

**EXPLORING THE PHYSIOTHERAPEUTIC NEEDS OF  
BREAST CANCER PATIENTS: A QUALITATIVE STUDY OF  
PATIENT EXPERIENCE**

**by**

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## **Abstract**

**Background:** It has been reported that patients should have access to physiotherapy at all stages throughout their treatment pathway following a diagnosis of breast cancer. As the number of breast cancer survivors increases the need for research into the impact of breast cancer and its treatment has been recognised as a priority for the NHS. It is acknowledged that breast cancer patients have specific support needs and if these remain unmet, this is likely to have implications for long term rehabilitation outcomes.

**Aim:** To explore the experience of physiotherapy care received by patients with breast cancer.

**Research design:** Based on an exploratory qualitative methodology design, participants (n=19) who had received physiotherapy care from a Specialist Breast Care Physiotherapy Service were stratified into one of three subgroups, dependant on their previous experience of physiotherapy. Phase One involved each subgroup taking part in a group discussion using a modified nominal group technique and in Phase Two one member of each subgroup who volunteered to take part was randomly selected to participate in a one-to-one in-depth interview. A thematic network analysis was undertaken on the data collected.

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**Results:** Participants valued a patient-centred holistic approach to care and access to a Specialist Service with an experienced clinician. In particular the importance of the therapeutic alliance and the value of psychological, emotional and educational support emerged, with the participants feeling empowered in their recovery.

**Conclusion:** Participants reported an overall positive experience of their physiotherapy care. Breast cancer patients require specialist physiotherapy input at all stages of their treatment pathway, including pre-operative intervention.

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## **1. Introduction**

### **1.1 Incidence of breast cancer**

Breast cancer has been the most common cancer in the United Kingdom since 1997 and it accounts for 31% of all new cases of cancer in females (Cancer Research UK, 2012). The rate of new diagnoses increases rapidly amongst those aged 40 years, rising from about 1 per 100,000 in young adults to just over 400 per 100,000 in those aged over 85 years (Office for National Statistics, 2011). Although much progress has been made in combating breast cancer, women diagnosed endure multiple assaults to the body from both the disease and treatments. Life prolonging surgical and adjuvant therapies are associated with complications and side effects that can lead to functional limitations, disability and a negative impact on quality of life, for some of the nearly three million people diagnosed annually (Harris et al., 2012; Reigle, 2006).

Many patients are working at the time of diagnosis and still have many years to live (Johansson et al., 2003). Therefore the importance of supporting patients to return to function and their working role, to promote independence and improve quality of care, has been increasingly recognised as a priority. In 2010 an economic modelling commissioned by Macmillan Cancer Support to demonstrate the value of co-ordinated cancer services reported that if just half of the breast cancer survivors who initially return to work but then leave, were helped to stay in work, the economy could save £30 million every year.

Receiving a breast cancer diagnosis is a major life event for many women and its impact can exert an immense burden both in the diagnostic and treatment phases (Topping, 2001), resulting in a striking impact on a person's daily life.

Recovery can be a long process that takes years rather than months (Mols et al., 2005). The significant improvements in cancer services over the past ten years mean cancer survival is improving (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010b). The latest age-standardised relative survival rates for breast cancer in England during 2005-2009 show that 95.8% of women are expected to survive their disease for at least one year and 85.1% surviving five years or more. The five year relative survival rates for breast cancer are among the highest of the 21 most common cancers in England (Office for National Statistics, 2011). These statistics emphasise that more attention should be directed to how breast cancer survivors cope with the consequences of the often intensive treatment and their needs after completion of treatment (Ewertz and Bonde Jensen, 2011).

## **1.2 Treatment of breast cancer**

Surgery is the mainstay for treatment of breast cancer and is usually the first treatment option. With earlier detection and diagnosis of the disease, breast conservation surgery with local excision of the tumour has been more frequently performed rather than mastectomy. Similarly, less axillary surgery has been necessary, especially with sentinel lymph node biopsies, reducing the morbidity of axillary clearance (National Institute for Health and Clinical Excellence, 2009).

Medical treatments for breast cancer may also include chemotherapy, hormone replacement therapy and radiation. Depending on the histology and extent of the disease, combinations of surgery and adjuvant therapy may be used (Fourie, 2008). Although effective in treatment of cancer, treatment is often

associated with side effects which may affect a patient's function and quality of life (Ghazinouri et al., 2005). Breast cancer treatment is often followed by a decline in upper body function, even at some time distant from therapy (Kärki et al., 2005).

The incidence of shoulder morbidity has been found to be significantly and substantially higher in women treated with post-surgical radiotherapy (17%) compared with a group of women who received no radiotherapy (2%) (Højris et al., 2000). Ewertz and Bonde Jensen (2011) reported that local therapies such as surgery and radiotherapy may cause persistent pain in the breast area, arm and shoulder in 30-50% of women after three to five years and restriction of arm and shoulder movement in 35% of women. Lauridsen et al (2000) reported that irradiated patients experience significantly more severe discomfort in terms of their symptoms of reduced strength and numbness and burning sensations.

### **1.3 Post treatment dysfunction**

Women's experience of breast cancer is complex, affecting all aspects of life, during and after treatment and can create a diversity of needs (Bloom et al., 2004; Thewes et al., 2004). The 'Health and Well Being Survey' conducted by Macmillan Cancer Support in 2008 found that cancer survivors reported poorer health and well-being than the general population. It reported that 84% of breast cancer survivors who responded to the survey said they had experienced at least one physical health problem within the last 12 months.

For decades, reduced shoulder range of movement and functional impairments have been recognised as a problem after breast cancer surgery and treatment

(Harris et al., 2012; Ewertz and Bonde Jensen, 2011; Lattanzi et al., 2010; Lee et al., 2010; Reigle, 2006; Kärki et al., 2005; Bendz and Olsen, 2002; Box et al., 2002a; Kwan et al., 2002; Tasmuth et al., 1996). Crosbie et al (2010) found that altered motor patterns of the scapula are associated with mastectomy on the same side. Other common side-effects of treatment include arm and breast lymphoedema, reduced arm strength, scar tightness, myofascial dysfunction, axillary web syndrome, donor site morbidity following reconstruction and pain (National Institute for Health and Clinical Excellence, 2009; Cheville and Tchou, 2007; Macdonald et al., 2005; Johansson et al., 2001; Lauridsen et al., 2000).

In their study in 2005, Kärki et al found that the most common impairments six months after operation were breast and axilla scar tightness, axilla oedema and neck-shoulder pain and about one-third of the patients still experienced neck-shoulder pain, breast and axillary scar tightness and upper limb numbness one year after the operation. Kwan et al (2002) found that a substantial percentage of patients suffered from persistent arm and shoulder symptoms two years or more after treatment for breast cancer. Approximately half of the study subjects (total=744) were symptomatic with arm or shoulder problems after treatment, increasing to 70% if both axillary surgery and axillary radiotherapy were used.

#### **1.4 Need for physiotherapy/rehabilitation**

The focus on improving patient experience is demonstrated in Domain Four of NHS Outcomes Framework 2011/2012 (Department of Health, 2010a) and the Department of Health demonstrated further commitment to this with the NHS Cancer Patient Experience Survey 2011-12 (Department of Health, 2012c). The concept of survivorship has become increasingly recognised over the last

decade, due to improved survival rates, more accessible data on the symptoms and effects of breast cancer treatment and improved 'patient voice' (Creswell, 2007). More patients are now recognising that their symptoms are treatable and are accessing rehabilitation services to support their recovery.

It is acknowledged that rehabilitation services delivered by allied health professionals are vital in promoting well-being and independence and maximising quality of life throughout the cancer pathway (Macmillan Cancer Support, 2011; National Cancer Action Team, 2009a; National Cancer Action Team, 2009b). Healthcare professionals acknowledge the importance of 'after care' following breast cancer surgery to reduce potential physical and psychological complications, and patients frequently express a need for access to timely preventative information (Lawrance and Stammers, 2008).

The 2004 National Institute for Health and Clinical Excellence guidelines entitled 'Improving supportive and palliative care for adults with cancer' promoted the role of rehabilitation and highlighted that more could be done for cancer survivors. In 2007 the Department of Health Cancer Reform Strategy brought increased attention to the long term consequences of a cancer diagnosis and the importance of enabling survivors to return to active lives following the completion of treatment. As described by NHS London in the AHP Cancer Care Toolkit (2012) and the NHS National Cancer Peer Review Programme 'Manual of Cancer Services: Rehabilitation Measures' (NHS, 2008), physiotherapists help to maximise the patient's potential in terms of functional ability and independence and help to reduce distressing symptoms.



As acknowledged by the Department of Health, Macmillan Cancer Support and NHS Improvement (2010b) in the National Cancer Survivorship Initiative (NCSI) Vision, the next challenge is to “understand the needs of those living with breast cancer today and to develop models of care which meet their needs” (page 4). Table 1.1 below highlights the key shifts and main areas of survivorship in the NCSI document.

**Table 1.1 NCSI Key shifts and main areas of survivorship**

<b>Key shifts</b>	<b>Main areas of survivorship</b>
Improving recovery	Support at the time of diagnosis
Promoting holistic and individual care	Promoting recovery
Supporting self-management	Sustaining recovery
Tailored support	Consequences of treatment
Routine measurement of patient experience	Recurrent or on-going disease

The document describes the need to empower patients to manage themselves based on their needs and preferences. It states the importance of promoting holistic and individual care. As defined by McEvoy and Duffy (2008) in their concept analysis study, holistic care embraces the mind, body and spirit of the patient, in a culture that supports a therapeutic relationship, resulting in wholeness, harmony and healing.

The NCSI document also acknowledges the need for services which are responsive to individual needs and ensuring access to specialist care when needed. This is also supported by Ewertz and Bonde Jensen (2011) who

recommend the need for high priority to be directed towards research into the rehabilitation needs of breast cancer patients.

As outlined in the Department of Health's (2012b) plans for the new Health and Care System from April 2013, the focus is working to champion health and wellbeing across government and increased attention on prevention and rehabilitation. There is an increased recognition of the importance of supporting the functioning of patients following a diagnosis of cancer, in order to support return to work. The Department of Health (2012a) NHS Mandate and Outcomes Framework 2013/2014 sets out the outcomes and corresponding indicators that will be used to hold the NHS Commissioning Board to account for improvements in health outcomes, as part of the government's mandate to the NHS Commissioning Board. The focus of this document is to stimulate continuous improvement and encourage partnerships with service users, especially with regards to Domain Three which focuses on helping people to recover from episodes of ill health or following injury. There is growing recognition of the importance of keeping people well and healthy, and empowering them to self-manage and function at an optimal level after completion of treatment for cancer.

Quality of life depends on physical function and with more women now living with their disease, issues of survivorship, both physical and psychosocial, are of increasing importance (Ewertz and Bonde Jensen, 2011; Fourie, 2008). After treatment, most patients have a wish to get physically fit again; being able to perform whatever activities they used to perform before the breast cancer and its treatment (Johansson, 2005). According to the World Health Organisation

(WHO), rehabilitation is a process aimed at enabling patients to reach and maintain optimal physical, intellectual, psychological, social and spiritual levels of functioning (Ewertz and Bonde Jensen, 2011).

The WHO International Classification of Function, Disability and Health (ICF) describe a framework that takes a biopsychosocial approach to describing function. As defined by Lundvik Gyllensten et al (1999) the biopsychosocial model focuses on the interacting role of biological, psychological and social factors in assessing an individual's health or illness in the process of diagnosis and treatment. The model makes explicit the significance of the relationship between body and mind as well as the relationship between patient and therapist for effective treatment.

Within the ICF framework, function is defined as the interactions between an individual, their health condition and the social and personal context in which they live. In the context of breast cancer, morbidity associated with the disease and its treatments can lead to impairments in body functions and structures, potentially leading to impairments in activity and participation (Campbell et al., 2012).

The ICF core set for breast cancer allows a comprehensive and systematic description and documentation of a patient's problems and resources, and represents the typical spectrum of problems in functioning and contextual factors that may influence patients with breast cancer (Glaessel et al., 2011). In their report of the results of the WHO consensus project to develop the first version of both the Comprehensive ICF Core Set and a Brief ICF Core Set for

breast cancer, Brach et al (2004) concluded that the Brief ICF Core Set included a total of 40 second-level categories, with 11 on body functions, five on body structures, 11 on activities and participation, and 13 on environmental factors. The fact that even in the Brief Core Set 40 categories are still included, reflects the important and complex impairments, limitations and restrictions of body functions, activities and participation involved, as well as the numerous interactions with environmental factors.

Women often report being uninformed regarding potential treatment side effects and the risk that these problems may persist long after treatment is completed. Patients express strong, unmet needs for education, information and intervention for these side effects (Binkley et al., 2012; Jones et al., 2011; Hodgkinson et al., 2007; Hack et al., 2005; Bloom et al., 2004). These unmet needs can be irrespective of years since diagnosis and length of time since diagnosis is not associated with lower needs (Hodgkinson et al., 2007).

An early American study in 1985 recognised that patients who receive physiotherapy achieve better function and return to pre-operative range of movement quicker post mastectomy than those who do not (Wingate, 1985). Since then it has been increasingly recognised that physiotherapy can significantly reduce post-treatment upper limb dysfunction and patients should be able to access physiotherapy at varying stages throughout their treatment pathway (Binkley et al., 2012; Lattanzi et al., 2010; National Cancer Action Team, 2009a; Çinar et al., 2008; Beurskens et al., 2007; Cheville and Tchou, 2007; Gordon et al., 2005; Lauridsen et al., 2005; Morimoto et al., 2003; Box et al., 2002a; Lauridsen et al., 2000; Wingate et al., 1989).

In their randomised controlled trial (RCT) in 2005, Lauridsen et al reported that physiotherapy can improve shoulder function significantly, even when instituted as long as six months post-operatively. For patients who are unable to achieve the shoulder range of movement post-operatively that is required for arm positioning for radiotherapy, physiotherapy intervention can prevent delays in treatment and allow patients to commence radiotherapy within the window of opportunity.

Despite the recognised awareness of the physical impairments that can occur after breast cancer treatments, there is little information in the peer-reviewed literature about how best to manage these impairments (Harris et al., 2012).

Although physiotherapy is widely accepted as beneficial there is variation as to which regimen to use (Todd and Topping, 2005). There is variation in protocols across breast units (Todd et al., 2008) and in some areas there is no physiotherapy provision at all. Referral to physiotherapy tends to be reactive rather than proactive, especially when limited movement interferes with radiotherapy planning (National Institute for Health and Clinical Excellence, 2009; Lauridsen et al., 2005). There is increased recognition of the need to move towards a more 'preventative' approach through early intervention and recognition of treatment complications (Gomide et al., 2007; Box et al., 2002a).

Evidence from RCTs suggests that physiotherapy or instructed exercise interventions are associated with improved patient compliance, a better range of arm movement and lower rates of lymphoedema compared to control arms in which patients receive booklets or other education for unsupervised exercise

(Çinar et al., 2008; Beurskens et al., 2007; Lauridsen et al., 2005; Box et al., 2002b).

A 2010 Cochrane review reported that structured exercise during the postoperative period had significant short-term benefits in improving shoulder range of movement, with physiotherapy resulting in additional benefits for shoulder function (McNeely et al., 2010). Physiotherapy interventions have the potential to overcome and improve upon upper extremity impairments, functional limitations, and quality of life for the patient battling and surviving breast cancer (Lattanzi et al., 2010). Emphasis is placed on minimising long-term side effects of treatment to facilitate return to healthy lives (Lee et al., 2010). It is recognised that if these rehabilitation needs are not met, this could lead to substantial costs for society due to increased morbidity, reduced ability to perform a full-time job, and premature retirement from the workforce (Ewertz and Bonde Jensen, 2011; Gordon et al., 2005).

The pathophysiological targets of rehabilitation include soft tissue fibrosis, deficits in muscle strength and flexibility, lymphatic insufficiency, muscle hypertonicity and neural hypersensitivity. Rehabilitation involves multi-modality approaches that ideally evolve over time in response to patient progress (Cheville and Tchou, 2007). Following surgery the adherence between muscles, subcutaneous tissue and the skin in the axilla and pectoral area mechanically inhibit shoulder movement and adjuvant radiotherapy and chemotherapy adds to the firm fibrous attachment among the structures. Many patients are afraid to overcome the tightness of scar tissue even when the painful side effects of

treatment pass. They accept the limitations in mobility and try to compensate by using the other arm or by changing work procedures (Lauridsen et al., 2005).

Psychological problems can remain an issue for many survivors and these patients have an increased risk of major depression (Ewertz and Bonde Jensen, 2011). Many women report the need for emotional support from their medical team for reassurance, to support recovery (Thewes et al., 2004) and to ensure well-being (Bloom et al., 2004). Physiotherapists are often called upon to adopt a counselling role when treating patients with emotional as well as physical problems (Thomson et al., 1997; Saunders and Maxwell, 1988).

As the number of survivor's increases the need for research into the impact of breast cancer and its treatment has been recognised as a priority for the NHS. It is recognised that breast cancer patients have specific support needs and if these remain unmet, they are likely to have implications for long term rehabilitation outcomes. In view of this realisation, there is now an urgent need for physiotherapists to develop effective and high quality rehabilitation protocols for breast cancer patients, to support their functioning and to prevent permanent, limiting disabilities (Campbell et al., 2012; Harris et al., 2012; Gomide et al., 2007; Reigle, 2006; Kärki et al., 2005).

### **1.5 Justification for research**

Patient engagement in the development and monitoring of health services and in the conduct of research has increased in importance in recent decades (Corner et al., 2007). It is now more recognised that qualitative methods and conceptual analysis can be used to attempt to understand the meaning and

interpretation of human social arrangements and to convey the experience of individuals (Lundvik Gyllensten et al., 1999; Fitzpatrick and Boulton, 1994).

As described by Creswell (2007), qualitative research can represent the voice of the participants, the reflexivity of the researcher and a complex description and interpretation of the findings. Qualitative methods have enormous potential to illuminate how health care operates and the impact of care on patients, however few studies give voice to the women participating in the physical rehabilitation programs following breast cancer treatment, intended to ameliorate their deficits (Lattanzi et al., 2010).

In their study investigating patient-centredness in physiotherapy from the perspective of the chronic low back pain patient, Cooper et al (2008) found value was placed on communication, individual care, decision-making, information, the physiotherapist and the organisation of care. Patient satisfaction with physiotherapy can be influenced by many factors, including the interaction between therapist and patient, which may involve more physical contact and active involvement of the patient than encounters with other health professionals. Therefore, it is suggested that physiotherapy patients' perceptions need a sensitive research methodology to attempt to explore this (Monnin and Perneger, 2002).

This study aims to contribute knowledge regarding the perceived physiotherapeutic needs of breast cancer patients, by allowing patients to express their own individual and personal views and the opportunity to explore these ideas with a researcher who has extensive experience in working with this



patient group. Little previous work has been done to explore what breast cancer patients feel they require in terms of physiotherapy and what aspects of their care they have valued the most and least.

Prior to commencing this study, the researcher had led a preliminary focus group with a sample of this patient population sponsored by Macmillan Cancer Support, as part of a submission of a Macmillan 'Case of Need'. The aim of that session was to gain insight into service user experience and to begin to explore what aspects of the Physiotherapy Service patients valued the most and least, in terms of their daily life. Although that study proved useful in terms of beginning to identify common themes, it was clear that the process had merely 'skimmed the surface' of the patients' experiences and further in-depth exploration was required in terms of physiotherapeutic needs.

By carrying out this study the researcher hopes to better understand the impact of the Specialist Breast Care Physiotherapy Service, which was established as a pilot service in June 2010, in accordance with the National Institute for Health and Clinical Excellence guidelines, 'Improving Supportive and Palliative Care for Adults with Cancer' (2004) and the National Cancer Action Team 'Breast Cancer Rehabilitation Pathway' (2009a). As outlined in the Department of Health, Macmillan Cancer Support and NHS Improvement National Cancer Survivorship Initiative (2010b), the service has been designed to accommodate the increasing numbers of breast cancer survivors in the future and to optimise the use of NHS resources. Prior to this Specialist Service for breast cancer patients, the Trust was falling short of Government guidelines, as there was no standard referral pathway for patients with breast cancer to access

physiotherapy, despite the high incidence of pain and shoulder dysfunction. This lack of support and acknowledgement of potential problems for breast cancer patients is widely acknowledged in previous literature (Cheville and Tchou, 2007; Lee et al., 2005).

The new Service has been developed to support patients post-operatively on the ward, with the provision of a Specialist Outpatient Service for treatment related problems. The Service is delivered by a physiotherapist who specialises in the treatment of breast cancer patients and who has extensive clinical experience working with this patient group. The need to evaluate the impact of the new Service was identified as a priority. Hence, this study aims to explore the experience of physiotherapy care received by patients with breast cancer in this population, with a view to making recommendations for clinical care pathways based on the study

### **1.6 Demonstrating reflexivity**

I recognised the impact of myself as an integral part of the research situation in which I participated and the potential influence I may have exerted on the practice that was being explored. However because qualitative research is intended to give priority to the meanings and attributions that respondents bring, I acknowledged the importance of recognising myself as someone who is actively involved in constructing those meanings rather than someone who is present to 'collect' them passively (Chew-Graham et al., 2002).

As acknowledged by Patton (2002), reflexivity requires self-reflection, self-knowledge and a willingness to consider the role of the researcher throughout

the entire research process. I strived to maintain a reflexive approach throughout this study, in order to enable the reader to understand how my role as both the researcher and clinician has impacted on those researched (McGarry et al., 2010; Arber, 2005). As McNair et al (2008) describes, I have acknowledged my role as a clinician-researcher may allow me to become a potential insider in relation to interviewees and I am aware of the importance of negotiating shared understanding to avoid insider assumptions.

As described by Fisher (2011), as an experienced clinician, I am well practiced in carrying out interviewing from a clinical perspective. However I reflected that I was less confident in carrying out a research interview, in which confidence was gained through the research process. This challenged me to attempt to 'think differently' and remain self-aware of my influence on the interview process as a dual-role clinician-researcher.

### **1.7 Dual role of clinician-researcher**

As acknowledged by Yanos and Ziedonis (2006), the dual role clinician-researcher can facilitate both the development of clinically relevant research and the dissemination of evidence-based treatments into routine clinical services. However there is a risk that this can pose both ethical and role conflicts for the researcher. They conclude that the establishment of an 'integrated identity' is ultimately the most comprehensive means of balancing and prioritising ethical issues. This strengthens the findings of Miller et al (1998) who describe the integration of dual roles to develop a 'coherent moral identity' that promotes good ethical judgement. I have remained committed to maintain my ethical responsibility as a dual role clinician-researcher throughout the entire

process of this research. A table demonstrating some of the positive and negative aspects of a dual role clinician-researcher are presented in Appendix One.

### **1.8 Aim and objectives of the study**

The aim of the study was to explore the experience of physiotherapy care received by patients with breast cancer.

The study objectives were to

- identify which aspects of care patients value most and least
- gain insights into why these aspects are valued or disliked
- make recommendations for clinical care pathways based on the outcomes of this study

## **2. Literature Review**

As discussed briefly in Section 1.5, there is a lack of previous studies exploring the perceived needs of breast cancer patients through exploration of their own experience. There is a growing body of evidence confirming that physiotherapy is effective in the management of post treatment dysfunction following a diagnosis of breast cancer. However more in-depth qualitative research is required in order to represent evidence based practice and explore the specific aspects of care patients value the most and least.

A narrative review of the literature has been conducted, focused on a selection of relevant studies that report the personal experience of patients with breast cancer. Due to the scope of this study, the researcher has selected a small number of studies within each sub-section, with an aim to summarise the most relevant findings pertinent to this topic area.

As discussed in Section 1.4, there is a growing awareness of the complex rehabilitation needs of breast cancer patients and the impact dysfunction can have on a patient's quality of life. Thus the researcher has attempted to demonstrate a selection of studies that have explored breast cancer treatment related dysfunction including lymphoedema and physical limitations, and also issues related to patient education. As demonstrated in Table 1.1, the NCSI key shifts include promoting holistic and individual care and measurement of patient experience. As stated in Section 1.4, the WHO ICF core sets for breast cancer also represent a biopsychosocial approach to describing function. Therefore the concepts of patient-centred care and the biopsychosocial approach to patient

care, the role of empathy and the relationship developed between therapist and patient has been discussed.

As stated in Section 1.5, the outcomes of this study will be used to evaluate the impact of the Specialist Physiotherapy Service that has been developed to support patients following a diagnosis of breast cancer. Therefore two studies that focus on service evaluation have been included in this review.

## **2.1 Lymphoedema**

A few qualitative studies have attempted to explore women's experiences with lymphoedema, however little is reported from the perspective of the patient themselves (Lattanzi et al., 2010). Johansson et al (2003) carried out an exploratory study of patients' experiences of breast cancer related lymphoedema (BCRL) in Sweden, using semi-structured interviews. Three main themes emerged: 1) attitudes from people in their surroundings, 2) discovery and understanding of oedema as a chronic disease and 3) its treatment and coping, including both problem-focused and emotion-focused strategies. This report of patients feeling poorly informed about the possibility of developing BCRL was also confirmed by Thomas-Maclean et al in 2005, who carried out a two phase study to explore patient experience of BCRL. A strength of this study was that validation of analysis was verified through the findings being shared with members of a breast cancer support group that included several women who suffered from BCRL.

The importance of patient education and the need for further studies exploring patient experience of BCRL has been highlighted above.

## **2.2 Physical impairment and exercise**

Kärki et al (2005) carried out a study to investigate the impairments of upper body activity limitations and participation restrictions six months and 12 months after an operation for breast cancer and to examine the impairments on activity limitations. It was reported that the number of impairments at six and 12 month follow-ups were quite constant and about one-third of the patients still experienced neck-shoulder pain, breast and axillary scar tightness and upper limb numbness one year after the operation. Activity limitations in lifting, carrying and reaching out were experienced by many of the subjects in the study. The findings confirmed that an effective, individually tailored education and therapy for supporting function will enhance working ability and overall well-being among breast cancer patients.

A Swedish qualitative study by Larsson et al (2008), explored the experience of physical activity after surgery of women treated for breast cancer. A common theme to emerge was patient perception of a lack of control over their situation and the feeling of loneliness. It was recognised that the incentive to remain or return to a normal physical condition is an important motive for physical activity after breast cancer surgery. They confirmed the importance of instructions and motivation in exercising and the importance of the therapist's skills to encourage them individually and to empower patients. However some participants felt that the physiotherapists did not have enough time for follow-up and there wasn't enough time for participants to express their thoughts and questions. A strength of this study is that the two physiotherapists who performed the interviews had no previous contact with the participants, therefore reducing the risk of researcher bias.

Another study to explore the experience of exercise by patients was conducted by Emslie et al (2007), who carried out a focus group study of women undergoing breast cancer treatment who had taken part in a supervised group exercise trial. Interestingly, their findings supported a more action-orientated format for the group, rather than a talk based group, which therefore challenges stereotypes about women invariably preferring to cope with cancer through emotional disclosure. The authors acknowledged the choice of a focus group for data collection had the potential to discourage some participants to express minority points of view, as majority opinions may close down discussion. They also highlighted the argument that the sample could be construed as self-selected and therefore biased towards women who have had a positive experience of the trial and were committed to exercise. They aimed to reduce this by sampling women who had attended fewer of the exercise classes, those in the control group and those who did not exercise regularly.

The studies discussed above have acknowledged the significant and often long-lasting physical impairments that may develop secondary to breast cancer treatment, and the importance of individualised care and encouragement in regaining function and empowering patients.

### **2.3 Patient education**

In an Australian exploratory cross-sectional survey study by Lee et al (2010) investigating patient perceptions of arm care and exercise advice after breast cancer surgery, topics raised by respondents included perceptions of inadequate and conflicting advice, lack of acknowledgement of women's concerns about upper limb impairments and fear of breast cancer related



lymphoedema (BCRL). They discuss one participant in particular who stated she did not feel the provision of a booklet was an adequate form of advice and the authors infer that this woman believed that advice about arm care and exercise should be individualised by healthcare professionals. Often in current practice, patients are simply given an exercise and advice booklet as part of their surgery information, without seeing a physiotherapist to carry out a formal pre-operative assessment or deliver individualised care. Another issue raised by this study acknowledges the wealth of information provided to women about BCRL and risk-reduction strategies, but when women presented with arm swelling, their symptoms were disregarded. The authors acknowledge that a possible explanation for this is a lack of knowledge about what can be done to manage BCRL and to whom professionals should refer patients. Women's comments were focused on dissatisfaction with advice received about exercise and arm impairments, care and use.

Another study that confirmed the unmet informational and psychosocial needs following completion of treatment for breast cancer was carried out by Jones et al in 2011. They confirmed that survivors are better able to recover and adjust if they possess realistic goal expectancies and the resources to achieve them. Binkley et al (2012) also expressed strong unmet needs for education, information and intervention for side effects secondary to breast cancer treatment. Their study supported a prospective surveillance model of rehabilitation that offered to meet the needs of patients identified through their own perspective, including physical impairments related to breast cancer treatment; activity and performance limitations; education, information, and support; and exercise and rehabilitation intervention.

In a study conducted by Thewes et al in 2004, a wide variety of on-going psychosocial and information needs were reported by breast cancer survivors including support needs, psychological needs, practical needs, physical needs and information needs. Many women spoke about an unmet need to determine whether their symptoms were normal, and a need to receive reassurance that their symptoms were not a sign of recurrence. The authors acknowledged the importance of coping strategies such as positive thinking, or the use of distraction to avoid thinking about their fears. A number of young women spoke about being in 'survival mode' during treatment and said emotional difficulties mainly emerged after treatment ended. Tiedtke et al (2010) highlight in their study the unmet informational needs expressed by many patients in their goal to return to work.

Pollock et al (2011) carried out an exploratory study into patients' experience of receiving information about cancer and derived that verbal information was much more highly valued than written and participants expressed a keen desire to receive only tailored, specific information relevant to their particular case. In a study carried out by Bloom et al (2004), almost all of the participants stressed the need for education during treatment for breast cancer, in their study exploring the quality of life of young breast cancer survivors.

As demonstrated above, there is a growing body of evidence highlighting the unmet information and education needs of breast cancer patients and the value of face-to-face verbal advice over the provision of only a booklet post-surgery.

## **2.4 Quality of life**

Manning-Walsh (2004) carried out a cross-sectional, correlational study with breast cancer patients, examining the relationships between symptom distress and quality of life when religious and personal support was introduced as mediating variables. She defined quality of life as a subjective multi-dimensional concept including physical, social and family, emotional, functional and spiritual dimensions. Although her results may not be generalisable due to convenience sampling and cross-sectional design, she reports that social support from family members and friends helped to decrease the negative effects of breast cancer treatment related symptoms on quality of life.

## **2.5 Rehabilitation**

A study conducted in America by Lattanzi et al (2010) explored the experience of physical rehabilitation, as well as to identify recommendations for physical and occupational therapy practice from the perspective of patients undergoing therapy for breast cancer related impairments. Using a purposive sampling technique, the study recruited a sample size of ten participants and data collection was carried out through semi-structured interviews. A strength of this study was that data analysis was cyclical and ongoing and involved all six researchers in analysing and triangulating all pieces of data. A number of themes emerged from analysis of the data, including challenges with obtaining referrals, challenges with patient education, improvements in functional impairments, emotional support and the benefits of a specialised clinic environment. They acknowledged the value of consistency in seeing the same therapist each time and the ability to form a therapeutic relationship.

The study concluded their support of pre-surgical therapy consultations and the need for competence in the management of all impairments and functional limitations associated with breast cancer treatment. In addition, an awareness of the emotional support the therapist has the capacity to provide or not provide, and the importance of creating an inviting, non-clinical environment were also identified as recommendations. The primary researcher was a physiotherapist with 20 years experience of working with patients with breast cancer. Whilst this might be a threat to validity given the potential for researcher bias, it is also a strength in that the researcher was familiar with breast cancer treatment procedures and practices.

## **2.6 Patient feedback**

The use of patient feedback has been utilised previously to explore the concept of patient satisfaction. Beatti et al (2005) acknowledged the high correlation between patient satisfaction and the quality of the physiotherapist-patient interaction and reported that patients who received their treatment from the same therapist were approximately three times more likely to report complete satisfaction with care than those who received care from more than one provider.

More recently, the use of patients' experiences is being recognised as a relevant way of evaluating services. A qualitative study by Kidd et al in 2011, using a purposive sample of eight participants, looked at patient perspectives of musculo-skeletal physiotherapy interactions. They discovered five categories to emerge from the data: the ability to communicate, confidence, knowledge and professionalism, an understanding of people and an ability to relate;

transparency of progress and outcome. Patients considered it important that the physiotherapist demonstrate empathy (especially in relation to pain), encouragement and the ability to relate to people and be friendly. Patients insisted that the physiotherapist should locate the patient at the centre of the therapeutic encounter, and make them feel understood and respected. The therapist's self-confidence and knowledge affect the patients' confidence in both the therapist and the therapy, and these concepts are linked to good communication, reassurance and progress. Therefore this improved internal confidence and confidence in the therapist can in turn lead to enhanced patient motivation levels and aid progression.

In a study carried out by Corner et al in 2007, patients rated the management of practical, social and emotional issues as a higher research priority than biological and treatment related aspects of science. This exploratory, qualitative study focused on identifying the research priorities of patients attending UK cancer treatment centres, using a modified nominal group technique study. Participants believed that the emphasis in research had centred on developing cancer treatments whereas the experience of managing the impact of cancer on individuals was felt to have been relatively neglected. Participants called for a balance in research effort so that the personal consequences of cancer are also addressed.

The value of patient feedback has been demonstrated, allowing a greater richness and depth to the research undertaken. The above studies acknowledge the significance of the relationship that can be developed between patient and therapist and the factors that can influence treatment outcomes.

The study by Corner et al (2007) highlights the need for increased awareness of the consequences of breast cancer treatment discussed in Sections 1.3 and 1.4.

## **2.7 Patient-centred/ biopsychosocial approach to patient care**

Over the last decade interest has grown in examining the implications for clinical care of more patient-centred approaches (Ong and Hooper, 2006). It has been recognised that patients value 'clinical encounters' highly and see them as central to their healthcare, especially when they feel empowered by 'being heard' (Dieppe et al., 2002; Williams and Calnan, 1991). The majority of research exploring therapeutic encounters has centred on doctors and patients. Increasing recognition however is given to the importance of understanding how other health professionals interact with patients because current clinical practice emphasises the importance of multi-disciplinary care (Ong and Hooper, 2006).

In 1996 Gilbar carried out a case study exploring the impact of introducing a biopsychosocial approach to patient care in an oncology institute. The conceptual framework of the change was holistic, based on a biopsychosocial approach to cancer. The new approach included a programme for post-mastectomy patients and self-help groups conducted by former mastectomy patients to help new breast cancer patients. Gilbar described the biopsychosocial approach as a holistic treatment of cancer which stresses the connection between body and mind in the process of recovery, as well as the patient's active participation in their recovery through positive thinking and learning coping skills. Patients who participated in the new framework felt more

in control of their lives, in contrast to the sense of helplessness they had felt when they were told they had cancer.

As defined in Section 1.4, Lundvik Gyllensten et al (1999) describe the biopsychosocial model as focusing on the interacting role of biological, psychological and social factors in assessing an individual's health or illness in the process of diagnosis and treatment. They report that the model makes explicit the significance of the relationship between body and mind as well as the relationship between patient and therapist for effective treatment. They acknowledge the impact of effective teamwork in providing care and their results showed emphasis on 'how' interaction was carried out, rather on focusing on 'what' the actual intervention was doing. The expert physiotherapists focused on a constructive dialogue with patients, with empathy, respect, engagement, sensitivity and the ability to listen. They also found that enhancing knowledge and understanding by giving information was another important category in the therapeutic process theme. The ability of the physiotherapist to show empathy, respect, warmth, really listen and be sensitive and intuitive, were seen as important.

These findings can be linked to those of Stenmar and Nordholm (1994) who investigated what physiotherapists believed to be the most important factors in successful treatment. They found that the patients' own resources and the patient-therapist relationship rather than the treatment techniques were the most important factors in explaining why physiotherapy works. They acknowledge that a possible interpretation of these findings is that physiotherapists have learned through experience that 'what' they do (treatment

technique) is less important than 'how' they do it (focusing on the quality of the patient-therapist relationship and the motivation of the patient).

In 2008 George conducted a study investigating the effectiveness of a biopsychosocial approach to individual physiotherapy care for chronic low back pain. The term biopsychosocial approach has not been clearly defined in health literature, however in this study it is described as a holistic intervention that addresses social, psychological and biological aspects of chronic pain. George acknowledges that clinical application of a biopsychosocial approach remains subject to individual interpretation, however states that interventions that support effective outcomes over longer periods could be reasonably considered of greater clinical value than shorter term outcomes.

The review provided a descriptive synthesis and moderately strong evidence for the effect of a biopsychosocial model of care provided by individual physiotherapists. Methods of implementing a biopsychosocial approach varied widely across the studies in the review. All of the studies advocated an intervention that falls within the professional knowledge base of physiotherapists and can be implemented by a sole practitioner, but George states reservations whether the average clinician has the skills to apply these interventions holistically. These findings correlate with Saunders and Maxwell in 1988 who felt that qualified physiotherapists did not possess the relevant interpersonal skills necessary to handle some situations in clinical practice.

These studies emphasise the value of a biopsychosocial approach to care, that incorporates the patients' needs as a whole. Again the value of the therapeutic



relationship has been acknowledged, as in Section 2.6 and discussed further below.

## **2.8 Therapeutic relationship/ alliance**

As demonstrated by Hall et al (2010), there is evidence that a good therapeutic alliance can positively influence treatment outcomes such as improvement in symptoms and health status and satisfaction with care. This study acknowledges the high level of patient-clinician interaction that can develop between the patient and physiotherapist and can subsequently lead to enhanced communication. Importantly, the quality of the alliance between clinicians and patients is in part determined by how clinicians and patients communicate. The term therapeutic alliance is defined in Hall's study as the collaboration between the clinician and patient, their affective bond and agreement on treatment goals. This study reports that when a clinician's interaction style facilitates the participation of the patient in the consultation; such as listening to what patients have to say and asking them questions with a focus on emotional issues, the therapeutic alliance is strengthened.

In order to maximise the benefits of physiotherapy, a patient-centred approach is recommended as the basis for the development of a good working relationship between physiotherapist and patient, with enhanced effectiveness of communication regarding specific tasks required to achieve treatment goals (Hall et al., 2010). The limited data would suggest that providing positive feedback, answering the patient's questions and providing clear instructions for home practice are positively correlated with a good working alliance and satisfaction with treatment.

Ong and Hooper (2006) explored the concept of the therapeutic relationship by comparing clinical and lay accounts of the diagnosis and treatment of back pain. They conclude that the analysis of the therapeutic relationship has to operate across two dimensions; first the belief system of patients and secondly the belief system of professionals. Furthermore therapeutic relationships have to be understood within the context of preferred communication styles, perceptions of personality and coping and the history of the relationship.

As reported by Roberts and Bucksey (2007), although the importance of communication in patient-clinician interactions is undisputed, its influence on treatment outcomes is less clear. They conclude that only by learning more about the context of communication can clinicians establish ways to optimise the patient-clinician relationship, maximise the non-specific treatment effects and enhance the patient's experience. It is known that communication does not rely only on what is said but also on the manner or style in which it is expressed, incorporating interplay between verbal and non-verbal factors. This study showed that experienced physiotherapists demonstrated effective behaviours more readily than their junior colleagues.

An investigation into the association between communication factors and constructs of the therapeutic alliance in the patient-clinician relationship conducted by Pinto et al (2012) reviewed 12 papers. The constructs of therapeutic alliance in the included studies were rapport, trust, communicative success and agreement. Interaction styles that showed positive large correlations with therapeutic alliance were those factors that help clinicians to engage more with patients by listening to what they have to say, asking

questions and showing sensitivity to their emotional concerns. The limited evidence suggests patient-centred interaction styles related to the provision of emotional support and allowing patient involvement in the consultation process enhance strategies that strengthen the therapeutic alliance. From a theoretical perspective, the communication factors found to be associated with the therapeutic alliance could be considered as factors that share common elements with the concept of patient-centred care.

Mead and Bower (2000) describe the patient-centred care approach as involving the following dimensions: a biopsychosocial perspective understanding the individual's experience of illness, sharing power and responsibility, developing a relationship based on care, sensitivity and empathy, and self-awareness and attention to emotional cues. The factors identified in the report by Pinto et al (2012) are more related to the provision of emotional support than to the shared decision-making approach.

Another study that focuses on the importance of emotional support was conducted by Bredin in 1999 and explores the experience of undergoing a mastectomy and changed body in the words of the patient. It discusses the anxiety that can be caused by a diagnosis of breast cancer and its progression and the threat of a mastectomy creating a distressing disturbance of body image, partly because of the breast's symbolic and physical association with being a woman. The study concluded that patient satisfaction and psychological well-being are enhanced when clinicians perform caring behaviours and when they attend to the emotional needs of patients.

As acknowledged by Leach (2005) another essential ingredient in the development of the therapeutic relationship is time. Leach confirms that the development of a strong therapeutic alliance and the subsequent production of positive client outcomes are dependant on effective communication skills, practitioner behaviour, collaboration, time and trust.

As summarised above, the relationship between therapist and patient can be powerful and the importance of effective communication has been a common theme throughout the studies reviewed. Taking into account the emotional and psychological, as well as physical needs of patients has also been re-iterated above, which is central to the patient-centred approach discussed in Section 2.7.

## **2.9 The role of empathy**

As reported by Davis (1990), promoting attitudes and behaviours such as self-awareness, non-judgemental positive regard for others, good listening skills and self-confidence are suggested as important in the development of clinicians who will demonstrate an empathic willingness. Davis states that empathy seems to be a communication process that develops as we mature and acknowledges the therapeutic use of oneself as more than just knowledge and skill alone, but also as a compassionate understanding of the patient. The study concludes that empathy enhances the therapist's therapeutic presence and deepens the therapist-patient interactions without fear of losing one's self in the process.

Empathy has been recognised as a process which encompasses a person's attempt to understand another person and then to demonstrate this

understanding by means of appropriate verbal and non-verbal responses. In their study in 1997, Thomson et al found that empathy increased with education and clinical experience but that less senior physiotherapists were found to be more empathic than their senior physiotherapists in their first sessions with new patients. However the researchers acknowledge that the first study took part in a contrived setting and the second in the outpatient department of a hospital and there is a possibility that this may have influenced the results.

## **2.10 Service development and evaluation**

Springer et al (2010) utilised a novel physiotherapy surveillance model in an attempt to determine the extent and time course of upper limb impairment and dysfunction in breast cancer patients. They report that this prospective physiotherapy model of surveillance allows for detection of early and late onset of impairment following surgery for breast cancer in their cohort of patients. They also report there is a possibility that upper limb function may deteriorate between one and two years post-surgery if not monitored on a periodic basis due to the intermediate and late effects of radiation therapy. They concluded that the absence of pain is not sufficient indication of upper limb functional recovery because further pain may develop several months after cessation of medical treatment.

In their study in 2008 Lawrance and Stammers discuss the development of a Multidisciplinary Specialist Advisory Clinic for post-operative breast cancer patients and its ongoing evaluation through the use of audit. The Clinic was developed following an identification of need, specifically for more timely information about lymphoedema prevention, improved post-operative

physiotherapy and a need for patients to feel empowered and become active participants in their care. A team of a lymphoedema specialist, physiotherapist and breast care nurse worked together as a 'one stop' advisory service, enabling patients to see all the relevant practitioners under one roof. The audit results demonstrated that overall patients found the format beneficial; alleviating anxieties and providing an opportunity to obtain information from informative staff.

These studies demonstrate the growing awareness of the need to continually improve healthcare services to support patients following a diagnosis of breast cancer and the need to evaluate intervention to assess effectiveness.

## **2.11 Summary**

These previous studies include investigations of post breast cancer treatment dysfunction, the role of the physiotherapist in providing rehabilitation and the consequent therapeutic relationship that can be developed between patient and therapist. The narrative literature search demonstrates the need for further exploration of the experience of physiotherapy care received by patients with breast cancer.

### **3. Research design**

#### **3.1 Exploratory qualitative methodology**

An exploratory approach (Padgett and Padgett, 2004) was chosen in order to gain new knowledge and a deeper understanding of the patient experience (Emslie et al., 2007). A two phase design was implemented, with first informing the second, to achieve increased rigour, richer conceptual analysis and deeper interpretation (Malacrida, 2007).

#### **3.2 Participants**

Participants were selected using a sampling frame of patients who had been referred to the Specialist Breast Care Physiotherapy Service and discharged within the last six months. The researcher accessed patient records to identify potential participants who met the inclusion criteria, as defined in Section 5.2.

In order to draw a representative sample from the population, a stratified purposeful sampling technique (Patton, 2002; Neyman, 1934) was used; with the patients being stratified into one of three subgroups dependant on their previous experience of physiotherapy (see Section 4.1). The researcher was interested to see whether the participant's previous experience of physiotherapy affected their experience of the Specialist Breast Care Physiotherapy Service.

Participants were purposefully selected to obtain a greater depth of information from a small number of carefully selected cases. A sample size of 18 participants was decided upon, based on six participants for each group. This

sample size was necessarily limited by the scope of this study, but it was anticipated that the research design would generate rich and meaningful data.

### **3.3 Phase One data generation**

The study involved two phases, the first being each subgroup taking part in a group session using a modified form of the nominal group technique (NGT) (Harvey and Holmes, 2012; Potter et al., 2004) (see Section 4.2). In order to achieve the study's aim to explore the topic area, whilst at the same time being considerate of the amount of time required from participants, the researcher decided upon a modified version of the NGT, without the use of ranking of ideas at the end.

The NGT method potentially allows more generation and recording of ideas in a group setting than by traditional discussion alone. It prevents domination by a single person and encourages all group members to participate. Individuals may give more carefully considered expressions of their views compared with focus groups and are constrained by the task to produce more structured and explicit priorities. However little is known about how social desirability affects the use of the NGT method and how conformity influences expression of views (Fitzpatrick and Boulton, 1994). It does minimise discussion and therefore does not allow for full development of ideas, strengthening the need for the second phase of the study to explore the initial findings more deeply with individual participants.

### **3.4 Phase Two data generation**

Participants from the three groups were then given an opportunity to volunteer to take part in the second phase of the study; an in-depth one to one interview



based on the qualitative research guide technique (Weiss, 1994) (see Section 4.3). Due to the nature and scale of the study, only a small number of participants could be selected to take part in the second phase, therefore one participant from each subgroup who consented to take part was randomly selected using a random number table. The order of the interviews taking place was also generated via this method.

The items developed from Phase One were used to guide the open-ended questions chosen for Phase Two, with the use of 'neutral probes' (Kidd et al., 2011). This allowed further exploration of the opinions expressed and allowed the interviewer to verify and check the way in which collective views had been interpreted. A primary advantage of in-depth interviews is that they allow the researcher to focus maximally on the participant's perceptions of their experience rather than imposing their own beliefs (Fitzpatrick and Boulton, 1994). The data obtained is privileged; it is more than just words that will be analysed, it is the participant's personal experience (McConnell-Henry et al., 2009).

Following discussion with the supervisory team, three main topic areas were identified. Experience of the Specialist Service itself was the first area, looking into how the Service is currently run and any suggestions to improve the Service. All three groups discussed the speciality of the Service, importance of regular input, accessibility and the personalised approach to therapy (see Appendix 7).

The second area focused on the physical impact of receiving physiotherapy treatment. Although this was touched upon during the group sessions and participants did mention improvement in symptoms, the emphasis seemed to be more on the psychological element of care; therefore the researcher felt it appropriate to explore this further.

As described above, a recurrent theme from the groups appeared to be the relationship formed with the therapist and the emotional and psychological impact of treatment. The researcher chose to ask each participant to try to describe a particular experience or situation that they found helpful or went well, in a similar approach to the critical incident technique, defined by Fitzpatrick and Boulton in 1994. This technique was utilised in an attempt to gain a deeper understanding of patient experience, which is difficult to ascertain in a group setting.

The researcher acknowledged the potential bias effect of the dual clinician-researcher role but felt confident in her ability to conduct the interviews in a flexible and adaptable manner to ensure responsiveness, consistency and reliability with the use of the protocol (Appendix 7). The researcher is a senior clinician and is experienced in treating patients who have been diagnosed with breast cancer, having set up the Specialist Breast Care Physiotherapy Service in 2010. Her intuitive skills have been strengthened with completion of the 'Connected' National Advanced Communication Skills Programme in 2011. However the clear differences between a clinical interview and research interview have been acknowledged, in terms of the research interview aiming to

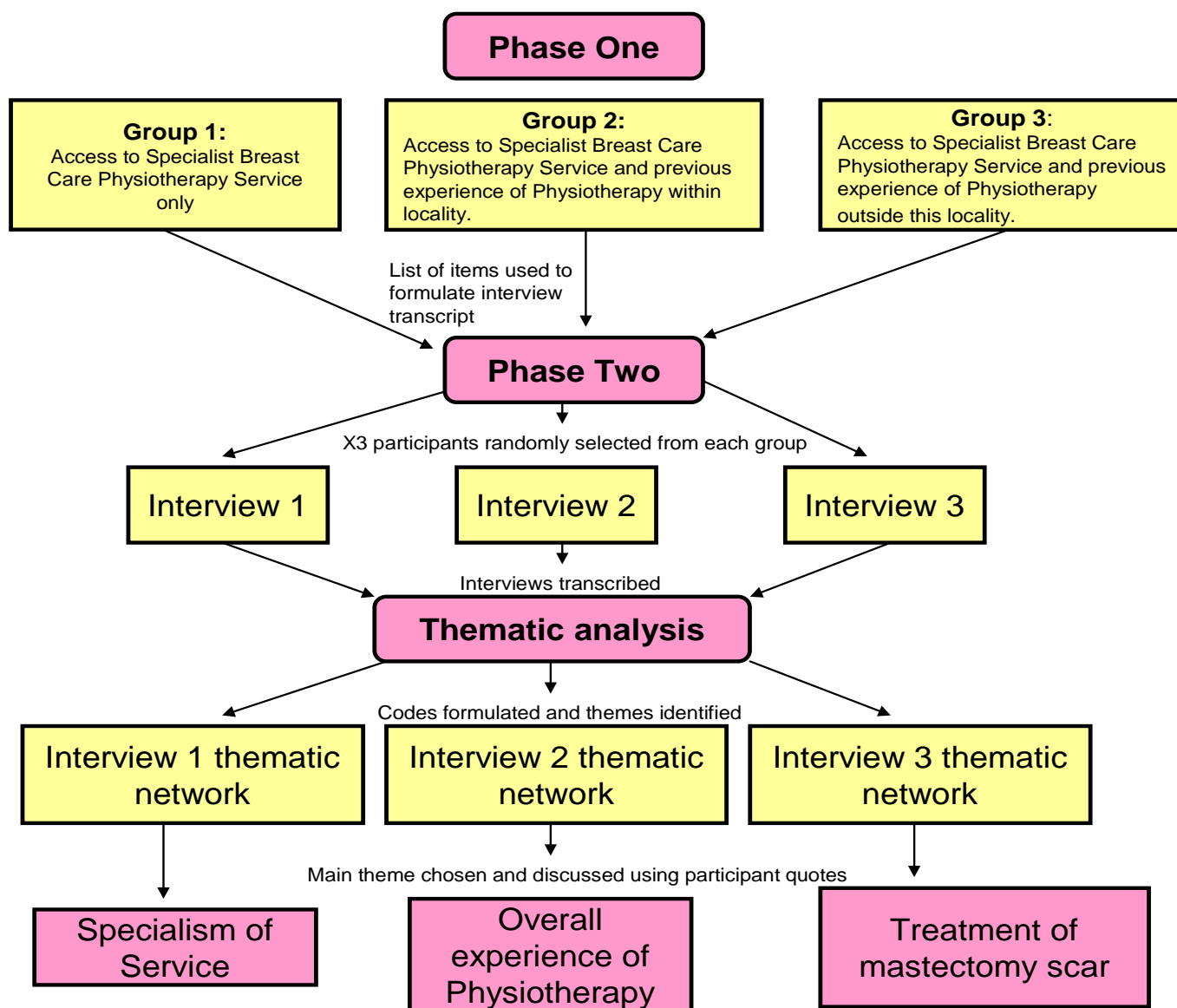
discover meanings, perceptions or opinions by facilitating or guiding rather than obtaining specific clinical information (Minichiello et al., 1995).

### **3.5 Method for data analysis**

For the interview transcripts from Phase Two, a thematic network analysis approach was adopted to interpret the data (Attride-Stirling, 2001), with all data represented by basic, organising and global themes (see Section 4.4). This technique was selected to aid the researcher to demonstrate an accurate and transparent interpretation of the patients' reported experiences through the use of a systematic and replicable technique. The approach enables insightful patterns and interpretations to be explored by looking at connections and associations between implicit and explicit meanings within the text (Thomson et al., 2012).

Figure 3.1 below represents participant flow throughout the study.

**Figure 3.1 Flow diagram illustrating participant flow throughout the study**



## **4. Method**

### **4.1 Participants**

Participants who met the inclusion criteria (see Section 5.2) were purposefully selected from the sampling frame, via patient records accessed by the researcher. Those selected were invited to participate by receiving a 'Letter of invitation' (Appendix 2), a 'Participant Information Sheet' (Appendix 3) and a copy of the 'Consent Form' (Appendix 4) via the post. If participants agreed to take part they rang the Physiotherapy Department to confirm this and were then informed of the location, time and date of their group. Participants who did not respond were then sent a 'Follow-up Letter' (Appendix 5) via post.

Those who agreed to take part were stratified into one of three subgroups, depending on their previous experience of physiotherapy. Group One comprised of patients who had accessed the Specialist Breast Care Physiotherapy Service only, Group Two comprised of patients who had accessed the Specialist Service and had previous experience of physiotherapy locally and Group Three comprised of patients who had accessed the Specialist Service and had previous experience of physiotherapy outside this locality.

### **4.2 Phase One data generation**

Phase One of data generation comprised of each subgroup taking part in a group session using a modified NGT. At each group the researcher facilitated the session, with the same member of the supervisory team present to provide support. Each session lasted approximately one hour and followed the format of the pre-designed script (Appendix 6).

The session was opened with a general statement welcoming the participants, thanking them for taking part, reiterating the importance of the task, explaining how the recorded information would be used and the importance of maintaining confidentiality of any information provided by others during the session.

Following completion of consent forms each participant was given a piece of card and pen and given five minutes to silently and independently write down the aspects of physiotherapy they had each valued the most and least. The next step was for each participant in turn to give an answer, which was then recorded on a flipchart by the researcher. This process was completed until all ideas had been documented and was carried out for all three groups.

Following each group, the researcher and one member of the supervisory team used the flipchart of findings to independently develop a list of initial themes highlighted during the session. Then together they discussed and compared these and produced a list of items from each group. The items from all three groups were then utilised to inform the interview script for Phase Two (Appendix 7).

#### **4.3 Phase Two data generation**

One participant from each subgroup was randomly selected from the collection of participants who volunteered to take part in Phase Two, to take part in a one-to-one in-depth interview. The researcher followed the interview protocol (Appendix 7) for each interview, which lasted between 30 minutes- 45 minutes and was audio-recorded to preserve the spoken words. Following each interview the data was then transcribed (Appendix 8).

#### **4.4 Method for data analysis**

Data analysis was then performed using the thematic network analysis technique (Attride-Stirling, 2001). For each interview the first stage of analysis was to generate a list of codes derived from the interview transcript. These codes and the issues they highlighted were then utilised to develop a list of themes. The next step was to refine these themes, which were then defined as basic themes. The basic themes were then reviewed and grouped together as organising themes. The final stage of analysis was to decide upon central global themes, which was felt to incorporate both the wider basic themes and the organising themes. The data was then illustrated as an analysis of themes to aid the visual interpretation for the reader. This process was completed for each interview. The names given in the quoted interview extracts are pseudonyms.

## **5. Ethical considerations**

### **5.1 Consent**

The researcher acknowledges that the principle of consent could be jeopardised if the participants feared that their refusal to participate would compromise the quality of care they may receive in the future (Shaw, 2003). With this in mind only patients who had been discharged from the Service were included and no patients currently undergoing physiotherapy treatment were approached. Participants were made aware that they could withdraw from taking part in the study at any time and did not have to give a reason, even after signing the consent form and this would not affect their future treatment.

Each participant was given an information sheet (Appendix 3) which detailed the purpose and nature of the study. This clearly stated what the research involved; each participant was given a minimum of one week prior to the NGT and was encouraged to contact their physiotherapist or breast care nurse to discuss any questions or concerns.

### **5.2 Inclusion and exclusion criteria**

Due to the pragmatic and exploratory nature of the study, participants were selected in order to obtain a maximum variation sample (Emslie et al., 2007) to gain a broad range of views. With this in mind the inclusion criteria for this study consisted of any patients who had been referred to the Specialist Physiotherapy Service following a diagnosis of breast cancer, since it was set up in June 2010.



In terms of exclusion criteria any patient who had been identified as requiring full-time cognitive or physical care was excluded. Any patients who for whatever reason would not be able to participate in a group setting were not included. Due to the nature of this study there would potentially have been issues surrounding the use of interpreters during the group setting as this could influence the sensitive issues that participants may wish to raise during the item recording stage but may feel reluctant to in front of an external person who is not involved in the study. Taking this into account it was deemed more beneficial for the purpose of the study to exclude participants who would require a translator or a family member to communicate.

### **5.3 Risks, burdens and benefits:**

**Non- maleficence:** There was a possibility that sensitive issues (Arber, 2005) may have been raised during both phases of the study. The researcher involved in the study is a senior experienced clinician and has extensive clinical experience of working with this patient group and has undertaken Advanced Communication Training. The researcher and the member of the supervisory team did their best to make all participants as comfortable as possible in terms of the discussion and all participants were encouraged to talk to the researchers if they had any worries or concerns. Procedures were put into place to provide care and support for participants if they did show any signs of distress, including access to the Macmillan Counselling Service at Salford Royal NHS Foundation Trust. There was also close links between the researcher and St Ann's Hospice and the Christie NHS Foundation Trust Hospital and the ability to refer onto the Consultant Clinical Psychologist if required.

The researcher understood that due to the nature of the study, some issues may have been discussed that some participants may have found upsetting or that the opinions of some participants may have differed to other members of the group. Participants were made fully aware that all information that was shared during the study was treated as personal and sensitive and that it was vital that all members should respect this and confidentiality.

The researcher was aware that by patients being involved in the study, there was a potential that this may influence their relationship with their physiotherapist. Also the potential that the researcher's familiarity with participants could blind her from certain aspects that may be taken for granted has been acknowledged (Arber, 2005). Thus the researcher involved endeavoured to remain as objective as possible during the study.

The ethical complexities and potential conflicts in clinical research (Yanos and Ziedonis, 2006) have been continually assessed throughout this process. The complexity of clinical research does not permit a clean cut between therapeutic and non-therapeutic studies, therefore alternating between a clinical or research orientation would not prove satisfactory. The researcher-clinician aimed to maintain a conception of moral identity that integrated the roles of the clinician and the researcher, without giving predominance to one or the other (Miller et al., 1998). This can be demonstrated through the action of reflection in Section 9.3.

Because in-depth interviews require the active participation and judgement of the interviewer, the researcher recognised the importance of having an ability to

demonstrate interest in the respondent without excessive involvement that may result in bias and an ability to ask both open ended facilitating questions and specific probes when relevant (Fitzpatrick and Boulton, 1994).

**5.4 Consideration of participants:** The timing and venue for both phases of the study was planned to minimise inconvenience to the participants and travel expenses reimbursed. Both phases of the study took place at Salford Royal NHS Foundation Trust Hospital. The researcher, where possible, discussed with participants their experience of the research in order to monitor any unforeseen negative effects or misconceptions.

**5.5 Beneficence:** To avoid the issue of ‘therapeutic misconception’ (Miller et al., 1998), participants were informed that there were no direct benefits to taking part in this study, except the opportunity to chat with other participants who may have had similar experiences and supporting the development and improvement of the existing Specialist Physiotherapy Service. All participants were given the option to receive a summary of the study findings when the project was complete, in order to gain an element of closure following their involvement (Appendix 9). It is also acknowledged that although the intent of the research process is data collection, participants were presented with an opportunity to voice their experiences which may be found to be therapeutic (Drury et al., 2007; Dickson-Swift et al., 2006; Rager, 2005).

**5.6 Confidentiality:** Subject to requirements of the Data Protection Act (1998) and Freedom of Information Act (2000), all information collected about a participant is confidential. In Phase One, participants were asked to agree to

maintain the confidentiality of any information provided by others during the session. All data was stored on password-enabled computers and consent forms stored separately in a locked cabinet. Data will be retained for a period of five years in a secure data archive at the University of Central Lancashire. Only the physiotherapist who was carrying out a dual role as a researcher and clinician had access to participants' personal data during the study.

**5.7 Risks to researcher:** There was a potential risk that the researcher herself may have found some of the issues that arose upsetting and could develop 'compassion stress' (Rager, 2005) due to the level of support sometimes required by this patient group. The researcher involved already had a support network in situ and had regular access to a clinical mentor (Dickson-Swift et al., 2006; Arber, 2005). The researcher also aimed to develop a reflexive approach to the study, to ensure a protective component for her emotional safety (Fisher, 2011).

**5.8 Conflict of interest:** At the time of the study taking place all of the participants had been under the care of the researcher. The researcher acknowledged the ethical issues posed by practitioner involvement (Shaw, 2003) and aimed to optimise objectivity by maintaining as much neutrality as possible. This included avoidance of biased questioning through the use of scripts for both phases and avoidance of subjective interpretations of the data gathered.

The positive aspect of the dual role of the researcher is that the participants may have felt more comfortable due to having built a patient-therapist

relationship during treatment and may have felt more confident in being more open and honest during the group discussion. Arber (2005) acknowledges that having an identity as an insider allows access to data that may not be accessed by an outsider.

The researcher was accompanied by one of the supervisory team at each group in order to optimise objectivity and undertook interview practice prior carrying out Phase Two.

### **5.9 Ethical approval**

The project was first registered with the University of Central Lancashire (UCLan) BuSH Ethics Committee in October 2011. Following this REC ethical approval was sought from the NRES Committee North West-Greater Manchester West (Ref 12/NW/0009) through the IRAS process in January 2012, after attendance at the Research Ethics Committee Meeting. The Committee considered and reviewed the project and surprisingly felt that the project would be more appropriately classified as service evaluation rather than research. It was advised to discuss this with the project Sponsor and lead R&D office, who both agreed with the change in designation to service evaluation. The study was therefore withdrawn from the database. Governance approval was obtained from the Salford R&D Department (Ref 2011/266can) on 25<sup>th</sup> January 2011 and ethics approval from the UCLan ethics panel (Ref BuSH 041) on 22<sup>nd</sup> March 2011.

## **6. Phase One Results**

### **6.1 Recruitment**

A total number of 19 participants (all female) were recruited to take part in the study. Due to the stratification of participants to group's dependant on their previous experience of physiotherapy, the numbers in each group range from two to ten participants.

Participant demographics are shown in Table 6.1. In Group One (Access to Specialist Physiotherapy Service only), seven participants who met the inclusion criteria agreed to participate in the study. They ranged in age from 48-75 years old. Three were employed and four were retired. Three participants were referred to the Specialist Breast Care Physiotherapy Service with upper limb dysfunction post breast cancer surgery/ radiotherapy, two were referred with scar tightness and two were referred with dysfunction post reconstructive surgery.

In Group Two (Access to Specialist Physiotherapy Service and previous physiotherapy locally), two participants who met the inclusion criteria agreed to participate in the study. They were aged 44 and 73 years old. One was employed and the other retired. They were both referred to the Specialist Breast Care Physiotherapy Service with upper limb dysfunction post breast cancer surgery/ radiotherapy.

In Group Three (Access to Specialist Physiotherapy Service and previous physiotherapy outside locality), ten participants who met the inclusion criteria agreed to participate in the study. They were aged 46-65 years old. Five were

employed and five were retired. Seven participants were referred to the Specialist Breast Care Physiotherapy Service with upper limb dysfunction post breast cancer surgery/ radiotherapy, one was referred with scar tightness and two were referred with dysfunction post reconstructive surgery.

**Table 6.1 Patient characteristics**

<b>Patient characteristics</b>	<b>Group One (Access to Specialist Physiotherapy Service only)</b>	<b>Group Two (Access to Specialist Physiotherapy Service &amp; previous physiotherapy locally)</b>	<b>Group Three (Access to Specialist Physiotherapy Service &amp; previous physiotherapy outside locality)</b>
<b>No. of participants</b>	7	2	10
<b>Age range</b>	48-75	44 & 73	46-65
<b>Employed</b>	3	1	5
<b>Retired</b>	4	1	5
<b>Referred with upper limb dysfunction post breast cancer surgery/ radiotherapy</b>	3	2	7
<b>Referred with scar tightness</b>	2	0	1
<b>Referred with dysfunction post reconstructive surgery</b>	2	0	2

## 6.2 Results of Phase One

Table 6.2 shows the list of items compiled from each of the groups.

**Table 6.2 Items from groups**

<b>Group One (Access to Specialist Physiotherapy Service only)</b>	<b>Group Two (Access to Specialist Physiotherapy Service &amp; previous physiotherapy locally)</b>	<b>Group Three (Access to Specialist Physiotherapy Service &amp; previous physiotherapy outside locality)</b>
Good understanding of physical impact	Referral to other Services (hydrotherapy & counselling)	Previous negative experience of Physiotherapy
Previous low expectations	Comfort/ not alone	Beneficial treatment
Recognised problem and did something about it	Professionalism	Speciality of Service
Physical improvement (improved range of movement)	Increased confidence	Negative: lack of physiotherapy input post-op
Good explanation	Increased coping skills	Accessible
Psychological support	Goal setting/ milestones/ achievements	Issues acted upon
Improved function	Provided continuity/ regular follow-ups/ same therapist	Reduced pain & increased ROM
Finished too early	Negative: didn't know of service until referred	Emotional support/ kindness
Hands-on treatment	Informative	Positivity
Personality of therapist (friendly/kind/caring/included husband)	Accessibility/ self-referral	Confidence/ self-esteem
Long-term exercise promotion	Positivity/ providing hope	Continuous improvement
Provided continuity	Exercise promotion	Monitoring lymphoedema
Accessible	Reduced impact of cancer	Holistic approach
Speciality of Service	Supportive	Honest
Personal	Personal/ individual	Independence
Confidence	Found someone that is going to do something for me	Improving body image
Empowerment	Enabled radiotherapy in window of opportunity by reducing pain & increasing ROM	
	Functional improvement	



### 6.3 Comparison of groups

Table 6.3 demonstrates a comparison of the items recorded from the three groups.

**Table 6.3 Comparison of groups**

	1	2	3
1. Speciality of Service/ therapist knowledge	✓	✓	✓
2. Referral to other Services	X	✓	X
3. Improved experience	✓	X	✓
4. Issues acted upon	✓	✓	✓
5. Physical improvement	✓	X	✓
6. Psychological support	✓	✓	✓
7. Functional improvement	✓	✓	X
8. Importance of goal setting	X	✓	X
9. Personality of therapist	✓	✓	✓
10. Long-term exercise promotion	✓	✓	X
11. Continuity/ regular input	✓	✓	✓
12. Accessibility of Service	✓	✓	✓
13. Personal care	✓	✓	✓
14. Encouragement/ positivity	✓	✓	✓
15. Confidence/ empowerment	✓	✓	✓
16. Improved coping skills	X	✓	X
17. Enabling cancer treatment	X	✓	X
18. Monitoring lymphoedema	X	X	✓

### 6.4 Summary of Phase One results

As demonstrated above in Table 6.3, there were many common items recorded between the three groups. Each participant was stratified to a sub-group dependant on their experience of physiotherapy, however as the results show, there are similar items recorded between the three groups, despite their varying previous experience.

The aim of Phase One was to inform Phase Two, therefore through a meeting between the researcher and her supervisory team, the items above were discussed and together a consensus of the main issues derived from Phase One was agreed. Due to the exploratory nature of the study and the time constraints of the interview process, a script containing three main questions was designed, based on the data collected (see Appendix 7). The first question centred upon the participant's views of change in their physical functioning and whether they had improved with physiotherapy, the second centred on their experience of the Specialist Service itself and the third was chosen to give the participant the opportunity to pick a particular experience during their physiotherapy that was meaningful to them, and to explore why this was of value.

## **7. Phase Two Results**

The results of Phase Two will first be presented in the form of tables to represent the process of the journey. The list of the initial codes generated from each interview transcript can be found in Appendix Ten. Each table represents the basic themes, organising themes and global themes for each interview. Finally an analysis of themes figure for each interview is presented. The three figures also include a selection of participant quotes from each transcript, to demonstrate transparency.

Finally a summary of the results will be presented, which includes further interpretation of the main theme to emerge from each interview, supported by direct participant quotes. Pseudonyms have been chosen for each of the three participants to protect their identity due to the personal and in-depth nature of the data.

### **7.1 INTERVIEW ONE: Laura**

Laura was a 44 year old female, who underwent a mastectomy and axillary node clearance on her dominant side, followed by chemotherapy. She accessed the Specialist Physiotherapy Service post-operatively on the ward and then self-referred to the Outpatient Service at two weeks post-op with shoulder movement dysfunction. She did not have any pre-operative limitations in her arm prior to surgery. She was pre-menopausal and a non-smoker. She was currently single and working as an IT Consultant at the time of her diagnosis. Her only past medical history to note was anaemia. Laura's physiotherapy intervention involved a 'hands-off' approach of exercise

progression and general exercise promotion, goal-setting, postural awareness, psychological and emotional support and referral to a Macmillan Counselling Service.

### Timeline 7.1 Laura's timeline

Timeline 7.1 represents the timing of Laura's treatment for breast cancer and her physiotherapy intervention.

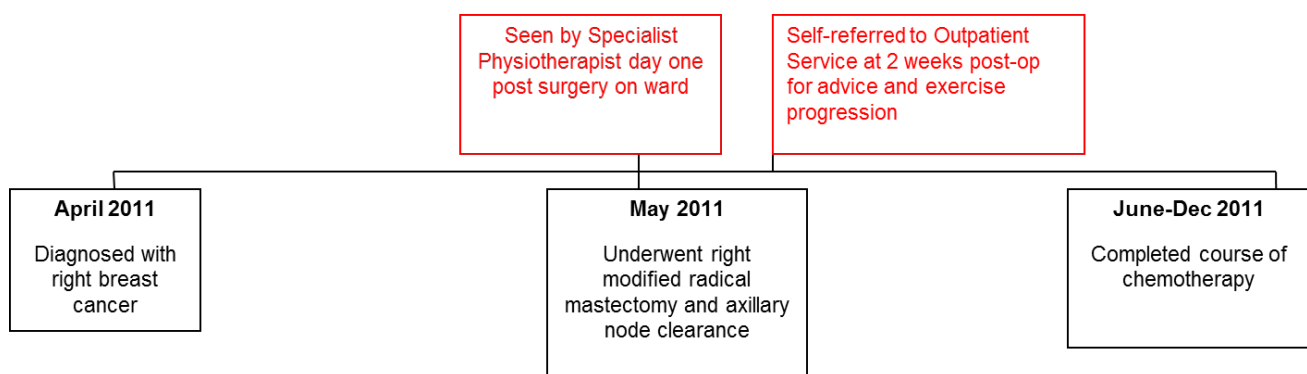


Table 7.1 on the following page illustrates the basic, organising and global themes from Laura's transcript.

**Table 7.1 Themes from Laura's interview**



Basic themes	Organising themes	Global themes
1.Intervention post-op 2.Early exercise intervention 3.Continuity/ regular input 4.Symbolic completion of Physiotherapy 5.Accessibility of Service 6.Flexibility of Service 7.Able to ring if needed 8.Discussing stages of treatment 9.Therapist perception 10.Multi-disciplinary approach to care 11.Specialism of therapist 12. Comparing progress to others 13.Referral to counselling 14. Service improvement 15 Feeling well looked after 16.Feeling of ‘unknown’ before surgery 17.Regaining range of movement in shoulder post-op 18.Goal setting/ providing focus/ realistic expectations 19.Impact of treatment on exercise tolerance 20.Return to function: driving, dancing 21.Individualised treatment 22. Emotional support 23.Motivation 24.Talking to therapist/ being able to offload 25.Positivity 26.Encouragement 27.Return to work 28.Family input 29.Use of sling (security blanket)	<p>1.Importance of early intervention post diagnosis and provision of a flexible and accessible Service</p> <p>2. Importance of holistic approach to care and multi-disciplinary approach; facilitating referral onto other disciplines</p> <p>3. Impact of the Speciality of the Service including therapist experience</p> <p>4. Service improvement in terms of online access</p> <p>5. Importance of effective communication and information giving</p> <p>6. Physical improvement and the importance of goal setting and individualised treatment</p> <p>7. Impact of providing emotional support including motivation, positivity and encouragement</p> <p>8.Importance of supporting patients to return to work</p> <p>9.Impact of family on rehabilitation process</p>	<p>Specialist Service</p> <p>Individualised care</p> <p>Psycho-social support</p>

Figure 7.1 on the following page illustrates the analysis of Laura's themes from her interview.

**Figure 7.1 Analysis of Laura's themes**



### Key of shapes for figure 7.1

<b>Global Theme</b>	
<b>Organising Theme</b>	
<b>Laura's quotes</b>	

### 7.2 INTERVIEW TWO: Pamela

Pamela was a 61 year old female who underwent a mastectomy and axillary node clearance on her non-dominant side, followed by radiotherapy. She was referred to the Specialist Physiotherapy Service one year post surgery via her Breast Care Nurse, with shoulder movement dysfunction and scar tightness. She did not have any pre-operative limitations in her arm prior to surgery. She was post-menopausal, on no medications and had a previous benign breast lump in 1993. She was a non-smoker, living with her husband. She was working in a College Kitchen up until her breast cancer diagnosis

Pamela's physiotherapy intervention included a 'hands-on' approach of fascial release working on her mastectomy scar and axillary tightness, exercise progression and postural re-education. Her husband was invited to take part in the therapy sessions and carried out massage and stretching on a daily basis with Pamela at home. Following her latissimus dorsi flap reconstruction surgery Pamela re-accessed the Specialist Service for post-operative rehabilitation.

## Timeline 7.2 Pamela's timeline

Timeline 7.2 represents the timing of Pamela's treatment for breast cancer and her physiotherapy intervention.

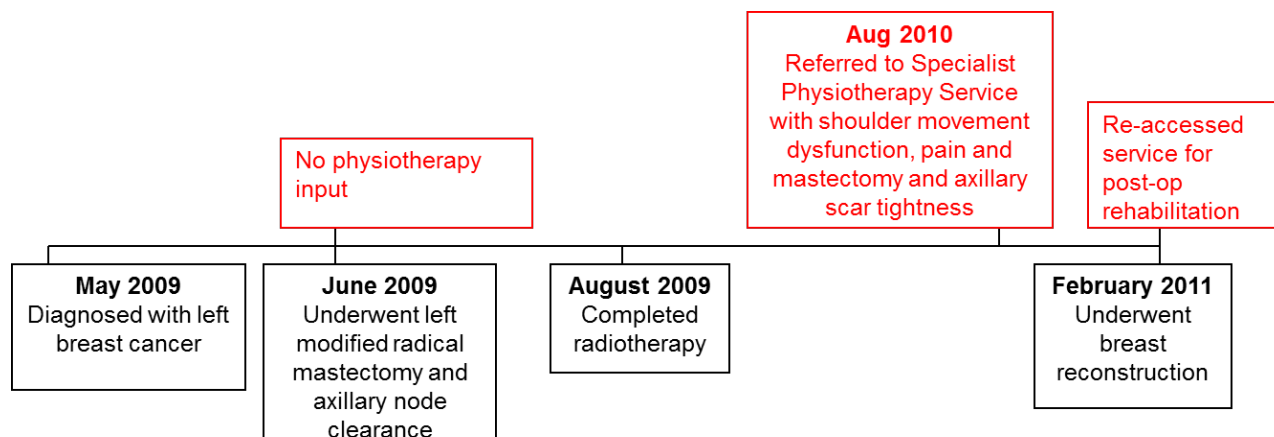


Table 7.2 on the following page illustrates the basic, organising and global themes from Pamela's transcript.

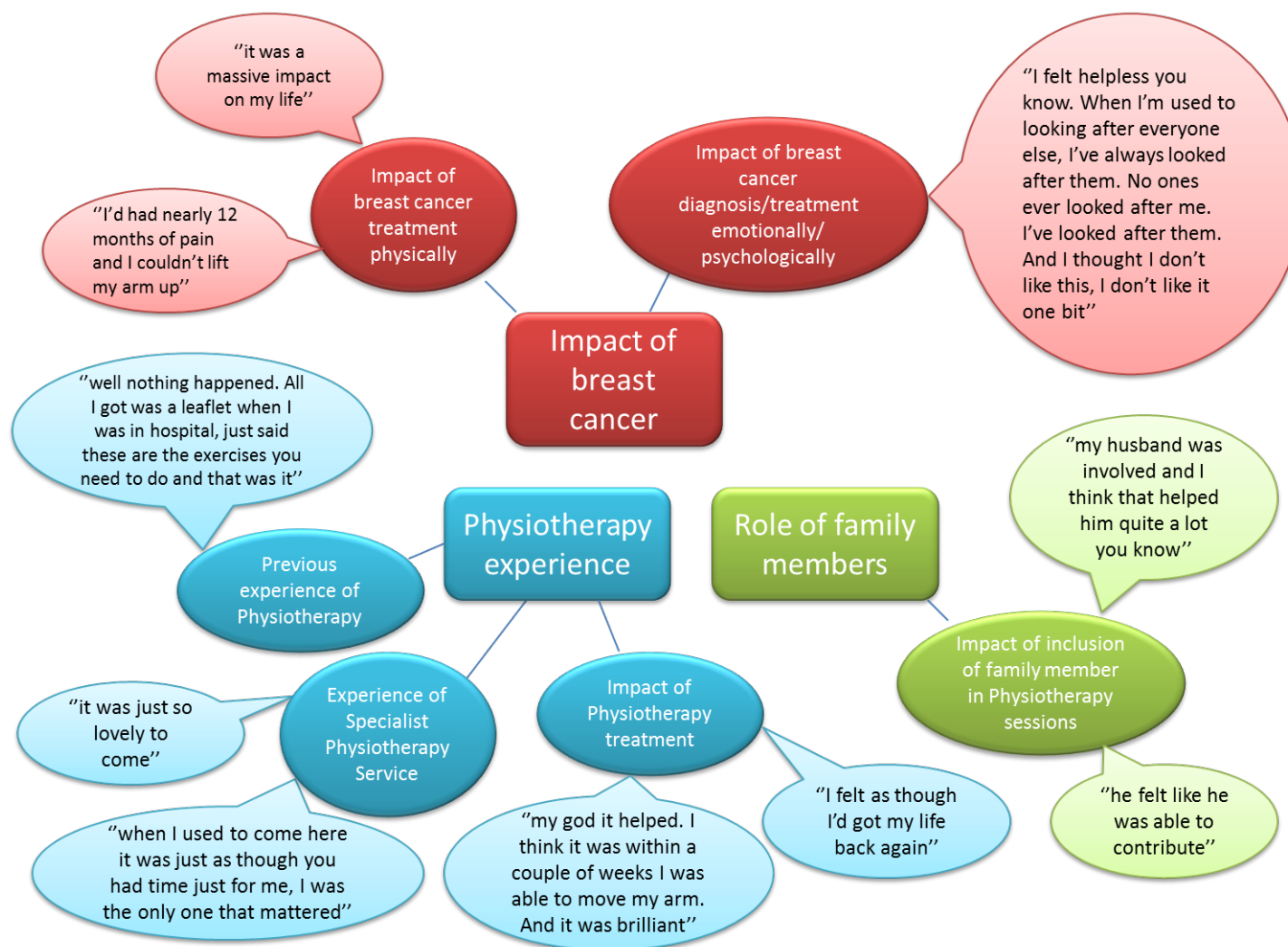


**Table 7.2 Themes from Pamela's interview**


Basic themes	Organising themes	Global themes
1. Post-op dysfunction 2. Emotional response to diagnosis 3. Previous Physiotherapy experience 4. Relationship with husband 5. Impact of dysfunction on family role 6. Reliance on others 7. Accessibility of Service  8. Experience of therapy sessions 9. Apprehension pre first appointment 10. Relationship with therapist 11. Impact of Physiotherapy treatment 12. Regaining independence 13. Positivity 14. Coping strategies  15. Inclusion of husband	1. Impact of breast cancer treatment physically  2. Impact of breast cancer diagnosis/treatment emotionally/ psychologically   3. Previous experience of Physiotherapy  4. Experience of Specialist Physiotherapy Service  5. Impact of Physiotherapy treatment   6. Impact of inclusion of family member in Physiotherapy sessions	Impact of breast cancer       Physiotherapy experience   Role of family members

Figure 7.2 on the following page illustrates the analysis of Pamela's theme

**Figure 7.2 Analysis of Pamela's themes**



### Key of shapes for figure 7.2

<b>Global Theme</b>	
<b>Organising Theme</b>	
<b>Pamela's quotes</b>	

### 7.3 INTERVIEW THREE: Chris

Chris was a 52 year old female who underwent a mastectomy and sentinel node biopsy, followed by axillary node clearance and on her non-dominant side. She then completed a course of chemotherapy. She was referred to the Specialist Physiotherapy Service by another physiotherapy colleague with lymphatic cording, shoulder movement dysfunction and scar tightness. Lymphatic cording or axillary web syndrome can develop after axillary dissection and refers to a rope-like structure that develops mainly under the axilla but can extend to involve the medial aspect of the ipsilateral arm down to the antecubital fossa (Tilley et al., 2009). Chris also developed lymphoedema during her chemotherapy. She did not have any pre-operative limitations in her arm prior to surgery. She was pre-menopausal and had four children, the youngest aged sixteen. Previous medical history included viral peri-carditis three years previous. She was working as a Primary School Teacher at the time of her diagnosis.

Chris's physiotherapy intervention involved a 'hands-on' approach of fascial release working on her mastectomy scar and axillary tightness and cording,

scar management, exercise promotion, lymphoedema management and psychological and emotional support.

### Timeline 7.3 Chris's timeline

Timeline 7.3 represents the timing of Chris's treatment for breast cancer and her physiotherapy intervention.

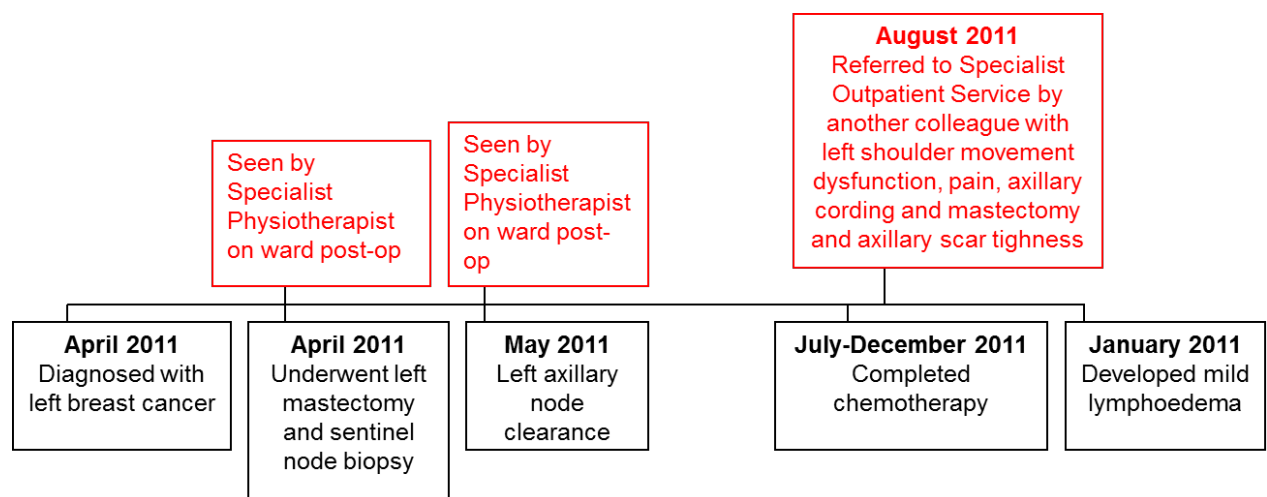
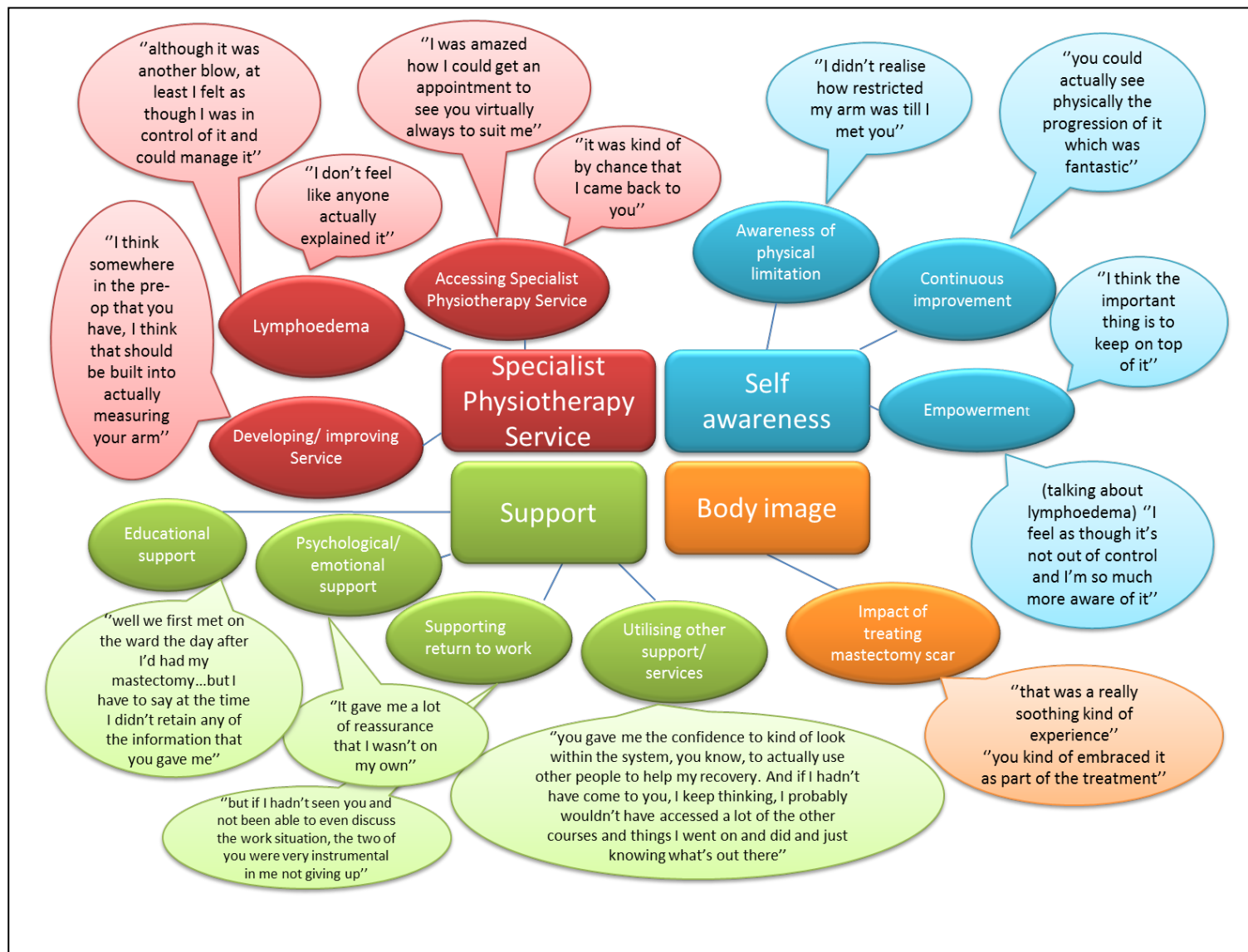


Table 7.3 on the following page illustrates the basic, organising and global themes from Chris's transcript.

### Table 7.3 Themes from Chris's interview




Basic themes	Organising themes	Global themes
1.Post-op intervention 2. Referral process 3.Regularity of appointments 4. Flexibility of appointments 5. Location of Physiotherapy Department 6.Duration/ timeframe of treatment 7. Accessibility of Service 8.Expectations of recovery 9. Professionalism/ therapist approach 10. Therapeutic relationship 11.Monitoring regarding lymphoedema 12. Diagnosis of lymphoedema 13. Proactivity regarding lymphoedema 14.Developing Specialist Service 15.Awareness of limitation 16. Physical limitations post surgery 17. Self-awareness 18.Continual improvement 19.Confidence to self-manage 20. Empowerment 21.Reassurance/ emotional support 22. Encouragement/ positivity 23. Process of acceptance 24. Adjustment process 25. Inability to retain info at time of diagnosis 26. Need for more information 27. Impact on return to work 28.Confidence to access other Services 29. Referral to other Services 30.Body image 31. Impact of mastectomy 32. Treating mastectomy scar	1.Accessing Specialist Physiotherapy Service  2.Lymphoedema  3.Developing/ improving Service 4.Awareness of physical limitation 5.Continuous improvement  6. Empowerment 7.Psychological/ emotional support  8.Educational support  9. Supporting return to work 10.Utilising other support/ services  11. Impact of treating mastectomy scar	Specialist Physiotherapy Service          Self-awareness       Support       Body image

Figure 7.3 on the following page illustrates an analysis of Chris's themes.



**Figure 7.3 Analysis of Chris's themes**

### Key of shapes for figure 7.3

Global Theme	
Organising Theme	
Chris's quotes	

### 7.4 In-depth exploration of participant perspectives

All of the issues generated through these interviews were analysed in greater depth than can be presented in this dissertation. One theme has been selected from each interview to illustrate the analysis process.

For Laura's interview, the importance of accessing a Specialist Service was explored. For Pamela's interview, her overall experience of physiotherapy was explored. And finally, for Chris's interview, the impact of her scar treatment was explored. Selected quotes have been utilised to contextualise the issues discussed.

#### **Laura's perspective**

One of the main themes to emerge from Laura's interview was the importance of the specialism of the Service available for patients with a diagnosis of breast cancer. Laura discussed feeling well supported and informed, which motivated and empowered her and seemed to give her an element of control of her situation. She really seemed to value the early intervention of seeing the therapist the day after her surgery on the ward and the impact of starting to exercise quickly. This gave her focus and gave her realistic expectations and goals:

*"It had a big impact in that I had something to work towards. It stopped my stressing about what else was going on, I had something to focus on. So it was really good to have the exercises cos I did them religiously and that gave me continuity through the whole process"*

Laura, line 45

Laura valued her therapist's perception of her progress as she felt it was being compared to others. She acknowledged her therapist's specialist experience; feeling comforted that the therapist was seeing other patients with similar problems and issues:

*"But I think without your help, I wouldn't have got here. You had that experience of seeing other people like me and knew what to do. So yeah, I can't imagine what it would have been like without that"*

Laura, line 165

Laura seemed to value the communication element of her treatment, in terms of being able to discuss the stages of her treatment pathway and link this to her personally. She gave an example of how one of her exercises had been adapted to suit her, which she found beneficial. She talked about the importance of a holistic and multi-disciplinary approach to her care:

*"I really liked that I knew you went to that meeting with the rest of the team and sat around and discussed each patient. I liked that you each knew what was going on and worked together, I liked that. I found it so positive"*

Laura, line 78

Her therapist also recognised the need for further psychological support and found her referral to Macmillan Counselling Service really helpful. Laura valued the accessibility and flexibility of the Service but suggested an improvement could be online access to her therapist via the internet.



### **Pamela's perspective**

One of the main themes to emerge from her interview was Pamela's overall physiotherapy experience, with the contrast between her lack of input following her surgery, compared to her experience of the Specialist Physiotherapy Service. She described the chronic discomfort, reduced confidence, frustration, low mood and negative impact on her quality of life she experienced following her surgery and being unable to access the support she required.

Following being seen post-operatively on the ward, she then struggled to gain access to physiotherapy and felt helpless in being unable to seek support for her ongoing problems as a consequence of her treatment for breast cancer. She expressed relief that her symptoms had been recognised and describes the referral to the Specialist Breast Cancer Physiotherapy Service as:

*"the best thing that ever happened"*

Pamela, line 55

Following completion of physiotherapy treatment she reflected that if she had of been able to access the Service earlier she may not have developed chronic dysfunction:

*"I think the main thing is if I'd have got physio more or less straight away I'm sure it would have been a lot easier"*

Pamela, line 139

Pamela described her experience of the Specialist Service in a positive way. She found her relationship with her therapist comforting:

*"As soon as I walked in and we met, it was as if we'd know each other forever"*

Pamela, line 237

She valued the personalised approach to her treatment:

*“When I used to come here it was just as though you had just time for me, like I was the only one who mattered. I know you had other people to see but it just felt like that. As though, it was just like I had you as a best friend for that short time”*

Pamela, line 238

This trust and confidence enabled treatment of her mastectomy scar and discussion of sensitive issues with the therapist. Pamela talks about the impact of the therapist including her husband in therapy sessions and teaching him techniques he could carry out for Pamela at home. This had a positive impact on both their relationship and him feeling involved in her care:

*“I think he (husband) just felt as though there was nothing he could do, he couldn’t help in any way at all and I think when he started coming with me to the physio and you were able to give him things to do, and I do think he feel like he was able to contribute, I really do”*

Pamela, line 106

Through improvement in movement and function, and reduction in pain, Pamela felt:

*“Well I felt as though I’d got my life back again. So now I don’t have to ask anybody for anything”*

Pamela, line 202

### **Chris’s perspective**

One of the main themes to emerge from her interview was the impact of the therapist’s ‘hands-on’ treatment of Chris’s mastectomy scar. When asked to describe a particular example of a situation that was meaningful to her, she talked about the first time the therapist assessed and treated her mastectomy scar:

*“When you said to me that you wanted to look at my scar, I couldn’t get over that you’d wanted to do that and I felt....I can’t tell you how very strange it felt*

*but you're the first person that had actually asked to see the scar and then when you said 'oh it looks good', and you said 'I know that sounds ridiculous' but that was a really soothing kind of experience"*

Chris, line 394

Chris talked about the therapist embracing it as part of the treatment and giving advice about how to care for her scar:

*"The fact that you actually wanted to see it and work on it and then give me advice on how to kind of massage it and put creams on and things like that, that was just...I just couldn't get over that"*

Chris, line 430

*You know because had you not said that, it would have been something I would have blocked out completely and I wouldn't have even wanted to look at it and now when I have a shower I do go through the massage and things like that"*

Chris, line 446

She talked about the realisation that on reflection she could see the physical benefit of this, but at the time it was the emotional impact of the therapist wanting to treat her mastectomy scar. She reports feeling comfortable in the situation and describes the handling of both the situation and herself as 'lovely':

*"I felt comfortable, although I never thought I would have been comfortable"*

Chris, line 464

Talking about this made her cry; as she initially felt she wanted to spare the therapist the burden of dealing with it, as she had tried to do for her children, who were a similar age as the therapist. She described having to undergo a mastectomy as 'traumatic' and wanting to hide away from herself, as well as hiding away from others. She felt 'disabled' as a consequence of her surgery. She talked about the fact she didn't feel it was something she could talk about, that the scar was:

*"Just this hideous thing that we don't mention. And you know we've just got to get past it"*

Chris, line 433

Chris described the emotional support provided by the therapist as giving her a kind of 'mental stability' and:

*"It gave me a lot of reassurance that I wasn't on my own and that I was coping with it as well as could be expected"*

Chris, line 223

*"Because you feel like you can talk and you've actually got a relationship whereas there isn't that anywhere in the system that you can make a relationship because the clinics are just so busy, so so busy"*

Chris, line 243

She described her experience of the Service as really positive, with her therapist being a central point to her care.

## **7.5 Summary of thematic analysis**

The researcher has aimed to bring together the different experiences of the three participants and identify common themes present within the data generated. In summary the overarching issue of the three interviews is the value of a patient-centred holistic approach to care. By comparing the global themes of the networks, it can be said that all three represent the value of the provision of a Specialist Physiotherapy Service by an experienced clinician, and within this the value of psychological and emotional support and also educational support.

## **8. Discussion**

This study has permitted the voices of women diagnosed with breast cancer who have accessed the Specialist Physiotherapy Service, to be heard. During Phase One of the study, where the participants took part in the group sessions using the modified NGT, common themes emerged in terms of the perceived values of these individuals. This confirms the findings of Binkley et al (2012) who state that although each woman's experience with breast cancer is unique, they share common perspectives related to the physical and functional side effects of breast cancer treatment.

It can also be stated that within the sample of participants that took part in the study, previous experience of physiotherapy has not affected the perceived value of their experience of the Specialist Breast Care Physiotherapy Service. This will be further discussed in Section 12.

### **8.1 Overall findings**

As the participants were stratified into distinct sub-groups related to their previous experience of physiotherapy, we cannot combine these findings together as one set of outcomes, but can make comparisons between findings and identify similarities. All three thematic analysis figures from Phase Two highlight the theme of the importance of a patient-centred holistic approach to care. The importance of the physiotherapist locating the patient at the centre of the therapeutic encounter confirms the findings of Kidd et al (2011) and also confirms the value of facilitating patients to take an active role in their recovery, as described by Gilbar (1996).

The value of receiving specialist physiotherapy from an experienced clinician was also consistent throughout the three groups, which fulfils the recommendations of the Department of Health, Macmillan Cancer Support and NHS Improvement (2010b) in the National Cancer Survivorship Initiative Vision in providing access to a Specialist Service. This also confirms the findings of Lattanzi et al (2010), who recognised the benefit of accessing specialist intervention. Participants talked about the confidence they felt in being treated by a therapist who specialised in treating breast cancer patients and had experience in the management of post breast cancer treatment dysfunction. This confirms the findings of Kidd et al in 2011 that recognised the importance of the therapist's knowledge and self-confidence.

The emerging themes have centred on the relationship between patient and therapist and link in with previous findings regarding the value of the therapeutic alliance, discussed in Section 2.8. The importance of effective communication has been confirmed in optimising patient satisfaction and experience. As discussed in the review by Pinto et al (2012), the value of showing sensitivity to patient's emotional concerns is demonstrated in the findings of this study.

## **8.2 Holistic approach to care**

It was demonstrated that the participants included in the study felt the Service had met their physiotherapy needs; emotionally and psychosocially, as well as physically. The general consensus was that the participants reported an overall positive experience. All three participants in Phase Two expressed gratitude at being able to access the Specialist Service. This perceived value of both physical and psychosocial support is very similar to the findings of Lattanzi et al (2010) where

participants acknowledged the importance of the therapist providing this support, especially for those who may not have anyone else with whom to share their struggles. Their study in 2010 was methodologically very similar to this study; with a similar sampling technique, inclusion criteria, overall findings and subsequent recommendations.

In Pamela's interview she talks about the therapist taking a personalised approach, stating '*it was just as though you had just time for me, like I was the only one who mattered*' (lines 238-239). The role of empathy in strengthening the patient-therapist relationship supports the findings of Davis (1990) discussed in Section 2.9 and also the findings of Leach (2005) in Section 2.8, who both acknowledge time as an essential ingredient in the development of a therapeutic relationship. This differs from the findings of some of the participants in the Larsson et al (2008) study; as described in Section 2.2, where they expressed that they didn't feel their physiotherapist had enough time for follow-up or for them to ask the questions they wanted to.

Another study with similar methodological technique was that carried out by Corner et al (2007), with the use of a similar sampling technique, use of the modified NGT for data generation and thematic analysis to interpret findings. The findings of that study complement this work in relation to the importance of emotional support and the acknowledgement of how a diagnosis of cancer can impact on life, how to live with cancer and related support issues.

The value of individualised care, goal setting and seeing continuous improvement was consistent for both Laura and Chris. Laura talked about the importance of goal setting and the value of monitoring her progress with her physiotherapist. As this empowered her and built her confidence, her therapy was delivered as a more 'hands-off' approach. The importance of realistic goal expectancies and the resources to achieve them is also supported by Jones et al (2011). Laura reflected that her exercises provided her with focus, which was also found by Emslie et al (2007). As discussed in Section 2.2, this study explored the experiences of women undergoing breast cancer treatment, who had taken part in a supervised group exercise trial. The results demonstrated that some participants found the exercise intervention provided motivation, was a welcome distraction to their treatment and gave structure to their day, which provided a sense of control.

### **8.3 Psychological support**

Participants talked about their value of the therapist's knowledge regarding the impact of a breast cancer diagnosis and subsequent treatment physically, emotionally and psychologically. All three participants focus strongly on the value of the provision of emotional support, specifically motivation, positivity and encouragement, which supports the findings of Bloom et al (2004).

Chris talked about the value of seeing the same therapist throughout her treatment, and the impact this had on being able to form a therapeutic relationship, which confirms the findings of Lattanzi et al (2010) and Beatti et al (2005). This was also found by Cooper et al (2008) in their study who found that seeing the same therapist enabled individualised treatment and recognised the importance of the



physiotherapist getting to know the patient, and treating them 'as a person not a number' (page 248).

Chris went on to reflect that the support provided by her therapist gave her the confidence to utilise other support and services and also played a key part of enabling her return to work, which was also valued by Laura. The need for supporting patients in their return to work has been recognised in the literature, including Binkley et al (2012) and Tiedtke et al (2010) who identified that patients often feel their needs are not met and by Thewes et al (2004) who identified the impact that their diagnosis and treatment had had on the lifestyle and career of younger women. In contrast, Emslie et al (2007) actually challenged stereotypes about women invariably preferring to cope with cancer through emotional disclosure and found that their participants favoured a more practical and physical approach to coping.

#### **8.4 Role of family members**

Both Laura and Pamela valued the role of family members in their rehabilitation process, with Pamela valuing the inclusion of her husband in the treatment sessions and the positive impact this had on him. Her 'hands-on' therapy approach allowed her husband to be included in the therapy sessions, as he was taught how to perform some of the treatment techniques at home. This not only benefited Pamela, but also allowed her husband to feel included and empowered to be able to help his wife.

However Laura describes how she went against her mother's advice to wear a sling after her mastectomy, in view of listening to her therapist. This confirms the findings

of Emslie et al (2007) who found respondents were very positive about the practical and emotional support they received from family, but some talked about families trying to 'wrap them up in cotton wool' (page 835). Johansson et al (2003) found that family members supervised the self-management of lymphoedema in a positive way. Manning-Walsh (2004) also found that social support from family members and friends helped to decrease the negative effects of breast cancer treatment related symptoms on quality of life.

### **8.5 Patient education**

The importance of educational support and effective communication was recognised by both Pamela and Chris, which supports the findings of Lee et al (2010). Emslie et al (2007) also talk about the value of expert instruction and support and Lattanzi et al (2010) concluded that therapists should be knowledgeable and competent in the management of all impairments and functional limitations associated with breast cancer treatment. It can be concluded that the importance of education and effective communication is paramount to high quality care (Binkley et al., 2012; Kidd et al., 2011; Pollock et al., 2011; Cooper et al., 2008; Bloom et al., 2004; Thewes et al., 2004; Bredin, 1999).

Chris valued the early identification and referral onwards with regards to her lymphoedema which is supported by Johansson et al (2003) whose study reports a lack of information from health care providers regarding BCRL. This has also been highlighted by Lee et al (2010) who reports that often patients that presented with arm swelling had their symptoms disregarded. Chris found her experience gave her a better self-awareness in terms of her physical limitation and she felt empowered by

this. Being unaware of the potential persistence of problems and the expectance that things will get better quickly was noted by Binkley et al (2012).

## **8.6 Overall physiotherapy experience**

When describing the physiotherapy experience as a whole, Pamela compared her previous experience of physiotherapy, where she struggled to get the help she needed, to the positive experience and relationship she developed with her therapist. She talked about the improvement in both physical functioning and the impact this subsequently had on her confidence and family role. The negative impact of physical limitation is widely acknowledged; Lattanzi et al (2010) report in their study that participants repeatedly noted how limitations in their range of movement and strength interfered with their activities of daily living and how physical rehabilitation helped restore motion, strength and overall function. Pamela discusses the impact of having to rely on others to help her do the tasks at home she previously carried out, which Johansson et al (2003) recognises in their study can have a negative impact on self-image. Kärki et al (2005) also confirm the activity limitations in lifting; carrying and reaching out were commonly experienced by participants in their study.

When Laura described her physiotherapy experience, she specifically described the importance of early intervention post diagnosis and the value of a flexible and easily accessible service. The value of early intervention supports the findings of Lattanzi et al (2010) who reported regular input and early identification of need to be beneficial and Cheville and Tchou who confirmed this resulted in reduced surgery-associated pain and dysfunction in their study in 2007.

Laura did feel however that the service could be improved by the availability of online access. This service development has been discussed with the Physiotherapy Manager, as a way to enhance communication with patients. She liked the multi-disciplinary approach to her care, which is consistent with the findings of Lawrance and Stammers in 2008, Johansson et al in 2003 and Lundvik Gyllensten et al in 1999. She specifically reflected that she felt well supported with the awareness that her care was being provided by a team who regularly communicated with each other, thus creating a holistic approach and facilitating referral onto other disciplines.

This finding can be confirmed by Lee et al (2010) where participants expressed concern and frustration with health professionals who were not eager to refer them for the treatment they required, Pollock et al (2011) who described the value of professional openness and Thewes et al (2004) who found that younger participants wanted a more holistic approach to their follow-up care. In their study in 2010, Lattanzi et al reported the value of emphasis on improving the patient's total body functioning to heal the whole person and enhance well-being and quality of life.

Chris describes her referral to the Specialist Service happened 'by chance' as she hadn't retained the information received on the ward post-operatively regarding self referral back into the Service. This confirms findings of Larsson et al (2008) who acknowledge the fact that women may still be in a state of shock when they go through surgery and cannot be expected to be receptive to information and also objective arguments for exercise. Lattanzi et al (2010) and Lauridsen et al (2000) also confirm this common theme among participants not remembering receiving instructions about what to do or not to do to optimise healing and function after

surgery. Binkley et al (2012) also acknowledge that the pressures and confusion after a cancer diagnosis can make this a vulnerable time, and may reduce some patients' comprehension of complex discussions of short and long-term morbidities.

Finally Thomas-MacLean et al (2005) report that in their study most participants did not recall receiving information on BCRL, either during treatment, or afterward. They surmised that patients may have received information early in their treatment but were likely inundated with medical information at the time. It is possible that their recollection of having received information was hampered by a combination of extreme distress, information overload, and the physical strain of breast cancer treatment.

### **8.7 Service improvement**

As stated above in Section 8.6, Laura felt that that the Service could be improved by the availability of online access. Pamela did not report any improvements that the Service could benefit from. Chris felt that the Service would be improved by the introduction of a pre-operative assessment and routine follow-up with the physiotherapist. This will be further discussed in Section 11 and is supported by recommendations also made by Lattanzi et al (2010) and Springer et al (2010) in implementing pre-operative intervention, including adequate and appropriate patient education.

### **8.8 Empowerment**

The value of motivation and individualised encouragement to empower patients was also confirmed by Larsson et al (2008), who confirmed that the therapist must be

aware of the patients' own motivation for exercise. The importance of addressing individual concerns is also supported by Binkley et al (2012), Kidd et al (2011) and Larsson et al (2008). Empowerment has been recognised as a critical treatment goal by the Department of Health, Macmillan Cancer Support and NHS Improvement National Cancer Survivorship Initiative Vision (2010b).

### **8.9 Body image**

The theme of body image was explored in Chris's interview, when she talked about when her therapist began treating her mastectomy scar. Her 'hands-on' physiotherapy approach enabled patient-clinician exploration of how her mastectomy had impacted on her self-image. The theme of dissatisfaction with appearance was reported by 77% of the participants in a study examining relationships between symptom distress and quality of life of 100 participants with breast cancer (Manning-Walsh, 2004). Chris reflected that the impact of her therapist treating her mastectomy scar affected her both emotionally but also physically, as she was able to touch her scar and massage it. This links to the findings of Bredin (1999) who reported that a participant felt more comfortable touching her breast scars following a course of massage and felt better able to cope with the change in self-image.

In their study in 2007, Emslie et al reported that participants discussed how treatment had affected their appearance and their coping with the loss of a breast or part of a breast. Talking about this actually made Chris cry, demonstrating how powerful and meaningful the experience was to her. This demonstrates the therapist's ability to deal with sensitive issues and communicate effectively. A participant quote from Lattanzi et al (2010) study captures the feeling of the

participant; “don’t be shy to do scar massage or drain someone under their breast or on the side; don’t be shy because we need that” (page 262). Rager (2005) talks about women being able to discuss their cancer and their learning experiences unemotionally, but were invariably moved to tears when they talked about the people who had helped them. This can also be said for Chris.

### **8.10 Clinical environment**

Interestingly, the environment of the physiotherapy service provision, that takes place in the Outpatient Physiotherapy Department, usually in a cubicle surrounded by curtains, was not raised as an issue. It has been felt by the therapist that this environment may not be as conducive to patient satisfaction as a more private clinical area, but in fact Chris stated she preferred the therapy taking place here as it was easier to access than the main outpatient area of the hospital. This differs from the recommendations of Lattanzi et al (2010) where service is delivered from a spa-like environment.

### **8.11 Summary of key findings**

In summary, the researcher can conclude that the participant’s described an overall positive experience of the Specialist Breast Care Physiotherapy Service. They valued the patient-centred holistic approach to care and access to a Specialist Service with an experienced clinician. In particular the importance of the therapeutic alliance and the value of psychological, emotional and educational support emerged, with the participants feeling empowered in their recovery.

## **9. Reflection**

**9.1 Before and during the design processes:** my initial feelings were based on the desire to choose the 'right' research methodology to suit the study and 'do justice' to the experiences of the participants. As a novice researcher, my reflection centred on feelings of nervousness and apprehension with regards to the potential issues regarding optimal recruitment of participants and the relative uncertainty about the quality of data that would be collected from the study. I was acutely aware of the potential bias and 'blurred boundaries' of a dual role clinician-researcher I could impose, especially in view of the previous therapeutic relationship that had been built with the patient. In view of the potential sensitive nature of discussion, I felt very strongly about my ethical commitment to protecting the participants from any risk of being upset during either phase of the study. Also following the process of obtaining ethical approval, I was aware of the potential impact of 'compassion stress' (Rager, 2005) to myself and the importance of optimising my emotional health through supportive techniques (Fisher, 2011).

### **9. 2 During implementation process:**

**Phase One:** I was aware of the possibility of social desirability bias (Fitzpatrick and Boulton, 1994), in terms of the participants' familiarity with me as their therapist and wanting to please me. In terms of facilitating the group sessions, I felt the need to try to 'keep on track' of the focus of the group and to avoid distraction away from the aim of the session, which was to explore the aspects of physiotherapy care the participants valued most and least. I reflected that on occasions, in an attempt not to miss any rich data, I lost direction at times when recording issues on flipchart. This



almost created a more 'focus group' style of discussion (Emslie et al. 2007), in which dominant characters have more opportunity to lead discussion onto majority opinions. Due to the group nature of the sessions, I was aware of this leading certain participants to compare themselves against others; which could potentially provoke both positive and negative feelings. Due to participants arriving either earlier or later than the agreed time, the introduction was not as succinct as I would have hoped. On reflection, due to the relatively large number of participants in Group Three, on occasions I found it difficult to maintain the 'round robin' approach during the session, achieving the balance of trying to exhaust all ideas and not wanting to prevent some participants 'shouting out ideas'.

**Phase Two:** During this phase I became more aware of my interview technique, in terms of the differences between carrying out patient assessments in a clinical setting versus a research interview (Fisher, 2011; Drury et al., 2007). On reflection I am now more aware of my communication style as a therapist; involving the use of encouragement, praise and positivity, which is effective in engaging patients in therapy. I am now aware I utilised a similar technique during data generation, with the obvious aim to obtain as much information as possible. Arber (2005) talks about the ability of impression management to optimise interaction and felt this enabled a degree of acceptance and potentially reducing the impact of social distancing. She identified the dynamic nature of presenting oneself, which requires constant work and monitoring of oneself and others' reactions and can be emotionally tiring. I am now aware of my skills of adapting my communication skills in attempt to optimise participant engagement.

Smith (2006) also talks about the use of empathetic questioning and social trigger questions to encourage participants to reveal more about their experiences. She describes the clinician revealing 'selected snippets of personal info', in order to produce richer data and also about the perceived power relationships between the participants and the researcher, and the importance of ensuring that participants know what is expected of them and are well informed during the data generation process. I strived to ensure participants felt well informed throughout the research process.

This technique of self-disclosure to encourage participant disclosure is also recognised by Dickson-Swift et al (2006). Cooper et al (2008) concluded that participants appreciated consulting a physiotherapist who was caring, friendly, pleasant and professional, who showed an interest in their patients and made them feel at ease. As displayed in Table 6.2, one of the items recorded from the Group One session stated the value of the therapist's personality, including being friendly, kind and caring.

McConnell-Henry et al (2009) describe a strategy they found useful to incorporate prior understanding into the data generation process, by framing questions with pre-existing knowledge. They believe that 'couching' of the question in such a way serves two purposes. Firstly the researcher is openly acknowledging any presuppositions. Secondly, by contextualising the question the risk of the participant leaving something out of the story in the belief that the researcher already knows that information is diminished. I can reflect that I utilised this technique, particularly in Pamela's interview, where she needed some encouragement in parts to describe her

experience, obviously aware that as her therapist, I knew a great deal about her experience already. Another important technique I utilised is the use of reflective listening, which is described by Drury et al (2007) as a vital tool to encourage the researcher to question how the participant sees themselves and their situation.

I became even more aware of the need to maintain a balance between encouraging the participants and not biasing the data with my involvement. It is acknowledged that the motivation of gaining some personal benefit is an important factor in participants deciding whether or not to take part in research (Locok and Smith, 2011) and the process of participating in research and discussing the emotional impact of treatment can potentially provide a form of 'closure' for some patients and can actually form a positive 'part of therapy'.

Another important aspect of reflection was my reaction to Chris when she started to cry when talking about her experience of first treating her mastectomy scar. I chose to turn the tape off when she began to cry. On reflection I am torn between acting as the 'therapist' in protecting her and the 'researcher', in which I gave Chris time to compose herself. This demonstrates the difficulty between separating the two roles, which is acknowledged by Arber (2005), who talks about the experience of being an outsider (researcher) an insider (clinician) and the challenge of being on the boundary between these two roles, which can cause strain for the researcher. As discussed by Drury et al (2007), although it is vital to maintain boundaries and not go into a clinical therapeutic role, it is of equal importance that the participant is not left in an emotionally vulnerable position. As a dual role practitioner, I feel as both a researcher and clinician I was acting in the participant's best interests.

Malacrida (2007) talks about emotions in research, which she states are not only unavoidable but also desirable, to the goals of constructing emancipatory knowledge. This relates back to the ethical issues discussed in Section 5, where I acknowledge the potential impact a dual role of being both the clinician and researcher can impose on the research process.

**9.3 During write up:** I was aware of the different styles of writing up research that could be utilised, mainly focusing on the realist tale versus the confessional tale. Smith (2006) describes the difference between the realist tale; which enhances the researcher's role as an impersonal source of information and compares this to the confessional tale; which emphasises the voice of the researcher.

Both styles have been utilised during the write up of the study; for example the realist approach can be demonstrated when I describe my role as the therapist in third person in Chris's interview: 'when asked to describe a particular example of a situation that was meaningful to her, she talks about the first time the therapist assessed and treated her mastectomy scar'. The confessional approach can be demonstrated when I talk about why I chose to turn the tape recorder off when Chris started to cry in her interview: 'on reflection the researcher is torn between acting as the 'therapist' in protecting her and the 'researcher', in which she gave Chris time to compose herself'.

I have attempted to demonstrate participant visibility and service user empowerment, as well as my development as a researcher, through the write up of the study.

## **10. Strengths and weaknesses of the study**

### **10.1 Strengths**

One of the main strengths of this study is the relevance to current clinical practice; evaluating a Service that has been developed to meet the needs of patients following a diagnosis of breast cancer. Although the dual role of clinician-researcher can potentially be seen as a weakness in terms of potential bias impact, the integrated role of the researcher has facilitated attendance and participation, which participants may have found therapeutic as part of their recovery. The results found will be used to directly influence and improve the quality of patient care and experience and may be transferable to other patient groups.

The study itself is breaching a current gap in the literature, with regards to exploring the perceived physiotherapeutic needs of breast cancer patients and is relevant to current National initiatives to improve quality of care and involve patients in decision making. In terms of methodological rigour, the two phases of the study allow triangulation and verification of data, with the first informing the second phase. In terms of the dependability of the results, part of the inclusion criteria was patients who had been discharged from the Specialist Service within six months, therefore limiting the time that had passed between intervention and evaluation of experience. The researcher has strived to maintain the richness of data by not being too reductive in data analysis and enhance transparency by including direct participant quotes.

## **10.2 Weaknesses**

In terms of weaknesses, there was a relatively small sample size due to the nature and timescale of the study. There were a different number of participants in each sub-group, dependant on the participant's previous experience of physiotherapy. This meant that Group Two only had two participants, whereas both Group One and Group Three were larger. The researcher acknowledges that this may have impacted the issues discussed during the group sessions. This study has provided an in-depth exploration of a small sample of women from a particular geographical area, thus limiting the transferability of results.

The researcher recognises the implications of her role and potential bias in terms of being a dual role clinician-researcher and her role in analysing the data, given that she had a direct and personal role in collecting it. Other studies which have reduced this potential bias include Larsson et al (2008) who utilised two physiotherapists who had no previous contact with the participants and Emslie et al (2007) who used a communicator that had no previous contact with participants to emphasise the 'distance' between the facilitator and the trial, and to encourage respondents to discuss both negative and positive aspects of the study. However Todd et al (2008) recognised in their study that the additional involvement of investigators who are not contributing to clinical care may also have discouraged some women.

In relation to recruitment, Lattanzi et al (2010) recognised that participants who have had a positive experience may be more likely to agree to take part in a study than those you have had a less beneficial experience. In their study in 2011 Pollock et al concluded that patients are highly motivated to maintain a positive outlook, both as a

means of promoting their recovery and to avoid the psychological discomfort of acknowledging this may have been compromised by inadequate care. Therefore the researcher acknowledges that this concept may have influenced the nature of the data generated.

### **10.3 Differentiating between research and evaluation**

Following NHS Ethics review of the project, it was deemed a service evaluation, rather than research activity. As acknowledged by Gerrish and Mawson (2005), it is difficult to differentiate between research activity, which must comply with research governance requirements, and service evaluation, which falls within the clinical governance frameworks of NHS Trusts. The boundaries between these activities are often blurred yet the consequences of not complying with the appropriate governance requirements are serious, both for the individual and the organisation involved.

Research may be used to gain greater understanding of the experience of patients. The key feature that distinguishes research from service evaluation is the fact that research is concerned with generating new knowledge where no current reliable evidence exists. Moreover knowledge generated through research has application beyond the immediate context in which it was generated. In contrast to research, service evaluation is context specific and is undertaken to generate information that is of local relevance to informing the development of healthcare practices. It cannot be assumed that the outcomes from these initiatives are directly transferable to other settings.

#### **10.4 Summary**

The researcher has aimed to demonstrate awareness of her dual role of clinician-researcher impacting on the study and also the limitations of the study. The study has been successful in achieving its aims of exploring the perceived physiotherapeutic needs of breast cancer patients, through their own words. This has generated valid new insights and indicative themes to contribute to the knowledge base in the field.



## **11. Key implications for practice**

As acknowledged in Section 1.1, increased early detection rates, improved adjuvant therapy and improved survival rates reflect the necessity of further research into the needs of patients following a diagnosis of breast cancer (Gomide et al., 2007). As the role of the physiotherapist in providing rehabilitation for breast cancer patients emerges, so does the need to evaluate interventions, demonstrate effectiveness and review current service provision, in order to establish and secure future service provision. Previous literature has focused more on a 'prescriptive' approach to physiotherapy and what has remained unknown was the perspective of the patient themselves in terms of what aspects of physiotherapy care they value most and least and why. The aim of this study was to explore the experience of physiotherapy care received by patients with breast cancer and to identify which aspects of care patients value most and least and gain insight into why these aspects are valued or disliked.

As discussed in Section 1.4, although it is well recognised that patients require access to physiotherapy at varying stages throughout their treatment pathway, there are variations in service provision and more research is required to support the development and improvement of supportive care. The Specialist Service that has been evaluated in this study was developed in response to the identification of need and aims to deliver a holistic and individualised approach to care and support patients to return to function and optimise quality of life, following a diagnosis of breast cancer. The outcomes of this study will be used to make recommendations for future clinical care pathways and support continued service provision.

This study supports the need for physiotherapy at all stages of the treatment pathway, following a diagnosis of breast cancer. What has emerged from this study is the importance of treating a patient 'as a whole'; incorporating both the physical and the psychological and emotional impact of receiving a diagnosis of breast cancer and its subsequent treatment. The importance of the therapeutic relationship between patient and therapist has been identified, and the positive impact this can have on overall satisfaction and treatment outcomes.

As a single exploratory qualitative study, rich and descriptive data has been generated from a specific participant group. The experiences of the participants in this study are unique and the results represent common themes that have emerged from a small purposive sample of patients. However the findings of this study contribute to a pattern emerging from other studies discussed in Section 2.5, 2.7 and 2.8 with regards to the importance of developing a therapeutic relationship and delivering a patient-centred holistic approach to care, and therefore their significance can be established with increasing confidence (Pollock et al., 2011).

The analysis of themes demonstrated in Figures 7.1, 7.2 and 7.3 can be used to guide further work exploring the physiotherapeutic needs of this patient population. The second phase of the study has allowed the researcher to further explore the findings of the initial phase and permitted triangulation to facilitate verification. The combination of phases has allowed the researcher to bring together different experiences with common themes. The themes that have emerged support the categories included in the ICF Core Sets for breast cancer; as previously discussed

in Section 1.4, with the inclusion of emotional functions, family relationships, hand and arm use and the ability to perform housework.

This strengthens the findings of Glaessel et al (2011), who interviewed physiotherapists from around the world who were experienced in the treatment of patients with breast cancer, about patients' problems, patients' resources and environmental aspects involved in patient care. The results demonstrated that the content validity of the ICF Core Sets for breast cancer was largely supported by the physiotherapists who participated in the study. They conclude that physiotherapy is not limited to body functions, and all ICF components need to be considered in assessment and outcome evaluations.

As discussed in Section 2.3 previous literature states that breast cancer patients often have unmet information needs and the importance of educational support and effective communication has been demonstrated by both Pamela and Chris, as discussed in Section 8.5. As described in Section 8.7, Chris recommended that the Service would be improved by the introduction of a pre-operative assessment and routine follow-up with the physiotherapist. This recommendation is also supported in previous literature (Binkley et al., 2012; Lattanzi et al., 2010; Springer et al., 2010; Johansson et al., 2001) and therefore has implications for clinical practice.

## **12. Implications for future research**

The importance of an effective therapeutic relationship that can develop between patient and therapist has been demonstrated. Further studies to explore the concept of therapeutic relationship are needed to obtain a more conclusive understanding of the relationship between the alliance and its effects on treatment outcomes (Pinto et al., 2012; Kidd et al., 2011; Hall et al., 2010).

The impact of the development of lymphoedema was briefly touched upon in both the Phase One Group Three items and also in Chris's interview when she talks about the early recognition and management of her breast cancer related lymphoedema. Further exploration of this area was beyond the scope of this study, but highlights the need for evaluation of patient experience of this chronic condition (Thomas-Maclean et al., 2005; Johansson et al., 2003).

As stated in Section 8, within the sample of participants that took part in the study, previous experience of physiotherapy has not affected the perceived value of their experience of the Specialist Breast Care Physiotherapy Service. This suggests that the stratification of participants into sub-groups dependant on their previous experience of physiotherapy may not have been necessary. These can be used to inform and guide future studies within this patient population.

### **13. Summary**

As discussed in Section 1.4, there is variation in the provision of physiotherapy for breast cancer patients and protocols of care being delivered. This study supports the need for service providers to evaluate their current physiotherapy provision and subsequently develop Specialised Services to meet the physiotherapy needs of breast cancer patients. Access should be available at all stages of their treatment pathway from the delivery of pre-operative care through to post-treatment follow-up.

In summary, the aim of exploring the physiotherapeutic needs of breast cancer patients has been achieved and the results of the study demonstrate what aspects of care patient's value most from their physiotherapy care. The findings of this study identify that breast cancer patients require specialist physiotherapy input at all stages of their treatment pathway. Patients have reported the value of receiving physiotherapy from a specialist clinician who has extensive experience in working with breast cancer patients and value the patient-centred holistic approach to care; which incorporates their physical, psychological, emotional and information needs.

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## **List of appendices**

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# A1: Positive and negative aspects of dual role clinician-researcher

Positive	Negative
Access to study participants (Asselin, 2003): <a href="#">via Physiotherapy Service</a>	Unable to preserve therapist anonymity: <a href="#">therapist known to participants and delivered physiotherapy care</a>
Attendance and participation (Yanos and Ziedonis, 2006): <a href="#">possible social desirability bias and relationship with therapist</a>	Potential for bias (Yanos and Ziedonis, 2006): <a href="#">due to social desirability</a>
Full disclosure can be obtained via Participant Information Sheet therefore demonstrating ethical responsibility to both the individual participant and society at large (Yanos and Ziedonis, 2006): <a href="#">see Appendix 2</a>	Issues with professional neutrality (Chew-Graham et al., 2002): <a href="#">as clinician both researcher and integral part of study</a>
Potential for clinician to provide insight and ensure relevance to routine clinical practice and 'real-world settings' (McNair et al., 2008): <a href="#">researcher also experienced specialist clinician</a>	Potential for moral conflict (Miller et al., 1998): <a href="#">researcher aimed to maintain good ethical judgement throughout</a>
Can facilitate an interactive flow of ideas between the clinical and research domains (Yanos and Ziedonis, 2006): <a href="#">clinician undertaking Masters in Research qualification</a>	No distance neutrality: <a href="#">as clinician both researcher and integral part of study</a>
Utilise the intuitive nature of therapist (trained in 'Connected' National Advanced Communication Skills Programme and uniquely qualified to anticipate problems in communication or co-ordination of research: <a href="#">clinical experience of therapist</a>	

## A2: Letter of invitation



Salford Royal **NHS**  
NHS Foundation Trust

*University Teaching Hospital*

**safe • clean • personal**

**Exploring the physiotherapeutic needs of breast  
cancer patients; a qualitative study of patient  
experience**

As you have been referred to the Specialist Physiotherapy Service for breast cancer in the past, we are writing to invite you to take part in our study.

Before you decide whether you want to take part in the study we would like you to understand why the research is being done and what it would involve for you, therefore please take the time to read the Patient Information Sheet and Consent Form enclosed.

It is completely up to you whether you choose to take part or not, it will not affect your care in any way.

The session is taking place on **Monday 23<sup>rd</sup> April 6-7pm at Meeting Room 1, Mayo Building, Salford Royal Hospital**

**If you would like to take part, please contact Karen McClean at the  
Physiotherapy Department by ringing:**

**0161 206 1077**

Many thanks

## A3: Participant information sheet



### Exploring the physiotherapeutic needs of breast cancer patients; a qualitative study of patient experience

We would like you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

#### ***Why is the study being carried out?***

This study aims to explore your experience of Physiotherapy care following your diagnosis of breast cancer and to try to identify which aspects of care you have valued most and least, and why.

#### ***Who is doing the research?***

The research is being carried out by the University of Central Lancashire in partnership with Salford Royal NHS Foundation Trust.

#### ***Selecting participants***

You have been invited to take part as you have been referred to the Specialist Physiotherapy Service and are currently receiving Physiotherapy treatment or have received treatment in the past. In order to evaluate this service and make improvements, we would very much value your views.

#### ***Recruiting participants***

Participants will be recruited via invitation letter sent in the post, along with the Patient Information Sheet and Consent Form. If you then ring to let us know you would like to take part, we will give you details of the date and time of the group discussion. When you attend you will have the opportunity to discuss your participation with one of the Research Team who will ask you to sign the consent form.

#### ***What is involved in this study?***

The study will involve 2 phases: the first phase is taking part in a group discussion of between 6-10 participants. The purpose of this group discussion will be to generate and record your individual ideas, discuss these ideas as a group and then finally you will have the chance to vote for which ideas you feel are most relevant.

Participants can then volunteer to take part in the second phase of the study, which will be a one-to-one interview. Due to the nature and scale of the study, only a small number of participants can be selected to take part in the second phase. The participants for the second phase will be selected at random from those who volunteer for this part of the study. The purpose of this type of study is to allow the Researchers to gain more insight into your experience of the Specialist Physiotherapy Service and for you to discuss your ideas and opinions in more detail.

#### ***Who has approved the study?***

The study has been approved by the NHS Health Research Authority: NRES Committee North West – Greater Manchester West, the NHS Salford Acute and Primary Care Research Team – Greater Manchester Primary Care Research Governance Partnership and the University of Central Lancashire ethics committee.



### ***What will happen to the information?***

All information collected during the study will be confidential and anonymous. The data will be kept securely by the University of Central Lancashire. The information will become part of a research thesis and may be presented at conferences and in research journal paper. During the group discussion, all participants will be asked to agree to maintain the confidentiality of any information provided by others during the discussions.

The interviews will be audio recorded and after they have been transcribed, the recordings will be destroyed in accordance with the University of Central Lancashire guidelines. Direct quotes will be used but they will be anonymised so that you cannot be identified.

If during the study you lose the capacity to consent, you and all identifiable data would be withdrawn from the study and any data which is not identifiable to the research team will be retained.

### ***How much time will it take?***

The group discussion will take about 1- 1.5 hours. If at a later date you are selected for an interview, this will take about 1 hour.

### ***When and where is the research taking place?***

The project is expected to start in 2012. The dates and times will be confirmed with you nearer the time. The study will be completed by April 2013.

The group discussion will take place at Salford Royal Physiotherapy Department. If you are selected for the interview this will also be at Salford Royal Physiotherapy Department.

### ***Will I receive “out of pocket” expenses?***

We will reimburse you with public transport fares or car parking fees for attending the group session and the interview if you are selected. Receipts for expenses must be submitted. We are unable to cover other costs such as child-minding.

### ***What are the possible risks and benefits of taking part in this study?***

Possible risks: We understand that due to the nature of the study, issues will be discussed that some participants may find upsetting or that the opinions of some participants may differ to other members of the discussion group. All information that is shared during the study will be treated as personal and sensitive and it is vital that all group members should respect this and their confidentiality.

We will try our best to make all participants as comfortable as possible in terms of the discussion and all participants will be encouraged to talk to the Researchers if they have any worries or concerns. Additional support will be accessible if required, including the Macmillan Counselling Service based at Salford Royal Hospital.

Possible benefits: The study findings will help us to continue and develop the Specialist Physiotherapy Breast Service, and will also give participants the opportunity to meet and chat to other people who have possibly had similar experiences. Everyone who takes part will be given the option receive a summary of the study findings if they so wish.

### ***Do I have to take part?***

No, it is up to you to decide and whether you choose to take part or not, it will not affect your Physiotherapy care. Please take time to read the information. You can speak to the Physiotherapy Department or contact your Breast Care Nurse. We want everyone to have at least 48 hours to consider their decision. If you agree to take part, we will ask you to sign a copy of the consent form when you arrive for the meeting (see form attached).

**If you would like to take part, please contact the Physiotherapy Department by ringing 0161 206 1077.**

### ***What will happen if I don't want to continue with the study?***

You can decide not to take part at any stage – even if you have signed the consent form. You don't have to tell us why you have changed your mind. Your decision to withdraw will not affect you, or the care you receive in any way.

If you change your mind after the group discussion, we will continue to use the information because it is completely anonymous and cannot be traced back to you.

### ***What can I do if I am not happy with the study?***

If for any reason you are not happy with any aspect of the study please ask to speak to one of the research team who will do their best to answer your questions.

Karen McClean [KEMcClean@uclan.ac.uk](mailto:KEMcClean@uclan.ac.uk) Tel: 0161 206 1077

Gill Rawlinson [GRawlinson@uclan.ac.uk](mailto:GRawlinson@uclan.ac.uk) Tel: 01772 894579

If you remain unhappy and wish to complain formally, you can do this through the University of Central Lancashire complaints procedure. Details can be found on the website:

[www.uclan.ac.uk](http://www.uclan.ac.uk)

You can also use the NHS Complaints Procedure via the PALS service (Patient advice and liaison service) on 0161 206 2003 or via email [pals@srft.nhs.uk](mailto:pals@srft.nhs.uk)

### ***What if there is a problem?***

In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Central Lancashire but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Finally we would like to thank you for taking the time to read this information leaflet.

## A4: Consent form



## Consent form for patients

**Title of Project:** Exploring the physiotherapeutic needs of breast cancer patients; a qualitative study of patient experience

**Researcher:** Karen McClean

**Academic Supervisors:** James Selfe, Hazel Roddam, Gill Rawlinson

**Please initial box**

1. I confirm that I have read and understand the information leaflet for the above study dated February 2012. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason ☐
3. I give consent to take part in Phase 1 of the study: the discussion group ☐
4. If I am selected, I give consent to take part in Phase 2 of the study: a one-to-one interview ☐
5. I give consent for my participation in both Phase 1 and Phase 2 (if selected) to be audio-recorded ☐
6. I understand that all data gathered during the study will be stored in accordance with the Data Protection Act (1998) and retained for a period of 5 years in a secure data archive at the University of Central Lancashire ☐
7. I understand that reports from this study will not contain any identifiable personal information. Direct quotes may be used, but will not be attributable to any participant ☐
8. I understand that relevant data collected during the study, may be looked at by individuals from the University of Central Lancashire, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data ☐
9. I understand that if I should lose the capacity to consent during the study I and any identifiable data would be withdrawn from the study and any data which is not identifiable to the research team may be retained ☐
10. I agree to anonymised data being utilised within reports, publications and or presentations ☐
11. If you would like to receive a report of the end of study findings, please ☐

place a cross in the box and write your correspondence address below

Correspondence address:

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\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Name (person taking consent)  
consent)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature (person taking

When completed: 1 for Patient & 1 for Researcher.

**A5: Follow up letter**



**Exploring the physiotherapeutic needs of breast cancer patients; a qualitative study of patient experience**

Dear

Hopefully you will have recently received information regarding the above study inviting you to take part.

Thank you for taking the time to read the information. We are writing again to remind you of this invitation as we have not heard back from you regarding whether you would like to participate.

If you would like to take part please phone the Physiotherapy Department on:

**0161 206 1077**

If you would like to discuss this further you can ring the Physiotherapy Department on the above number or contact your Breast Care Nurse.

We would like to remind you it is completely up to you whether you choose to take part or not, it will not affect your care in any way.

Thank you again for your ongoing help

Yours sincerely

Karen McClean  
Specialist Breast Care Physiotherapist

## A6: Script for Phase One data generation



### **Script for Phase One:** **Nominal Group Technique**

#### **Opening statement:**

- Welcome and introductions
- Thank you for agreeing to take part in the study
- A statement of the importance of the task
- Re-iterate importance of each participants contributions
- Recap how the information recorded will be used
- Ask participants to agree to maintain confidentiality of any information provided by others during the session

#### **Generation of ideas:**

- 'What aspects of your Physiotherapy have you valued the most and least' (+ve and –ve in different colour pens)
- Ask participants to write down their ideas and work silently and independently

#### **Recording ideas:**

- Participants take turns giving their answers
- This proceeds until all ideas have been documented

#### **Ending session:**

- Thank participants for their participation
- Any questions?
- Participants who have requested feedback summary on Consent Form will receive this in 2013

## A7: Script for Phase Two data generation



### Exploring the physiotherapeutic needs of breast cancer patients; a qualitative study of patient experience

Firstly I would like to take this opportunity to thank you again for agreeing to take part in this study. Your participation is greatly valued and appreciated and will help to evaluate and make improvements to the service.

Just to recap the purpose of this second phase: you have taken part in the first Phase of the study which involved a group discussion, to explore patient experience of Physiotherapy following a diagnosis of breast cancer.

Following this you have been randomly selected to take part in this second phase, which is a one-to-one interview.

The aim of this interview is to further explore the findings of the group discussions and to get a better understanding of your own personal experience of this Physiotherapy Service. I will be recording our conversation as I don't want to miss any important bits and I may make some written notes. But I can't possibly write fast enough to get it all down. Because we're on tape, please be sure to speak out so that we don't miss your comments.

All responses will be kept confidential. This means that anything you say that is used in our report will not identify you in any way. Remember, you don't have to talk about anything you don't want to and may end the interview at any time.

It is expected that the interview process will take a maximum of one hour.

I am planning on talking to you about 3 main topics which are:

1. To discuss your personal experience of the service and how it is run
2. To discuss whether your physical symptoms have changed and if so give examples
3. To discuss, if possible, a particular experience or situation that you found helpful or found went well and why you felt like this

Do you have any questions about what I have just explained?

- 1. The first thing I would like to discuss is your personal experience of this Service. Can you tell me about how you feel the Service is currently run and any ways you could suggest this could be improved in your opinion?**

Prompts if required:

- What aspects of your care particularly worked well for you?
- Why do you think this worked well or not so well?
- Would there be anything that you would change or make better? (for example referral process, location, availability of appointments, treatment received)

- 2. I would now like to introduce another aspect of your care with regards to change in your physical symptoms following access to Physiotherapy. Could you tell me about how things have changed for you in physical terms and how this has impacted on your day to day life? (For example has your movement or flexibility changed? Is your pain changed or do you feel your ability to reach or using your arm has changed?)**

Prompts if required:

- Can you give me any examples of activities that have gotten any easier?
- How have these changes made you feel?
- Is this impacted on any other aspects of your life in terms of family/ work/ socially?

- 3. Finally I would like you to think back to when you first came for Physiotherapy and your follow-up appointments. Would you be able to pick a particular occasion, for example a conversation you had or an experience you can think of, which you found helpful? Please could you tell me about this, and think about why you found it helpful.**

Prompts if required:

- Is there a particular session of Physiotherapy that you felt went well? Why was that?
- Could you tell me anymore about that?
- How did that make you feel?
- Is there anything else you would like to add?

**Closing statement:** I think we have covered all the areas now that we had planned to discuss. Is there anything you would like to add before we finish?

Ok I think we will end the interview there now. Thank you again for taking part and for your time.



## **A8: Interview exerts**

### **Interview 1: Lines 140-167**

**Interviewer:** So, finally I'd like you to think back to what we said earlier, so if you can think back to when we first met and then your subsequent appointments, could you think of anything in particular, a particular appointment or a specific time where you felt that you remember it now and you think, yeh that was good or that really helped me? If you could just pick one particular experience.

Pause

**Interviewer:** So we saw each other on the ward, or it could be one of the appointments where you had your treatment or you mentioned the progression side of things. Can you think of anything that stands out in your mind?

**Participant:** Well I would have said when we met on the ward but I think we've covered that. I do remember feeling really happy on our last appointment because it was nice as I was just about to start chemo and you said I was doing really well with my arm. I can remember you saying throughout that you need to get your arm as good as possible before chemo and I didn't know why but then I realised once I started that you were right. So I felt really happy because of my progress.

**Interviewer:** So you felt that was quite symbolic?

**Participant:** Yes definitely. It was good to be at the end. And I was really pleased you were happy with me. I did have a tough time during chemo, I didn't realise how hard it was going to be. So yeh that last meeting was memorable.

**Interviewer:** Great. So in terms of how it made you feel, you said that made you feel good? Did you feel anything else?

**Participant:** I guess because I knew I wasn't seeing you again, it was like, oh ok, you need to do this on your own now kind of thing. I was like where will I get my support without my Karen??

**Interviewer:** And how did that work out for you? Did you feel that it was the right time for you?

**Participant:** Well you know I don't think there's ever a right time but I was ready. You were, you know, not pushy but you really encouraged me to get the movement in my arm back and, even when I just didn't get it. You know why, what was the big deal? But I think without your help, I wouldn't have got here. You had that experience of seeing other people like me and knew what to do. So yeh, I can't imagine what it would have been like without that.

### **Interview 2: Lines 152-206**

**Interviewer:** Well I think that leads us quite well into question 2 about the changes that happened after your surgery and the changes that happened with the Physio. So if you tell me a little bit about from the surgery onwards before we met what kind of problems were you having? So were you in pain?

**Participant:** I was in a lot of pain.

**Interviewer:** Yeh so quite a lot of pain. Was it there a lot of the time?

**Participant:** It was there all the time

**Interviewer:** And did you rely on painkillers?

**Participant:** Yeh I did I think it was called diclofenac

**Interviewer:** So what kind of impact did that have on you day to day, you've mentioned a few things like not being able to reach up

**Participant:** I couldn't even dry my hair properly. I couldn't even fasten my bra. There was a lot of things, And my shoes, when I bent forward it really hurt and pulled across my chest cos my friend had to fasten my shoelaces when I was out. It was a lot I couldn't do.

**Interviewer:** So quite a big impact then. So when we started doing the Physio, did you feel like that helped?

**Participant:** My god it helped. I think it was within a couple of weeks I was able to move my arm. And it was brilliant.

**Interviewer:** So all those things you were struggling with, you started to find a bit easier?

**Participant:** A lot easier.

**Interviewer:** And did the pain improve?

**Participant:** It did.

**Interviewer:** So from what I can remember we worked on your scar and we worked on your shoulder and then we got your husband doing that at home as well. So things that went easier were.....

**Participant:** dressing, household kind of things, and I couldn't get out of the bath, I couldn't have a bath. I got in it and that was it I was stuck! I couldn't get out cos I couldn't put any weight on that arm to get out. So it was showers all the way after that. It was a massive impact on my life.

**Interviewer:** So you started to notice the improvement there, how did being able to do more impact on things like your family?

**Participant:** Well I felt as though I'd got my life back again. So now I don't have to ask anybody for anything. Anything heavy I have to ask for a lift but day to day running of the house I'm just back to normal with everything. I can even hang my own washing now; I can do all of that. , which I couldn't do before.

### **Interview 3: Lines 137-180**

**Interviewer:** So once we started seeing each other, did you feel that the location for example was ok, and appointment times, days etc

**Participant:** That was great, I was amazed how I could get an appointment to see you virtually always to suit me, and we would book a couple of appointments in advance to suit me. Like when I wasn't working I'd like to come early in the day and when I started back at work having my appointments late on in the afternoon, that suited me fine. So I found it very flexible. I'm only 5-10 minutes away by car and even coming straight from work it's on my way home. There are certain times when the car-park can be an absolute nightmare, a real nightmare but taking that on board I found the Service was really flexible and the fact that you are slightly separate from the Hospital and you don't have to go into the churn of the Reception Desk over the road and you have your own place to come in, I found worked really well for me. And the fact that if I needed to change an appointment it was a simple phone call to reschedule so I found that side made things very easy and manageable.

**Interviewer:** In terms of the length of when we saw each other, did you feel that went on long enough, did you feel like we needed to carry on longer or did we finish too early. How do you feel about the duration of treatment?

**Participant:** Because I enjoyed coming and I enjoyed the manipulation of the shoulder, because it did give me quite a bit of relief, I probably would still be coming when I'm a 102 (laughing). So the fact that you were saying 'no actually I think we've done what we needed to do', I was disappointed not to come, but I felt no you're right, I'm now ready for the next stage, I had recovered as much, I'd got really good movement out of my arm and I'm now using the bandage now and when. I notice myself when it gets heavy I try to use the bandage a little bit more, so you gave me the confidence to manage that and like I said I would have been quite happy coming for years (laughing) but the fact that you said 'we've done as much as we can and you've got brilliant movement in your arm', so it was probably just the right length for me.

**Interviewer:** And do you feel like you would be able to, in terms of re-referral back in, would you be happy and feel like you could do that? Do you feel like you could do that if you needed to?

**Participant:** Yes I'm presuming that when I do have the reconstruction that I may need a little bit more help with my shoulder and making sure that I have full mobility back, so I am hoping that I can use the Service after the reconstruction takes place and possibly again keeping an eye on it because of the lymphoedema, I think that would be quite advisable

## A9: Participant Summary Sheet



### Exploring the physiotherapeutic needs of breast cancer patients; a qualitative study of patient experience

You have received a copy of the Participant summary sheet to feedback the outcomes of the above study, as you requested on your consent form.

Many thanks again for agreeing to take part in the above study, your participation and attendance was greatly valued.

The research project has now been completed and written up. The results have shown that patients report an overall positive experience of receiving physiotherapy following a diagnosis of breast cancer.

In particular the results have shown us that patient's value seeing a physiotherapist who specialises in this type of treatment and who has experience in this area. The value of building up a good relationship between patient and physiotherapist has also been shown.

The findings will be used to support the continuation of the Physiotherapy Service for breast cancer patients and have been used to evaluate the current Service that is being provided. An improvement that has been recommended is that all patients are offered a physiotherapy appointment before their surgery, in order to receive information and run through the exercises. We are now planning on delivering this as part of the physiotherapy service.

If you would like to discuss any of the points above or have any problems with this summary please contact **Karen McClean** in the Physiotherapy Department on **0161 2065328**.

Again many thanks for your time, it is greatly appreciated.

## A10: Codes from Phase Two

### From codes to themes Laura's interview

Codes (Step 1)	Issues discussed	Themes identified (Step 2)
<ul style="list-style-type: none"> <li>- Intervention post-op</li> <li>- Early exercise intervention</li> <li>- Continuity/ regular input</li> <li>- Symbolic completion of Physio</li> </ul>	<ul style="list-style-type: none"> <li>* Seeing therapist day one post surgery</li> <li>* Happy with progress</li> <li>* Provide continuity</li> <li>* Progress</li> </ul>	<ul style="list-style-type: none"> <li>1.Intervention post-op</li> <li>2.Early exercise intervention</li> <li>3.Continuity/ regular input</li> <li>4.Symbolic completion of Physiotherapy</li> </ul>
<ul style="list-style-type: none"> <li>- Accessibility of Service</li> <li>- Flexibility of Service</li> <li>- Able to ring if needed</li> </ul>	<ul style="list-style-type: none"> <li>* Forgot appt but still seen</li> <li>* Came on wrong day but still seen</li> </ul>	<ul style="list-style-type: none"> <li>5.Accessibility of Service</li> <li>6.Flexibility of Service</li> <li>7.Able to ring if needed</li> </ul>
<ul style="list-style-type: none"> <li>- Discussing stages of treatment</li> <li>- Therapist perception</li> <li>- Multi-disciplinary approach to care</li> <li>- Specialism of therapist</li> <li>- Comparing progress to others</li> <li>- Referral to counselling</li> </ul>	<ul style="list-style-type: none"> <li>* Talking through surgery/ radiotherapy/ chemotherapy</li> <li>* Therapist 'seen it all before'</li> <li>* Patient's discussed</li> <li>* Working together</li> <li>* Happy</li> <li>* Really helped</li> <li>* Would have really struggled without it</li> </ul>	<ul style="list-style-type: none"> <li>8.Discussing stages of treatment</li> <li>9.Therapist perception</li> <li>10.Multi-disciplinary approach to care</li> <li>11.Specialism of therapist</li> <li>12. Comparing progress to others</li> <li>13.Referral to counselling</li> </ul>
<ul style="list-style-type: none"> <li>- Service improvement</li> <li>- Feeling well looked after</li> <li>- Feeling of 'unknown' before surgery</li> <li>- Regaining range of movement in shoulder post-op</li> <li>- Goal setting/ providing focus/ realistic expectations</li> <li>- Impact of treatment on exercise tolerance</li> <li>- Return to function: driving, dancing</li> <li>- Individualised treatment</li> </ul>	<ul style="list-style-type: none"> <li>* Able to contact online</li> <li>* Surrounded by people who cared</li> <li>* Initially upsetting</li> <li>* Importance of regaining shoulder range of movement</li> <li>* Back to how it used to be</li> <li>* Something to work towards</li> </ul>	<ul style="list-style-type: none"> <li>14. Service improvement</li> <li>15.Feeling well looked after</li> <li>16.Feeling of 'unknown' before surgery</li> <li>17.Regaining range of movement in shoulder post-op</li> <li>18.Goal setting/ providing focus/ realistic expectations</li> <li>19.Impact of treatment on exercise tolerance</li> <li>20.Return to function: driving, dancing</li> <li>21.Individualised treatment</li> </ul>
<ul style="list-style-type: none"> <li>- Motivation</li> </ul>	<ul style="list-style-type: none"> <li>* Adapting exercises</li> <li>* Reduce stress</li> <li>* Keep mind focused</li> <li>* Support</li> </ul>	<ul style="list-style-type: none"> <li>22. Emotional support</li> <li>23.Motivation</li> </ul>
<ul style="list-style-type: none"> <li>- Talking to therapist/ being able to offload</li> </ul>	<ul style="list-style-type: none"> <li>* Took time to talk about emotions</li> <li>* Went outside box of 'just exercises'</li> <li>* Recognised altered state of mind and accommodated that</li> <li>* Feeling proud</li> <li>* Able to see difference</li> <li>* Happy</li> <li>* Felt good about what was going on</li> </ul>	<ul style="list-style-type: none"> <li>24.Talking to therapist/ being able to offload</li> <li>25.Positivity</li> <li>26.Encouragement</li> </ul>
<ul style="list-style-type: none"> <li>- Return to work</li> </ul>	<ul style="list-style-type: none"> <li>* Use arm all the time at work</li> </ul>	<ul style="list-style-type: none"> <li>27.Return to work</li> </ul>
<ul style="list-style-type: none"> <li>- Family input</li> <li>- Use of sling (security blanket)</li> </ul>	<ul style="list-style-type: none"> <li>* Protecting/ fear avoidance</li> </ul>	<ul style="list-style-type: none"> <li>28.Family input</li> <li>29.Use of sling (security blanket)</li> </ul>

**From codes to themes Pamela's interview**

<b>Codes (Step 1)</b>	<b>Issues discussed</b>	<b>Themes identified (Step 2)</b>
<ul style="list-style-type: none"> <li>- Post-op dysfunction</li> <li>- Emotional response to diagnosis</li> <li>- Coping strategies</li> <li>- Previous Physiotherapy experience</li> <li>- Relationship with husband</li> <li>- Inclusion of husband</li> <li>- Impact of dysfunction on family role</li> <li>- Reliance on others</li> <li>- Accessibility of Service</li> <li>- Experience of therapy sessions</li> <li>- Apprehension pre first appointment</li> <li>- Relationship with therapist</li> <li>- Impact of Physiotherapy treatment</li> <li>- Regaining independence</li> <li>- Positivity</li> </ul>	<ul style="list-style-type: none"> <li>* Pain</li> <li>* Restricted movement</li> <li>* Reliance on analgesia</li> <li>* Impact on function</li> <li>* Husband's reaction</li> <li>* Daughter's reaction</li> <li>* Returning to 'normal'</li> <li>* Lack of Specialist Service available</li> <li>* Benefit of including husband</li> <li>* Teamwork</li> <li>* Feeling of helplessness</li> <li>* Wanting to continue role of helping others</li> <li>* Transport</li> <li>* Able to self refer if needed</li> <li>* Improved function</li> <li>* Improved movement</li> <li>* Reduced pain</li> <li>* Improved function</li> <li>* Improved confidence</li> <li>* Improved wellbeing</li> </ul>	<ul style="list-style-type: none"> <li>1. Post-op dysfunction</li> <li>2. Emotional response to diagnosis</li> <li>3. Coping strategies</li> <li>4. Previous Physiotherapy experience</li> <li>5. Relationship with husband</li> <li>6. Inclusion of husband</li> <li>7. Impact of dysfunction on family role</li> <li>8. Reliance on others</li> <li>9. Accessibility of Service</li> <li>10. Experience of therapy sessions</li> <li>11. Apprehension pre first appointment</li> <li>12. Relationship with therapist</li> <li>13. Impact of Physiotherapy treatment</li> <li>14. Regaining independence</li> <li>15. Positivity</li> </ul>

### From codes to themes Chris's interview

Codes (Step 1)	Issues discussed	Themes identified (Step 2)
<ul style="list-style-type: none"> <li>- Post-op intervention</li> <li>- Referral process</li> <li>- Regularity of appointments</li> <li>- Flexibility of appointments</li> <li>- Location of Physiotherapy Department</li> <li>- Duration/ timeframe of treatment</li> <li>- Accessibility of Service</li> <li>- Adjustment process</li> <li>- Professionalism/ therapist approach</li> <li>- Therapeutic relationship</li> <li>- Monitoring re lymphoedema</li> <li>- Diagnosis of lymphoedema</li> <li>- Proactivity re lymphoedema</li> <li>- Developing Specialist Service</li> <li>- Awareness of limitation</li> <li>- Physical limitations post surgery</li> <li>- Self-awareness</li> <li>- Empowerment</li> <li>- Process of acceptance</li> <li>- Confidence to self-manage</li> <li>- Reassurance/ emotional support</li> <li>- Expectations of recovery</li> <li>- Encouragement/ positivity</li> <li>- Inability to retain info at time of diagnosis</li> <li>- Need for more information</li> <li>- Impact on return to work</li> <li>- Confidence to access other Services</li> <li>- Referral to other Services</li> <li>- Treating mastectomy scar</li> <li>- Body image</li> <li>- Impact of mastectomy</li> </ul>	<ul style="list-style-type: none"> <li>* Post-op on ward</li> <li>* Advice and exercises</li> <li>* Info not sinking in</li> <li>* Close/ regular monitoring</li> <li>* Able to reschedule</li> <li>* Therapist experienced in treating patients with breast cancer</li> <li>* Continuity</li> <li>* Support</li> <li>* Seeing same therapist each time</li> <li>* Enable early intervention</li> <li>* Would have otherwise ignored problem</li> <li>* Developing pre-op Service</li> <li>* Developing post-op Service</li> <li>* Restriction of movement</li> <li>* Improved movement</li> <li>* Demonstration by therapist</li> <li>- Continual improvement</li> <li>* Feel 'less alone'</li> <li>* Providing 'mental stability'</li> <li>* Comparing yourself to others</li> <li>* Powerful having something you can do for yourself</li> <li>* Gaining control</li> <li>* Realistic expectations</li> <li>* Reassurance</li> <li>* Encouragement</li> <li>* Feeling supported</li> <li>* Positive experience</li> <li>* Giving strength</li> <li>* Written info not enough</li> <li>* Need for more emphasis on lymphoedema education</li> <li>* Need for more explanation</li> <li>* Support re return to work</li> <li>* Improved confidence</li> <li>* Soothing experience</li> <li>* Advice re care of scar</li> <li>* Embraced scar as part of treatment</li> <li>* Emotional benefit</li> <li>* Physical benefit</li> <li>* Felt comfortable</li> <li>* Seeing mastectomy as a disability/ disfigurement</li> </ul>	<ol style="list-style-type: none"> <li>1. Post-op intervention</li> <li>2. Referral process</li> <li>3. Regularity of appointments</li> <li>4. Flexibility of appointments</li> <li>5. Location of Physiotherapy Department</li> <li>6. Duration/ timeframe of treatment</li> <li>7. Accessibility of Service</li> <li>8. Expectations of recovery</li> <li>9. Professionalism/ therapist approach</li> <li>10. Therapeutic relationship</li> <li>11. Monitoring regarding lymphoedema</li> <li>12. Diagnosis of lymphoedema</li> <li>13. Proactivity regarding lymphoedema</li> <li>14. Developing Specialist Service</li> <li>15. Awareness of limitation</li> <li>16. Physical limitations post surgery</li> <li>17. Self-awareness</li> <li>18. Continual improvement</li> <li>19. Confidence to self-manage</li> <li>20. Empowerment</li> <li>21. Reassurance/ emotional support</li> <li>22. Encouragement/ positivity</li> <li>23. Process of acceptance</li> <li>24. Adjustment process</li> <li>25. Inability to retain info at time of diagnosis</li> <li>26. Need for more information</li> <li>27. Impact on return to work</li> <li>28. Confidence to access other Services</li> <li>29. Referral to other Services</li> <li>30. Body image</li> <li>31. Impact of mastectomy</li> <li>32. Treating mastectomy scar</li> </ol>

