examine the effect of patient education interventions on	Reviewed 50 studies; data retrieved from 31 studies relevant to the review.	At first follow up (3 months) there were significant effects of patient education on: <ul style="list-style-type: none"> • Disability (measured by the Health Assessment Questionnaire) 	Authors recognised that follow up times varied.

	health status in patients with rheumatoid arthritis.		<ul style="list-style-type: none"> • Patient global assessment (AIMS arthritic impact scale) • Psychological status (AIMS2-affect scales) • Depression (CES-D scale). <p>At later follow up (3-14 months) there were no significant effects.</p>	
Toelle & Ram (2004)	To determine if provision of a written individualised self-management plan increased adherence and improved outcomes in children and adults with asthma.	Reviewed 7 trials using written management plans based on either peak flow or symptoms, compared to no management plan.	<p>Variety of outcomes used: medication adherence; hospitalisation; emergency department visits; lung function; days lost to work; and respiratory infections.</p> <ul style="list-style-type: none"> • No consistent evidence that written plans provided better patient outcomes than no written plans. 	Authors identified small trial samples and inconsistent results.
Walters <i>et al.</i> (2010)	To assess the efficacy of action plans in the management of COPD.	Reviewed 5 studies, of participants (n=574) with moderate or severe COPD; follow up was from six to twelve months.	<ul style="list-style-type: none"> • Action plans may aid recognition and response to an exacerbation • No evidence of reduced health care resource utilisation or improved health-related quality of life • Knowledge about self-management did not translate into reduced use of healthcare resources. <p>Reviewers concluded that multifaceted self-management programmes or on-going case management were required.</p>	Trials compared a control (usual clinical care) with individualised action plans with limited or no patient education.

Appendix 3: Summary of relevant non-Cochrane reviews 2000-2010

Authors	Aim of the review	Method/background	Key findings	Comments
Barlow <i>et al.</i> (2002)	To identify approaches to self-management (SM) and consider the effectiveness of different approaches.	Reviewed 145 papers. Brief table included to classify papers.	<p>Interventions: were mostly led by professionals; undertaken in various settings such as hospital, home, adult education, community, rehabilitation centres; were disease-specific and generic; used varied modes of delivery (group-based, individualised, face-to-face, online, telephone; online, written information, workbook); included diverse content such as disease information, drug management, symptom management, dealing with psychosocial consequences, lifestyle, social support, communication, goal setting, action plans, group psychotherapy and/or spirituality.</p> <p>Findings:</p> <ul style="list-style-type: none"> • Short term evidence that self-management approaches increased participants' knowledge, symptom management, self-management behaviours, self-efficacy and aspects of health such as depression • Little difference in the effectiveness of different approaches • Commonality of psychological consequences across different conditions. 	<p>Reviewers identified methodological weaknesses: small study samples; short follow up; lack of randomisation; and varied outcomes used.</p> <p>Self-management viewed by the reviewers in terms of 'training patients' to utilise relevant skills.</p>

<p>Berzins <i>et al.</i> (2009)</p>	<p>To describe the impact of UK self-care support interventions on participants aged 50 and over.</p>	<p>Reviewed 18 papers (from 1485) that fitted the inclusion and exclusion criteria; 1997-2008.</p> <p>Review process and detailed evidence summary table provided.</p>	<p>Interventions: patient education; exercise promotion; psychological support; pain management; dietary advice; carer education; medication adherence; group support, individual support; and written materials.</p> <p>Findings:</p> <ul style="list-style-type: none"> • A wide range of outcomes used in studies (pain, treatment adherence, depression, anxiety, self-efficacy, quality of life and health service usage). • Follow up periods ranged from 3-18 months • Modest improvements in outcomes and no firm conclusions can be drawn due to methodological limitations • 'Dosage' of intervention not specified. <p>Reviewers considered that changes may occur irrespective of interventions as individuals become motivated to manage their conditions. Support for those over 75 years requires further study.</p>	<p>Part of an NHS funded study of the relationship between self-care and professional care management.</p>
<p>Chapple & Rogers (2001)</p>	<p>To review qualitative studies that focussed on self-care activities employed by people as a means of managing illness.</p>	<p>Reviewed 27 studies from 400 abstracts (1980 to 1998).</p> <p>Inclusion criteria: papers concerned with self-care in the context of conditions most</p>	<p>Findings:</p> <ul style="list-style-type: none"> • Diversity of need • Family and friends influence how self-care activities are used, particularly if there is an issue of stigma • Context , socio-cultural and economic factors affect ability to self-care. 	

		<p>usually dealt with in primary care (diabetes, mental illness, rheumatoid arthritis, HIV infection and multiple sclerosis).</p> <p>Selective summary table included.</p>	<p>Reviewers considered that most research into self-care has been quantitative, using standardised questionnaires and focussing on specific responses to symptom episodes.</p> <p>Reviewers concluded that interventions for self-care support should recognise the individualised context, and dynamic nature of self-care.</p>	
Chodosh, Morton & Mojica (2005)	<p>A meta-analysis to assess the effectiveness and essential components of self-management programmes for hypertension, osteoarthritis and diabetes mellitus in older adults.</p>	<p>Meta-analysis of data from 53 randomised controlled trials (from 749 screened); 1980-1995.</p> <p>Studies reviewed by two people; used various statistical analyses including Hedges' <i>g</i> effect and standard deviation.</p> <p>Included flowchart of evidence and diagrams of forest plots relating to the three conditions; comprehensive evidence table.</p>	<p>Findings:</p> <ul style="list-style-type: none"> • Pooled results on arthritis studies suggested significant differences between intervention and control groups • Positive outcomes were those for which effective medication was available; thus, reviewers considered that the effect of programs may be due to enhanced adherence to medication • Lack of evidence about the essential elements of a self-management programme. 	<p>Reviewers commented on the heterogeneity of studies and limited attention to cost effectiveness.</p> <p>Reviewers considered that results indicating potential for improved physical outcomes should be interpreted with caution due to possible publication bias.</p>

<p>Coster & Norman (2009)</p>	<p>To assess the evidence for educational and self-management programmes within the Cochrane library, assess the contribution of nurses in the reported clinical trials and implications for nursing practice in providing beneficial educational outcomes. Also evaluate Cochrane database in guiding practice.</p>	<p>Reviewed 30 Cochrane reviews up to January 2008, with 76% within 2005-8 (incorporated 339 studies).</p> <p>Evidence table provided.</p> <p>Reviews independently assessed by two reviewers</p> <p>Inclusion criteria: population (people with a chronic health problem), intervention (an educational or self-management intervention by nurse or other professional), comparison study, measurable outcome.</p> <p>Exclusion criteria: reviews focussed on preventative illness behaviours; psychological interventions; or those designed primarily for lay-delivery.</p>	<p>Interventions: ranged from patient education to complex self-management programmes; education included actions plans, advice, and use of written or multi-media materials: approaches included individual and group delivery; duration ranged from 10 minutes to 4 years.</p> <p>Outcomes used in studies: physiological; functional, cognitive and health service use; and a minority undertook economic evaluation.</p> <p>Findings:</p> <ul style="list-style-type: none"> • Patients can learn to adjust their asthma medications to achieve positive health outcomes if they have regular review • Effect of action plans is unclear • Providing information without self-management training is less effective than a combined approach • In diabetics, group education programmes were effective at improving clinical outcomes and some psychological outcomes • Using participatory, empowering or adult-centred principles was likely to be more effective • Methodology too limited to draw conclusions on implications of self-management education on epilepsy. 	<p>Reviewers commented on poor methodology of studies including: standard or routine care poorly defined and variable; lack of blinding or allocation concealment; delay in trials being reviewed and possibility for standard care to change; and often insufficient evidence to show if the intervention was more or less effective than the comparator.</p> <p>Reviewers considered: assumptions were made in studies about the association between knowledge or attitude change and behavioural change; the contribution of nurses was often not specified; the quality of written information was rarely assessed; and there was limited theory to guide approaches.</p>
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<p>Dennis <i>et al.</i> (2008)</p>	<p>To review the effectiveness of chronic disease management interventions for physical health problems in the primary care setting, and identify policy options for implementation of successful interventions in Australia.</p>	<p>Reviewed 141 studies and 23 systematic reviews (January 1990 - February 2006). Unable to undertake meta-analysis due to heterogeneity of studies.</p> <p>Chronic care model used as framework. Findings discussed with stakeholders and policy makers.</p> <p>Table included key elements of the chronic care model, examples of effective interventions and their effect on outcome.</p>	<p>Interventions: patient educational session; patient motivational counselling; and distribution of educational materials.</p> <p>Outcomes used in studies: physiological measures; quality of life; health and functional status; satisfaction with service; risk behaviour; knowledge; service use; and treatment adherence.</p> <p>Findings:</p> <ul style="list-style-type: none"> Interventions to support self-management or change delivery system design were most likely to result in improved patient and process outcomes, with most evidence in those with diabetes and hypertension. 	<p>Reviewers commented: self-management programmes were not embedded in primary care; system design must ensure members do not duplicate each others' work; clinical information systems must provide audit and feedback, encourage decision support and enhance follow up; and culturally diverse care is required.</p>
<p>Devos-Comby, Cronan & Roesch (2006)</p>	<p>To examine the effectiveness of exercise and self-management interventions on the physical and psychological well-being of patients with knee osteoarthritis (OA).</p>	<p>Meta-analysis of 16 studies reporting exercise and/or self-management interventions for patients with knee OA.</p> <p>Exercise defined as any form of physical training or activity.</p>	<p>Interventions: varied but generally focussed on health, exercise and arthritis; approaches included one-to-one, with spouses, or group; content included cognitive and behavioural coping such as relaxation, imagery and distraction; and also exercise, such as pacing, muscle strengthening.</p> <p>Outcomes used in studies: physical,</p>	<p>Reviewers suggested that self-management programmes should include an exercise component.</p> <p>Reviewers considered that OA influences psychological wellbeing, and as the condition</p>

		<p>Self-management defined as any form of programmes that focussed on education about OA, or self-help courses.</p> <p>Inclusion criteria given; used standardised data extraction form; calculated effect sizes.</p> <p>Study participant numbers: 20-786 (total of 2154); attrition rates average of 14%; mean age 65.8 years; most used randomisation.</p> <p>Included detailed evidence table</p>	<p>(scales); psychological including scales such as self-efficacy or depressive symptoms; direct measures of improvement such as physiological measures of swelling or body weight.</p> <p>Findings:</p> <ul style="list-style-type: none"> • Exercise programs had a positive but small effect on wellbeing but led to improved perceived physical health • Self-management programs had a small but significant effect on psychological outcomes, but did not significantly influence physical health • Two studies of cost-effectiveness suggested programmes were cost-effective. <p>Reviewers concluded that multiple physical and psychological health outcomes and cost-benefit analyses were required.</p>	<p>cannot be easily alleviated, individuals may lack self-efficacy and feel helpless and depressed; and addressing the mental burden may reduce attrition rates and increase adherence to exercise programs.</p> <p>Reviewers identified that details of programmes were often not given.</p>
Godfrey <i>et al.</i> (2010b)	An integrative study across different diseases and impairments to explore the strategies that support self-care activities.	A Joanna Briggs Institute (JBI) review of 30 Cochrane reviews that addressed interventions to initiate or enhance self-care; total of 91,170 participants.	<p>Findings:</p> <ul style="list-style-type: none"> • Identified two strategies (educational sessions and self-care management plans) that could be used generically as supportive care by professionals. 	Reviewers reported varying review methodologies used and heterogeneous data that prevented effective synthesis of current evidence.

		<p>Inclusion criteria guided by Orem's Theory of Self-care.</p> <p>Used JBI critical appraisal Instruments.</p>		
Johnston <i>et al.</i> (2009)	To find out what self-care strategies patients used in their end of life care.	<p>Reviewed 18 papers (three referred specifically to end of life or hospice care).</p> <p>Details given of search and data extraction processes. Evidence table included.</p> <p>Key questions addressed by the review:</p> <ul style="list-style-type: none"> • What evidence base is there around utilising self care at the end of life? • What self care strategies enable a patient and carer to engage with their end of life care? • How can self care in advanced cancer 	<p>Self-care strategies included: social support; symptom improvement; taking medication; and using complementary and alternative medicine.</p> <p>Support interventions included: educational programmes and symptom focussed approaches.</p> <p>Influences on self-care may include: education level; poor socio-economic status; psychological distress, physical limitations; and symptom burden.</p> <p>Findings:</p> <ul style="list-style-type: none"> • A lack of data on self-care at end of life • No research using a patient-centred approach to explore what self care strategies were being used • A lack of UK studies • Interventions not based on patient experience. <p>Reviewers concluded that support with self-care at end of life is more likely to be</p>	<p>Reviewers included qualitative and quantitative research.</p> <p>Reviewers identified: many heterogeneous and descriptive papers; and little focus on ethnicity, social deprivation or older people. The relevance of the chronic care model was not made clear in reviewed papers.</p> <p>Reviewers suggested there are implications for how professionals such as Specialist and District Nurses integrate support with self-care into their role.</p> <p>Reviewers considered that supported self-care should be designed from patient-</p>

		be improved?	symptom-related, linked to emotional self care, psychological adjustment and helping individuals prepare for death.	centred and patient/family initiated research evidence, in developing intervention studies.
Newbould, Taylor & Bury (2006)	To clarify what is known about self-care in chronic illness and the impact of lay-led self-management programmes.	<p>Reviewed 17 papers and two conference papers.</p> <p>Focussed on context of the Expert Patient Programme developed from work by Kate Lorig and colleagues.</p> <p>A generally discursive review.</p>	<p>Findings:</p> <ul style="list-style-type: none"> Professional and lay led approaches have similar outcomes so the latter may not be as beneficial as suggested Papers may falsely assume that the lay approach has benefits over others such as professionally facilitated support Health professionals may find it difficult to engage with the 'expert' patient notion. <p>Reviewers recommended an integrated NHS approach to supporting self-care that recognises sociological, economic and epidemiological characteristics of communities.</p>	<p>Reviewers considered studies: used self-selective samples; included fewer men and non-English-speaking subjects; involved those with higher level of education; and may report greater self-efficacy and overstate the result. Overall public health burden may not be significantly influenced by these programmes, and health inequalities may be increased by skewed uptake, moving resources from other valuable ways of supporting people.</p>
Rees & Williams (2009)	To systematically review the effectiveness and meaningfulness of the patient-practitioner encounter, and how professionals may promote and	<p>A JBI review of 18 papers reporting 16 studies relating to the effectiveness of the patient-practitioner encounter.</p> <p>Meta-synthesis of 5 qualitative studies</p>	<p>Findings:</p> <ul style="list-style-type: none"> Using patient-centred approaches had a positive effect on the encounter, but the effect on self-care was not clear Patient education and regular review and follow up, and patient-orientated interventions improved patient health outcomes (this included the use of a guidebook, care plans, treatment 	<p>Meta-synthesis of quantitative studies could not be undertaken due to heterogeneity of studies.</p> <p>Reviewers considered that more research was required to improve understanding of the</p>

	support self-care management for adults living in the community with physical chronic illness.	<p>using JBI-QARI software.</p> <p>Used JBI appraisal instruments to examine: effectiveness; the individual and organisational factors which help or hinder the use of self-care; and the differences in how effectiveness was defined by patients and practitioners.</p>	<p>structured using checklists and education of staff in working collaboratively)</p> <ul style="list-style-type: none"> • Organisational factors (time, resources, expectations of a consultation, open access to appointment, ability to see the same professional and early referral to other groups) affected the ability to support self-care • Consultations about self-care tend to be medically focussed. 	processes that inspire effective partnership between patients and professionals.
Richardson <i>et al.</i> (2005)	To assess the extent and quality of economic evaluations of self-care support interventions.	<p>Reviewed 39 studies (from 573 papers) that claimed self-care support interventions are cost-effective or cost saving.</p> <p>Assessed against a criteria list, by two independent reviewers.</p> <p>Evidence table of all studies provided.</p> <p>Details: post-1993; 19 were US-based, 6 were UK-based and others were from Norway,</p>	<p>Findings:</p> <ul style="list-style-type: none"> • Overall quality of studies was poor due to flaws in design, narrow definition of costs, short follow up periods, and heterogeneity in conditions, settings and geographical locations • Details of interventions were not given in many reviews. <p>Reviewers concluded that there was no support for the general conclusion that self-care support interventions are cost-effective.</p> <p>Reviewers considered: many studies were of effectiveness (change in outcome), rather than cost-effectiveness; the latter requires a full economic evaluation and comparison</p>	Reviewers noted that only one UK based study suggested self-care support was cost effective, but despite this, Expert patient programmes are being rolled out across England.

		Sweden, Finland and Denmark; 22 were randomised controlled trials; 13 were cost-effectiveness analyses or cost utility analyses; they include varied conditions (asthma, diabetes, arthritis, heart disease).	with an appropriate alternative; comparators are poorly defined; placebos cannot be provided nor subjects blinded to interventions; people will be practising some form of self-care; a Hawthorne effect may occur; and easy contamination of controls may occur. Reviewers suggested a need to: compare active interventions; recognise that trials take place in natural surroundings (reduced demand will reduce waiting list in one area and influence waiting times for others), thus full socio-economic data may be required; and patient costs in terms of time off, and travel should also be included.	
Smith, Kumar & Pelling (2009)	To examine the effectiveness of self-management educational interventions for osteoarthritis of the knee.	A JBI review of 13 trials that were randomised controlled or clinical controlled trials evaluating any self-management intervention for OA of the knee. Used JBI critical appraisal instruments and provided an evidence table.	Programme content included: symptom management; relaxation; visualisation; nutrition; dealing with depression; and spouse assisted pain coping. Findings: <ul style="list-style-type: none"> • A beneficial effect identified from self-management strategies in reducing pain, but no effect on physical function or quality of life • The exercise component of self management in four trials showed benefit in reducing pain, improving function and quality of life. 	Reviewers noted significant heterogeneity between trials.

<p>Spenceley & Williams (2006)</p>	<p>To identify the barriers to and facilitators of self-care from the perspective of people with diabetes.</p> <p>The review focussed on understanding self-care from the perspective of those living with diabetes, and the implications for healthcare policy.</p>	<p>Reviewed 42 quantitative and qualitative studies and reports from a total of 461 papers that were identified in a search of nine databases from 1993-2003. Included studies undertaken in UK, New Zealand, Australia and Canada.</p> <p>Each paper was reviewed using a series of questions developed by the authors.</p> <p>Evidence table included summarising definitions of self-care from four conceptual perspectives, with barriers and facilitators outlined for each.</p>	<p>Findings:</p> <ul style="list-style-type: none"> • Standard patient education offers little creativity in self-care • It is unclear if people want to be self-care 'experts' • Self-care is evolutionary, relational and dynamic, and a personal journey • There are philosophical differences between disease-centred and life-centred approaches to supporting self-care • Professionals should provide anticipatory self-care education and help individuals to mobilise resources internally and externally • A trusting partnership between person and professional is the basis for effective self-care • Nurses practise at the interface between self-care as taught, and self-care as lived. 	<p>Reviewers considered that health policy must support more than just basic requirements for diabetes self-care. It should recognise how self-care evolves.</p>
<p>van Dam <i>et al.</i> (2003)</p>	<p>To review the effects on patient self-care and outcomes of the provider-patient interaction in diabetes care.</p>	<p>Reviewed 8 studies, from search dates 1980-2001, that used a randomised trial design to test the effects of the provider-patient interaction on diabetes</p>	<p>Interventions: training of providers in patient-centred consulting style; support for GPs to negotiate realistic individual goals; an automated telephone diabetes management programme; and empowerment-focussed group education programmes.</p>	

		self-management and diabetes outcome	<p>Findings:</p> <ul style="list-style-type: none"> • A direct approach to support patient participation in diabetes care and self-care was most effective, including the telephone management programme and group education • Organisational changes should support doctor and patient behaviour in negotiating realistic outcomes for individuals with diabetes. 	
Warsi <i>et al.</i> (2004)	To evaluate the efficacy of patient self-management educational programs for chronic diseases, including a critical evaluation of the methodology.	<p>Reviewed 71 trials from 305 identified in a search from 1964-1999.</p> <p>Inclusion criteria: studies reported a self-management intervention, had a concurrent control group and evaluated clinical outcomes.</p> <p>Papers independently reviewed by 2 or 3 authors.</p>	<p>Findings:</p> <ul style="list-style-type: none"> • Lack of randomisation; limited information on the education programme; and limited theory to underpin approaches used • Education effective only for certain conditions where compliance with medication and diet may be the main influence • Pooled effects of arthritis self-management education interventions did not suggest a significant benefit. <p>Reviewers concluded that not all self-management programmes are effective in improving health outcomes and reducing health care costs, although they may be conceptually appealing as a way to empower patients.</p>	Reviewers applied a meta-regression model to identify variables associated with greater clinical improvement, and used funnel plots to assess for possibility of publication bias.

Appendix 4: Research Information Form 1 (July 2007)

Focus/Small group discussion

About the study

We are inviting you to take part in a research study. Before you decide if you wish to take part, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information and talk to others about the study if you wish.

The purpose of the study is to explore how women deal with having lymphoedema after breast cancer. It would involve you taking part in a small group discussion (focus group) with around 3-4 other women at Maggie's Cancer Centre, Edinburgh.

The group discussion is part of a larger study that also explores the experiences of other women newly diagnosed with lymphoedema and the work of lymphoedema nurses and physiotherapists. An NHS Research Ethics Committee has approved the study.

Why have I been invited to take part?

You have been invited to take part as you have had lymphoedema for more than two years, following breast cancer treatment, and have attended the lymphoedema support group at Maggie's Cancer Centre.

What will happen to me if I take part?

If you decide to take part in the study, you will be invited to a group discussion at Maggie's Centre. This will last around 1 hour. The researcher (Anne Williams) who is a lymphoedema nurse, and another colleague from Maggie's Cancer Centre, will be at the group to ask questions to open up the discussion.

We will make the group as relaxed as possible so you feel able to share your thoughts and views. The discussion will be taped and the tape will be transcribed (typed out). We will ask for your name and contact details. We will also ask for your age group and brief information about your lymphoedema. With your permission, we will also contact your GP by letter to let them know that you are taking part in this study. All information will be kept strictly

confidential and your name will not be identified outside the group. Travel expenses to and from the focus group will be available.

What are the possible benefits of taking part?

We hope you will find it helpful to talk to other women who may have similar experiences to yourself. We will let you know about the final results from the study and hope that the findings can be used to help improve lymphoedema services in the future.

What are the possible disadvantages of taking part?

Some people may feel awkward or upset when talking about their experience of having lymphoedema after breast cancer. We will ensure that there is a relaxed and supportive approach to the group discussion. If you wish to talk things through individually with someone, we can arrange this through Maggie's Cancer Centre or with a lymphoedema practitioner in your area, with your permission.

What happens if I do not want to take part?

Taking part in this study is entirely voluntary and if you decide not to take part, or wish to withdraw from the study at any time, this will not affect your future treatment or care in any way. When deciding if you want to take part, you may wish to talk it over with the researcher, your doctor, family or others such as the staff at Maggie's Cancer Centre, your lymphoedema practitioner or an independent advisor (see details at the end of this sheet).

How will the information I provide be kept confidential?

The group discussion will be audio-taped and the tape will be transcribed (typed out). Only the researcher, research supervisors and the secretary transcribing this tape will see the typed discussion or hear the tape. The tape, typed discussion and any documents containing your details will be kept in a locked filing cabinet and destroyed once the research is completed.

Your name will not be made available to anyone and you will not be identified within any of the reports or publications of the research.

What will happen to the results of the study?

A report of the study results will be submitted to Edinburgh Napier University for the award of Doctor of Philosophy. Results will also be published in professional journals and may be presented at conferences.

If I am interested in taking part, what should I do?

If you are interested in taking part or want more information, please contact the researcher Anne Williams by telephone or email (see below). Alternatively you could complete and return the attached form in the stamped, addressed envelope provided. The researcher will then contact you directly to provide more information and give you an opportunity to ask questions about the study. You should keep a copy of this information sheet for reference if you wish. You will be asked to sign a consent form stating that you agree to take part in the study and will be given a copy of this consent form to keep.

Arrangements will then be made for the focus group discussion, which will take place at Maggie's Centre, Edinburgh at a date and time that is convenient to all those who are taking part.

Contacts

The Principal Researcher is Anne Williams who can be contacted at Edinburgh Napier University, 74 Canaan Lane, Edinburgh EH9 2TB; telephone 0131 455 5602 or 07939 06822 (mobile); email an.williams@napier.ac.uk.

The Research Supervisor is Dr Catriona Kennedy, Napier University; telephone 0131 455 5620; email c.kennedy@napier.ac.uk.

An Independent Advisor who is not involved with the research but may be able to give advice is: xxxxxxxxxxxx

Reply slip: Group discussion

A research study of self-care in women with breast cancer-related lymphoedema

I confirm that I am happy to be contacted about the research study:

Please complete your details:

Name: _____

Address: _____

Telephone: Home: _____

Work: _____

Mobile: _____

Email address: _____

Preferred means of contact: _____

Please return to: Anne Williams, Research Fellow, Napier University, 74 Canaan Lane, Edinburgh, EH9 2TB in stamped, addressed envelope.

Please note that this is NOT a consent form and is only being used to indicate your interest in being contacted about the study.

Appendix 5: Consent Form

Protocol: 07/S1401/35

Centre Number:

Patient identification no:

CONSENT FORM

Title: Self-care in women with lymphoedema associated with breast cancer

Researcher: Anne F Williams

1. I confirm that I have read and understood the information sheet dated July 2007 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw at anytime without giving any reason, without my medical care or legal rights being affected.	<input type="checkbox"/>
3. I agree to take part in the study.	<input type="checkbox"/>

Name of participant

Date

Signature

Name of person taking
consent

Date

Signature

Appendix 6: Research Information Form 2 (July 2007)

Lymphoedema Practitioner

About the study

We are inviting you to take part in a research study. Before you decide if you wish to take part, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information and talk to others about the study if you wish.

The purpose of the study is to explore self-care in women who have lymphoedema after breast cancer. We are inviting you to be involved in two ways by:

- Identifying women newly diagnosed with breast cancer-related lymphoedema who could be invited to take part in a series of three interviews with the researcher (Anne Williams) over a period of six months
- Giving your permission for the researcher to observe two to four routine first assessments or review appointments with women who have breast cancer-related lymphoedema, in your lymphoedema clinic setting. This will be followed by a discussion between the researcher and yourself.

The study also involves two group discussions taking place at Maggie's Cancer Centre, with women who have had lymphoedema for more than two years. An NHS Research Ethics Committee has approved the study.

Why have I been invited to take part?

You have been invited to take part as you are a lymphoedema practitioner with a qualification in lymphoedema management and you currently provide treatment for women with breast cancer-related lymphoedema.

What will happen to me if I take part?

If you decide to take part in the study, you will be invited to identify routine lymphoedema clinic appointments when you will assess or review women with breast cancer-related lymphoedema. These will not be appointments when you see patients for manual lymph drainage or bandaging treatment.

The assessment or review appointment will proceed as usual with the researcher sitting in the room. The aim is to understand the self-care needs of the women and the work of the lymphoedema practitioner in the natural setting.

We will ask you to distribute the information sheets about the observation (Form 3) to the women attending the clinic. Their verbal consent will be required prior to the observation. The researcher will arrange to observe these appointments as convenient for yourself and the women with lymphoedema. The researcher may take brief notes but the observation will not be taped. Once the patient has left the appointment you will be invited to discuss your thoughts with the researcher and this will be audio-taped.

We will also ask you to distribute the relevant information sheets (Form 4) to women who might be interested in taking part in the series of three interviews. In some cases, these may be the same women who take part in the non-participant observation, but not necessarily.

What are the possible benefits of taking part?

We hope that the results of the study will be used to contribute to future improvements in lymphoedema treatment and care. We will keep you informed about the progress and results of the study.

What are the possible risks?

We recognise that you may feel awkward about having someone observe your work but will make all efforts to ensure the observation is non-threatening and comfortable for you and the patient. We emphasise that the study is interested in the everyday work of lymphoedema practitioners and is not concerned with judging performance. Your participation is entirely voluntary and you will be free to withdraw from the study at any time, without having to give any explanation.

How will the information I provide be kept confidential?

The discussion between yourself and the researcher, following the patient appointment, will be transcribed. Only the researcher, research supervisor and the secretary transcribing this tape will see the typed discussion or hear the

tape. The tape, the typed discussion, notes from the observation and any other documents containing your details will be kept in a locked filing cabinet and destroyed once the research is completed.

Your name will not be made available to anyone or used within any of the reports or publications of the research. All efforts will be made to ensure that you cannot be identified from any of the research data.

What will happen to the results of the study?

A report of the study results will be submitted to Edinburgh Napier University for the award of Doctor of Philosophy. Results will also be published in professional journals and may be presented at conferences.

If I am interested in taking part, what should I do?

If you are interested in taking part, please contact the researcher (Anne Williams) by telephone, email (as below) or by returning the attached form in the stamped addressed envelope. The researcher will then contact you to provide more information on the research process and give you an opportunity to ask questions. You will be asked to sign a consent form if you agree to take part in the study, and will be given a copy of this form to keep. You should also keep a copy of this information sheet for reference.

Contacts

The Principal Researcher is Anne Williams who can be contacted at Napier University, 74 Canaan Lane, Edinburgh EH9 2TB; telephone 0131 455 5602 or 07939 06822 (mobile); email an.williams@napier.ac.uk.

The Research Supervisor is Dr Catriona Kennedy, Napier University; telephone 0131 455 5620; email c.kennedy@napier.ac.uk.

An Independent Advisor who may be able to give advice is: xxxxxxxxxxxx

Reply slip: Form 2

A research study of self-care in women with breast cancer-related lymphoedema

I confirm that I am happy to be contacted about the research study:

Please complete your details:

Name: _____

Address: _____

Telephone: Home: _____

Work: _____

Mobile: _____

Email address: _____

Preferred means of contact: _____

Please return to: Anne Williams, Research Fellow, Napier University, 74 Canaan Lane, Edinburgh, EH9 2TB

Please note that this is NOT a consent form and is only being used to indicate your interest in being contacted about the study.

Appendix 7: Research Information Form 3 (July 2007)

Observation of lymphoedema appointment

About the study

We are inviting you to take part in a research study. Before you decide if you wish to take part, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information and ask questions about the study if you wish.

The purpose of the study is to explore the experiences of women who have lymphoedema after breast cancer. This involves observation of routine lymphoedema clinic appointments between a woman who has breast cancer-related lymphoedema and her lymphoedema practitioner.

The observation is part of a larger study that also uses focus groups to explore the experiences of women who have had lymphoedema for more than two years and individual interviews with women newly diagnosed with lymphoedema. Some women have also taken part in a series of three interviews with the researcher over six months.

An NHS Research Ethics Committee has approved this study.

Why have I been invited to take part?

You have been invited to take part as you have lymphoedema after breast cancer and are attending an appointment at a lymphoedema clinic.

What will happen to me if I take part?

If you decide to take part in the study, you will be invited to give your permission for the researcher, who is a lymphoedema nurse, to be present at your clinic appointment. Your appointment at the lymphoedema clinic will proceed as usual and the researcher will sit quietly in the room. She is interested in understanding the experiences of women who have lymphoedema after breast cancer and the work of lymphoedema practitioners.

What are the possible benefits?

The results of the study will be used to help develop lymphoedema services.

What are the possible difficulties or risks to me?

We recognise that you may feel awkward about having someone observe your appointment but will make all efforts to ensure you feel comfortable. The appointment will proceed as usual and the researcher will leave the room at any point if requested by yourself or the lymphoedema practitioner.

What will happen if I do not wish to take part?

Taking part in this observation is entirely voluntary and you will be free to refuse to take part without this affecting your treatment or care in any way.

How will the information I provide be kept confidential?

The researcher may take brief notes during the observation. Following the observation, the researcher will have a short discussion with your lymphoedema practitioner, which will be audio-taped. The tape will be transcribed (typed out). Only the researcher, research supervisor, and the secretary transcribing this tape will see the typed discussion or hear the tape. The tape, typed discussion and any documents containing your details will be kept in a locked filing cabinet and destroyed once the research is completed.

Your name will not be made available to anyone and you will not be identified within any of the reports or publications of the research.

What will happen to the results of the study?

A report of the study results will be submitted to Edinburgh Napier University for the award of Doctor of Philosophy. Results will also be published in professional journals and may be presented at conferences. Your name will not be made available to anyone or used within any of the reports or publications of the research.

Who should I contact for further information?

You are welcome to contact us at any time for more information and you should keep a copy of this information sheet for reference if you wish.

Contacts

The Principal Researcher is Anne Williams who can be contacted at Napier University, 74 Canaan Lane, Edinburgh EH9 2TB; telephone 0131 455 5602 or 07939 068222 (mobile); email an.williams@napier.ac.uk.

The Research Supervisor is Dr Catriona Kennedy, Napier University; telephone 0131 455 5620; email c.kennedy@napier.ac.uk.

An Independent Advisor who is not involved with the research but may be able to give advice is: xxxxxxxxxxxxxx

Appendix 8: Research Information Form 4 (July 2007)
Interviews with women who have lymphoedema

About the study

We are inviting you to take part in a research study. Before you decide if you wish to take part, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information and talk to others about the study if you wish.

The purpose of the study is to explore how women deal with having lymphoedema after breast cancer. It would involve you taking part in three informal discussions (interviews) with a lymphoedema researcher, over six months.

These interviews are part of a larger study that also explores the work of lymphoedema nurses and physiotherapists and the experiences of other women who have had lymphoedema for over two years. An NHS Research Ethics Committee has approved the study.

Why have I been invited to take part?

You have been invited to take part as you have recently developed lymphoedema following breast cancer treatment and have attended (or will attend) a lymphoedema clinic.

What will happen to me if I take part?

If you decided to take part in the study, we will arrange three informal discussions with the researcher (Anne Williams), who is a lymphoedema nurse. These will take place at your convenience but usually around three months apart, over a six month period. The discussions will take place in a place of your choice, usually your home. A family member or carer may be present if you wish. Each discussion will last around one hour and will be audio-taped. The researcher will ask a few questions to start the discussion but we are really interested in your thoughts, feelings and ways of dealing with lymphoedema.

Your name, address and telephone number will be required so we can contact you to arrange the meetings and keep in touch with you about the study

results. We will also require your general practitioner details so we can write to them to let them know you are taking part in this study. Travel expenses will be available should you have to travel to the interviews.

What are the possible benefits?

We hope that the results of the study will contribute to the development of lymphoedema services.

What are the possible risks?

Some people may feel awkward or upset when talking about their experience of having lymphoedema after breast cancer. We will ensure that there is a relaxed and supportive approach to the discussion. If you want to talk things through individually with someone, we can arrange this through a lymphoedema practitioner in your area, with your permission.

What happens if I do not want to take part?

Taking part in this study is entirely voluntary and if you decide not to take part, or wish to withdraw from the study at any time, this will not affect your future treatment or care in any way. When deciding if you want to take part, you may wish to talk with the researcher, your doctor, family or others such as your lymphoedema practitioner or an independent advisor (see details at the end of this sheet).

How will the information I provide be kept confidential?

The discussions will be audio-taped and the tapes will be transcribed (typed out). Only the researcher, research supervisor and the secretary transcribing the tapes will be able to see the typed discussion or hear the tapes. The tapes, typed discussion and any documents containing your details will be kept in a locked filing cabinet and destroyed once the research is completed.

Your name will not be made available to anyone and you will not be identified within any of the reports or publications of the research.

What will happen to the results of the study?

A report of the study results will be submitted to Edinburgh Napier University for the award of Doctor of Philosophy. Results will also be published in professional journals and may be presented at conferences.

If I am interested in taking part, what should I do?

If you are interested in taking part or want more information, please contact the researcher by telephone or email (as below). Alternatively you could complete and return the attached form in the stamped addressed envelope. The researcher (Anne Williams) will then contact you to give you an opportunity to ask questions and arrange a convenient time to meet you. She will also ask you to sign a consent form if you agree to take part in the study and you will be given a copy of this form to keep. You should keep a copy of this information sheet for reference if you wish.

Contacts

The Principal Researcher is Anne Williams who can be contacted at Napier University, 74 Canaan Lane, Edinburgh EH9 2TB; telephone 0131 455 5602 or 07939 06822 (mobile); email an.williams@napier.ac.uk.

The Research Supervisor is Dr Catriona Kennedy, Napier University; telephone 0131 455 5620; email c.kennedy@napier.ac.uk.

An Independent Advisor who is not involved with the research but may be able to give advice is: xxxxxxxxxxxxxx

Appendix 9: Letter to General Practitioner

Edinburgh Napier University
74 Canaan Lane
Edinburgh
EH6 2TB

Tel: 0131 455 5602
Email: an.williams@napier.ac.uk

GP name

GP address

Dear Dr.....

Woman name, address and date of birth

The above woman has agreed to take part in a research study of supported self-care in women with breast cancer-related lymphoedema. The study aims to explore the experiences of women who undertake self-care activities in managing their lymphoedema and also the work of their lymphoedema practitioners.

(*Woman name*) will take part in a one-off group discussion/a series of 3 interviews over the next 6 months. I have enclosed an information sheet for this part of the study. Please contact me if you would like any further details.

Yours sincerely

Anne F Williams
Cancer Nursing Research Fellow

Appendix 10: Introduction to the small group discussions.

Welcome to this group discussion. Many thanks for coming along today. I hope you will feel comfortable about talking and sharing your experiences today. As you know my name is Anne Williams. I am a researcher at Edinburgh Napier University and I'm doing a research study over three years. In this part of the study I am talking to women who have had lymphoedema for some time; at least for two years. I believe it is important to hear from people like yourselves as you know what it is like to live with lymphoedema. Today, I am particularly interested in hearing more about this, for example, how you deal with or care for your lymphoedema on a day to day basis, in a practical sense. Sometimes this is called self care. I am also interested in what sort of support you have and what you feel you need to help you deal with your lymphoedema.

This is the first part of the study and after this I will be spending time in lymphoedema clinics in different parts of Scotland, observing women's appointments with lymphoedema practitioners and also talking to some of these women who have newly developed lymphoedema to find out what it is like for them. So this group discussion today is a starting point for me. As we agreed, I am taping our conversation today, and this is really so that I don't miss anything you say by having to stop to write things down. I want to emphasise that what you tell me is confidential in that your name will never be given and others will not know you have taken part in the research. However I may quote some of what you say today when I write up and present the findings from the research.

My main aim with this research is to find out what is happening to support women with lymphoedema at the moment and see where this can be improved. I hope the research can help to inform more people such as health professionals and those involved in developing services for women like yourselves.

I am planning to ask a number of questions that help us 'focus' on certain things but I hope you will also feel comfortable to share things that are important to you. Sometimes hearing others talk can trigger different thoughts for you. It is important to say that there is no right or wrong and I am interested in everyone's views, even if you disagree. You may all have different thoughts and ideas. I expect the discussion will take around one hour but if you need to leave before that please feel free to do so. Is there anything you would like to ask before we start?

To start and by way of an introduction, could I ask you to give your name and briefly tell us about yourself.

Appendix 11: Topic guide for the group discussions.

	Discussion topic area/question	Considerations/prompts
	Introduction by the researcher: discuss purpose of the study and interest in self-care and support; plan for the group; timing; interested in all different views; important to hear from people who know what it is like to have lymphoedema	Any questions before we start?
1	Invite each person to talk about when she first realised she had lymphoedema.	Consider different symptoms; body changes; and experiences and ways of understanding lymphoedema at the start?
2	What do you do to care for your lymphoedema on a day to day basis?	What is most useful and why?; what is most difficult and why?; what choices do you make and why?; and are there difficulties or barriers?
3	In what ways have things changed over the years in how you deal with having lymphoedema?	Practical changes, attitudes, sense of control or expertise (or not), what caused changes; what choices are made, if any and what is context?; and things avoided?
4	What treatments have you had for your lymphoedema over the years; what are your thoughts about these?	Different or similar experiences in the group.
5	What specific help, advice or support do you get or would you wish for/ expect from a lymphoedema service, or other sources of support?	Family; others women with same; health professionals; and practical/other types of support, help.
6	What do you understand by the term supported self-care?	Any examples?

Appendix 12: Observation guide: lymphoedema appointments

	Topic of observation	Notes
1	Clinic environment <ul style="list-style-type: none"> - Physical space; social setting and layout - Constraints and influences - Medical context/influence 	
2	People and roles <ul style="list-style-type: none"> - Experience/disciplinary background of practitioner - Women: extent and time with lymphoedema - Others involved 	
3	Assessment and related activities <ul style="list-style-type: none"> - Sequence - Timing of various activities and influencing factors - 'Measurement' of self-care and support needs - Ways of documenting - Awareness of cues from the women 	
4	Storytelling by the women <ul style="list-style-type: none"> - Linguistic and emotional elements - Specific focus on medical experiences - Woman's understanding and perception of lymphoedema and treatments 	
5	The body <ul style="list-style-type: none"> - Use of body by the women and practitioner - Touching, body awareness, space - Expression, non-verbal 	
6	Self-care <ul style="list-style-type: none"> - 'Types' of self-care/influences - Consideration of choices, difficulties - Previous/future self-care 	
7	Supported self-care <ul style="list-style-type: none"> - 'Types' of support/influences - Information giving; style and level - Different views of woman and practitioner 	

Appendix 13: Topic guide for the lymphoedema practitioner interviews

	Discussion topic areas	Considerations
1	Practitioner thoughts, anything you would like to pick up on from the appointment?	In what ways do you think my being here has altered or affected what you did today?
2	Researcher: identify examples from the appointment; and ask about decisions made	Why did you...? Would you always? Do you think...?
3	Making an assessment <ul style="list-style-type: none"> - Important aspects and cues relevant to this woman/women - Views on examining and measuring - Anticipating future issues/needs - Awareness of low mood 	Common problems or issues/differences Type of documentation
4	Making decisions about support and treatment <ul style="list-style-type: none"> - Decisions about self-care - Predicting and anticipating future need and self-care activity - Views on teaching about self-care e.g. self-massage - Views on information/education materials - Dealing with expectations of the woman - Altering practice- when and why? 	Experiences with other women Views on choice available to woman
5	Views on supported self-care <ul style="list-style-type: none"> - Relevance to own work - Views on what this means; and possible examples from what do or would like to do 	
6	Service context <ul style="list-style-type: none"> - 'Patient' group seen at clinic - Clinic/other context of work - Constraints and difficulties - Expectations of others - Idea of practice wisdom- examples of changing practice in self and others - Resources used/required 	Workload Possible choices or aspirations for future change
7	Education and development <ul style="list-style-type: none"> - Level of education, disciplinary background - Time in post/context of experience - Perspective on speciality in terms of self-care 	Possible role models and why?

Appendix 14: Topic guide for the interviews with women

Interview 1	
	Discussion topic area
1	Introduction and purpose of interview
2	How have things been since I met you last week at the clinic?
3	<p>Experience of lymphoedema in context of breast cancer What changes did you notice about your body that made you think you had lymphoedema?</p> <p>Do you speak to your breast cancer doctors at all about lymphoedema; what are their views?</p>
4	<p>Experience of self-care. What sort of things do you do on a day-to-day basis to care for your arm/deal with your lymphoedema?</p> <p>How helpful are these in dealing with your lymphoedema?</p>
5	<p>Context/influences What influences what you do: others; your situation; work; home and family life?</p>
6	<p>Types of support In what ways do others support you or help you in dealing with your lymphoedema?</p>
7	<p>Experience of the lymphoedema clinic When you went to the clinic, was it what you expected?</p> <p>Have you talked to the lymphoedema nurse/physiotherapist since then or anyone else from the clinic/hospital/GP about your lymphoedema?</p>
8	<p>Supported self-care This study is interested in supported self care (for example, how women can be supported to deal with their lymphoedema), what do you understand by that term and what it might mean for you?</p>
9	Have you an idea in your mind about what to expect in the next 3 months?

Interview 2 at 3 months	
	Discussion topic area
1	Introduction and purpose of interview
2	How have you been since last time we met in xxx?
3	In what ways is the lymphoedema bothering you just now, if at all? What do you notice at the moment about the lymphoedema and how it affects you and your body?
4	Experience of self-care What sort of things are you doing to care for your arm and how helpful are they?; explore practicalities. Do you feel you can make choices about what you do and what influences your choices? Are there any things you have had particular difficulties with?
5	Types of support In what ways are others such as family and friends giving you help or support with your lymphoedema?
6	Experience of the lymphoedema clinic Have you had contact with the LP since last time- what do you feel you need from her?
7	Last time you said...., what are your thoughts on that now? Last time you seemed...., how do you feel now?
8	Have you an idea in your mind about what to expect in the next 3 months?

Interview 3 at 6 months	
	Discussion topic area
1	Introduction and purpose of interview
2	How have you been since last time we met in xxx?
3	<p>In what ways is the lymphoedema bothering you just now, if at all?</p> <p>What do you notice at the moment about the lymphoedema and how it affects you and your body?</p> <p>In what ways do you feel the changes that happened in your body after having breast cancer treatment affected how you feel about yourself/ and how you care for yourself?</p>
4	<p>Experience of self-care</p> <p>In what ways do you think you have changed the way you deal with/care for your lymphoedema since we first met six months ago? Do you feel you are getting to know more about how lymphoedema affects you and what you can do?</p> <p>Are there any things you have had particular difficulties with at the moment? Do you feel you can make choices?</p> <p>Do you feel you have all the information you might need to make choices or decision about dealing with your lymphoedema in the future; where will you go for help or information?</p>
5	<p>Types of support</p> <p>In thinking and about how others (such as family, friends and the health professionals) might help or support you with your lymphoedema; what are the most useful types of support?</p> <p>What other ways might you like to get help with lymphoedema (e.g. groups, specialist exercise)?</p>
6	<p>Experience of the lymphoedema clinic</p> <p>Have you had contact with the LP or other health professionals about your lymphoedema in the last three months?</p> <p>What treatments have you had from the clinic/LP and how helpful</p>

	<p>have they been?</p> <p>How important is the relationship you build up with someone like a health professional and are there ever any instances where you don't feel people have listened to you or recognised you might be worried or upset?</p>
7	<p>Last time you said...., what are your thoughts on that now? Last time you seemed...., how do you feel now?</p>
8	<p>Some people say it is better to be forewarned about lymphoedema and diagnose it early, what are your thoughts about that?</p>
9	<p>If you met someone who had just developed lymphoedema, what advice would you give them?</p>
10	<p>Have you an idea in your mind about what to expect in the future?</p>

Appendix 15: Coding framework from small group discussion data analysis showing early themes

1. Medicalised world around women with breast cancer

- Dealing with health care professionals and the health care environment
'His pride was dented'
- Lack of health care professional knowledge or interest
- Lymphoedema blame and cause in terms of breast cancer treatment

2. 'There's the infamous arm'

- When and why it started: changes over time
- Living in a/my body with lymphoedema
- Clothing issues

3. Options and expectations

- 'Frustration that so little can be done'
- Making 'good' and 'bad' choices to fit in with lifestyle
- Faithfully following advice
- Wondering 'will it go?'
- Looking for other options, i.e. liposuction, MLD

4. 'Got to get a perspective'

- Glad to be alive, 'lucky ones'
- Acceptance
- Comparing with others
- Finding out how others deal with it
- Changing perspectives
- Political awareness of different needs; altruism

5. 'How much of a story do you want to give anybody?'

- Relating to others, talking and sharing information
- Comparing with others
- Presenting self; sleeve draws attention; clothing issues

6. Experiences of supported self care

- Experiences of the lymphoedema practitioner; 'someone to call on'; 'good at getting back'; 'happy for you to ask questions'; and 'wonderful to talk to'
- Support and expertise: e.g. experiences of cellulitis
- Views on supported self care in other conditions